The Social Organisation of Exclusion, *“Abandonment”* and Compulsory Advance Care Planning Conversations:

How Ruling Concepts and Practices about Death, Dying and the *Do Not Attempt Cardiopulmonary Resuscitation* form entered, organised and ruled the working practices of Senior Social Care Workers in a Residential Care Home in Scotland: An Institutional Ethnography

(Volume One)

By

Lorna Margaret Reid

A thesis submitted in partial fulfilment of the requirements of Edinburgh Napier University, for the award of Doctor of Philosophy

March 2017

Abstract

Institutional Ethnography (IE) is a method of inquiry into the social organisation of knowledge. It begins with a disjuncture/troubling experience impacting a specific group of workers and adopts their standpoint/subject positon to look out into the wider institution and trace the work and textual practices that organised (and produced) the disjuncture under investigation.

The study took the standpoint of Senior Social Care Workers (SSCWs) from one RCH in Scotland to uncover the complex social organisation of "abandonment" SSCWs described when there was insufficient support from NHS services to care appropriately for sick and dying residents. The focal point of inquiry was on SSCWs descriptions of being "pushed" into "difficult" decision-making conversions with family members about "serious illness" and the Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) – without the support of doctors (or nurses).

To inquire into how SSCWs work had become tied into the medical, legal and bureaucratic practices that rule death, dying and Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision making in Scotland's RCHs the study drew on ten open-ended interviews (SSCWs, n= 4 and others whose work influenced SSCWs working practices, n= 6). Interview transcripts were examined to uncover SSCWs accounts of their knowledgeable work related to managing illness, death and dying - along with the characteristic tensions, frustrations and contradictions embedded in those accounts.

The study traced how doctors and nurses were routinely, and systematically, absent from RCHs - leaving residents systematically excluded from the level of care that they needed. It also traced how SSCWs work with "serious illness" and "difficult" conversations was co-ordinated in disquieting ways in an apparent commitment to high quality "palliative care".

What was discussed between SSCWs and family members during conversations about "serious illness" and the DNACPR form was out of step with the DNACPR policy, the rhetoric of palliative care, and the actual needs of SSCWS, family members, and residents for medical support. However, the study shows that what happened in the RCH was not simply an error of practice. This is because it was textually planned, organised, and co-ordinated across healthcare

institutions, professional groups, the regulatory body acting on behalf of the Scottish Government and the management and care staff of the RCH itself. SSCWs - and others – were organised to take up the powerful ruling discourse of palliative care in ways which treated residents and family members with increasing objectivity, where institutional needs to reduce NHS spending and to protect the income generating potential of the care home as a business ruled over individual needs. In taking up and enacting the powerful ruling discourse of palliative care, SSCWs – and others- (intentionally but unknowingly) took up the very tools of oppression that dominated and overpowered their own and others lives.

The knowledge generated by this research can be used to show SSCWs and others how they unknowingly participate in taking up actions that are not in their own or others interests. This is the basis of changing the conditions of SSCWs and others lives thereby advancing anti-oppressive work.

Acknowledgements

As seems typical, this Ph.D. journey has been longer and more challenging than I anticipated it would have been when it began. At the same time, it has been a rich and expansive experience that has demonstrated what can be achieved when a person is lucky enough to have the enduring faith and confidence of personal and professional supporters. And, when she is persistent about showing up to do the work, completing just one task at a time.

Firstly, I would like to thank Dr. Angela Kydd, my Director of Studies. Angela, you believed I was capable of this level of study before I did. You made yourself available to answer queries and talk through problems at times and in places that suited my schedule and capacity. You read more variations of this thesis than seems reasonable. You challenged my thinking and my writing and my conclusions, all of which are much improved as a result. You let me go for almost two years when I became too sick to carry on with this work, and then you had enough faith to pick our project back up when I wanted to at least try to complete what we had started. We both believed it was important and worthwhile. You found an expert Institutional Ethnographer, Dr. Bonnie Slade, to join the supervision team to keep us right on all matters methodological. You have been a rock throughout this life-changing process, and just to say “thank you” does not seem enough. But, “thank you” nevertheless. We made it to the end dear Angela. We actually made it - all the way, to the end.

Next, I would like to thank Professor Austyn Snowdon, who was part of the supervisory team for the first two years, and Dr. Bonnie Slade who played a key part during the last two. It has been my great pleasure and privilege to have had such astute and supportive supervisors. Austyn and Bonnie, your kind and encouraging comments have kept me pressing on through thick and thin. I am deeply grateful for all your suggestions and comments and strength lending companionship during this process. Bonnie, I am so very, very, glad that Angela found you. And that you came along for the ride because you believed in me, and my work. What a gift.

In closing, I would like to thank my family for their love and support. I thank my “children”: Emilie (look at you, a great nurse and now a wife as well); Melissa (in the final year of her own PhD journey, keep going Miss Lissa, you can do it little friend, yes, you can!!); and Evan (philosopher extraordinaire, maybe I will give DFW a try now…maybe). I thank my parents, Jim and Anne (especially you, Anne McPherson for crashing a research conference to hear me present on this work) and my amazing cousin, Heather (counting blessings with you has keep me on the straight and narrow these past years). Most of all, I thank Andrew, my ever kind and helpful husband, personal IT consultant, and very best friend. Andrew, you have always given me a lot of room to be the person I am. We have marched to the beat of a different drummer, and led a less than conventional life as a result. You have listened as I talked things out from day one of this project – in the car, on the train, on the plane, in the garden, at the table and in the lounge. Six years is a long time to be engaging in conversations about CPR, ethnographic cartography, and dying. You have given wise technical advice and support with map making - which we worked on late at night and early in the morning. You took over the running of our home for the final nine months of this study - during which time you spent far too many weekends on your own. Your love and confidence make me brave. But, enough already. Let’s finally plan that trip to celebrate our 30th wedding anniversary, and maybe even talk about something else…

Table of Contents

Chapter One: My professional and academic entrée to this study

Prologue – Vignette 1

When I arrived at Residential Care Home (RCH) A to discuss an educational project we were working on together, the staff were anxious and upset because they could not make one of their residents, Mr. A, comfortable or settled. This was particularly difficult because they thought he may be dying.

RCH staff are dependent on external National Health Service (NHS) doctors and nurses for support with resident's needs as there are no doctors or nurses on-site. On this day staff knew they needed help *"to settle"* Mr. A so they had called his medical practice to ask a doctor to visit, but s/he had not arrived yet. I was at the home in my role as a hospice educator and project leader to discuss implementing a palliative care register to improve the co-ordination of care of those who were dying. As my experience is as a nurse with many years of practice in caring for people who were dying (in the hospice), staff asked if I could advise them. Initially, I felt conflicted because Mr A was not *my patient*, which meant I did not know the details of his case, leaving the potential to accidentally cause more harm than good. Also I was not employed as a nurse in the RCH, and had never worked as a nurse in the community – which meant I was not clear about community healthcare systems and was anxious about overstepping professional boundaries. At the same time I also recognised that I had a personal and professional responsibility to offer support where I could, so I agreed to go and see Mr. A.

Mr A. was an 82 year old man with a history of dementia and osteoarthritis. His general condition had gradually deteriorated over the past three weeks and he was experiencing more pain on movement and at rest. Also, he was increasingly fatigued so needed more assistance to move and dress and eat and wash. As a result staff had asked for advice and support on a few occasions from doctors at Mr. A's medical practice. Mr A. was seen by a different doctor on each occasion. The doctors gave advice on the specific issue they had been contacted about, but left no clear plan for the RCH staff to follow, nor did they arrange routine follow up visits.

Over the past three days Mr. A's condition had deteriorated further, which worried the staff. He had become *"more sleepy*". This meant that although he had taken sips of fluid he had not eaten, or been able to swallow his oral medication (including medication for pain) for the past 48 hours. Staff had reached out for help from doctors a number of times over the past three days and two nights. He was seen by another three doctors during that time. All gave different advice: a locum doctor from the medical practice advised withholding all medication meantime; a doctor from the out-of-hours service diagnosed a possible chest infection and prescribed an oral antibiotic – which Mr. A was unable to swallow; and a second doctor from the out-of-hours service had administered an intra-muscular injection of Diclofenac for pain. However, Mr. A was still restless and seemed distressed, which left the care home staff feeling helpless and frustrated because they did not know how to help Mr. A be comfortable and/or peaceful.

The situation had become even more difficult overnight, when along with being restless and distressed Mr. A's breathing had changed to become laboured and noisy. Thinking that Mr. A could now be dying imminently, staff called the out-of-hours service again for advice. They also called Mr. A's sons to come and be with their father.

When I first saw Mr. A, he was lying in bed with his head extended: his eyes were open and glazed; his breathing was shallow and noisy; his brow was furrowed; his mouth was dry; and he was moaning and pulling at his bedcovers. I could see that Mr A was uncomfortable, agitated and distressed.

In my previous role, as senior staff nurse in the In-Patient-Unit of a hospice, Mr. A would have been assessed daily by medical and nursing staff who were either on-site or easily contactable. Those staff would have known the patient's case and had knowledge about the personal and technical skills that minimise suffering and distress in a person who is dying. For example, Mr. A would have had a prescription chart with anticipatory medications prescribed on it. I, as a registered nurse, would have been authorised to administer those medications as I judged appropriate – up to a pre-determined limit when I could have called a doctor for further support. I would have had direct access to medical and nursing advice and support, should I need it. I would have had direct access to other supplies and equipment – such as, an airflow mattress to prevent skin breakdown and promote comfort, a fan to ease any breathlessness, and a range of mouth-care supplies. I would also have had access to staff members who knew it was part of their work to sit and maybe hold hands with a distressed person who was dying in an attempt to comfort them. On that day at the RCH, all I had was knowledge and experience about what might help, and a few pillows. So, I showed staff how to carefully re-position Mr. A and moisten his mouth with water to try and make him more comfortable. I also offered some general advice about how to speak softly to him and to gently and carefully rub his back and hands to see if that eased any stiffness and/or loneliness and/or fear.

Mr. A's general condition did suggest that he may have been actively dying. However, not knowing the background to his case I could not be sure. Therefore, although it was proving challenging to speak to a doctor, I agreed with the staff that it was important for a doctor **who knew Mr. A** to examine and assess him. To speed this process up I suggested that staff call the medical practice again and use specific language (e.g. *"Mr. A may be dying. He seems distressed and his condition needs to be assessed by a doctor as soon as possible, please"*) rather than the general language they had been using *("Mr. A's condition is poor, and we would like a visit from the doctor"*). I thought it was important clarify the situation for three reasons. Firstly, to treat any treatable cause for Mr. A's current condition; secondly, to decide if Mr. A was actually dying or not and thirdly, to make and communicate a supportive plan of care with the care home staff and the family.

Staff said they would do this, but were cautious about appearing to *"tell the doctor what they thought was wrong"* based on previous negative experiences from medics when they had offered such opinions.

I found it strange that there was no routine involvement from community nursing staff, I felt regular community nursing input could have better supported the staff and the resident. So, I also suggested that staff contact the community nursing team for advice on mouth supplies and for general nursing support.

The relevant phone calls were made and I went to my meeting in the care home. Before I left the care home for another appointment I visited Mr A again to make sure he was still comfortable, which after further re-positioning, mouth-care and gentle touch and verbal reassurance he was.

I felt anxious and unsettled about how things might progress with Mr. A. Also, not having a clinical role in the RCH or community, I felt helpless to be of any practical support. So, I spoke with the hospice management team to ask if one of our Community Nurse Specialists (CNS) could become involved. I hoped this CNS could speak with the NHS community healthcare team and arrange better support for the resident and the care home staff. This was agreed but could only be actioned on receipt of a medical referral from the residents' General Practitioner (GP). I called the RCH to advise them of this and encouraged them to ask the GP for an urgent telephone referral to the CNS service. I was told that Mr. A had become restless and agitated again shortly after I left. He was seen by another doctor who prescribed medication via a syringe pump. He was also seen by a district nurse (who *"delivered mouth-care supplies and left"* without offering any other help or support).

Sadly, Mr. A died before the referral could be made, and before the prescription for a syringe pump - which could have better managed his pain and agitation - could be organised. This meant that his death was neither peaceful nor comfortable.

The family told the RCH staff that they felt they (the RCH staff) had done everything they could have done for Mr. A. Nevertheless, they were understandably distressed about their father's difficult dying experience.

The care home staff said that they were angry and upset that a resident in their care should have died in such a way. They were also upset that a family should have had to witness such a difficult death. This experience left the care home staff feeling anxious about the level of support they could expect for any future resident who was dying.

1.1 Introduction

I felt perplexed and troubled about Mr. A's experience. I also felt perplexed and troubled about the RCH staffs' experience. This distressing case, and many others like it, led me to seek measures to improve advance and anticipatory planning and co-ordination of care for future residents and staff as part of my professional role. It also became the impetus of my research interest in the social organisation of care home work, particularly how living and dying are organised in care homes without nurses - RCHs. As a registered nurse I work to a professional code of conduct (Nursing and Midwifery Council (NMC) (2015). The latest version of this code states that as a nurse I must *"act as an advocate for the vulnerable, challenging poor practice and discriminatory attitudes and behaviour relating to their care"* (NMC 2015:5). Therefore, in my role as a nurse advocate, my intention for carrying out this research was focussed on ensuring that RCH staff and residents have access to the level of support they need to prevent the suffering in death that was experienced by Mr. A, his family and the staff attempting to care for him as he was dying.

Institutional Ethnography (IE) (about which more is said in Chapter Two) is a method of inquiry designed to examine and uncover the social organisation of knowledge, particularly in relation to the problems, tensions and contradictions that arise as people knowledgably carry out their everyday work. This inquiry is focussed on ethnographic descriptions of the knowledgeable work of RCH staff – specifically the work of Senior Social Care Workers (SSCWs). It empirically traces and maps how SSCWs experiences and working practices are organised within a complex web of institutional practices by focussing on what SSCWs know about the problems, tensions and contradictions that typically arise when they care for older adults with dementia in the last year(s) of their life.

My experience as a professional nurse with a longstanding commitment to improving the experience of people who are living with and dying from incurable conditions is the motivation behind this study. IE, with its assumptions about the social organisation of knowledge, gave me the tools to both use my knowledge about the alleviation of suffering for those facing death and dying and also interrogate many of my preconceptions, assumptions and explanations about how care is (or should be) organised for such people. As my knowledge is important in this research the thesis begins by outlining how that knowledge was socially organised through my professional and academic work. This also gives a brief introduction to the context of the study and highlights what I considered important at the beginning of this research - as a nurse and as a new research student. As the study progressed I had to learn to suspend my training and education about the conceptual practice of palliative care – which was actually nowhere to be found in the material world

- in order to notice and describe the concrete activities and practices that were organised and measured as *"palliative care"* – and which **could** be found in the material and everyday world of work.

This chapter concludes with a brief introduction to each of the subsequent chapters.

1.2 My professional and academic background

I started this study in 2010, one year after taking up a newly created three year fixed term educational outreach role at a hospice in central Scotland. The broad objective of this new role was to support local care home staff to develop their knowledge, skills, confidence and competence in adopting what was termed as a *palliative approach to care*[1].

My professional background before taking up this post included 12 years of experience as Staff Nurse – and Senior Staff Nurse - in the In-Patient Unit of the same hospice. During those years, from 2001 onwards, there was an internal drive within the hospice to encourage all nurses to upgrade their professional qualification to degree level. For me, this meant completing 11 modules of a post-registration undergraduate nursing studies degree over 4 1/2 years. During that time I focussed almost exclusively on the topic of *palliative care* in the assignments at the end of each module.

My professional and academic experience immersed me in the discourse of palliative care and led me to believe that I had a reasonable working knowledge of how to care for people who were living with and dying from

---

[1] Palliative care is the term that is commonly used to describe all aspects of care for people whose disease cannot be cured, and who will most likely die as a result of their disease. The topic what is currently meant and measured as palliative care became a focus in this study and so will be more fully explained and explored in Chapter Four.

incurable conditions. However, as I set out in my new role I recognised that my practical knowledge and experience was limited to the specific context of hospice care, where the patients were mostly dying from cancer and the systems of support were clear and easy to access. I was aware that I had limited knowledge about how care was organised or delivered in care homes - where most people did not die from cancer. Therefore, during the first six months in my new post I arranged to visit all the care home managers in the catchment area of the hospice (n=30). From reading Audit Scotland's Review of Palliative Services (2008), I believed that palliative care work and services were organised differently within geographic regions of Scotland. Therefore, along with introducing myself and explaining my role, I wanted to learn from the managers' knowledge and experience about how palliative care services was organised in and for care homes in the area we both served.

1.3 Developing insight

I conducted informal conversational interviews during my visits to care home managers. Twenty four of the possible group of 30 care home managers opted to participate. These interviews were structured around 20 general questions about care in their care homes. I gathered information on the number of residents living in the care home, the number of medical practices the care home worked with, the number of deaths among residents in the previous year, the aspects of care that the managers thought their care home and staff already did well, and what they thought they could do better with some educational support[2].

---

[2] Neither these visits, nor the data generated from them, are the focus of this study. They are mentioned here to provide a background and a context for the formation of my thinking about the topics of palliative care for care home residents in the geographic area under investigation.

When I asked the care home managers to tell me about palliative care at their care homes they all assumed I was asking about the care of the person who was imminently dying, and dying with cancer. This was a narrower definition of palliative care than I had come to understand from my recent education and the scope and remit of my new role -although it accurately described my experience and clinical practice in the hospice.

Interviewing the care home managers was more emotionally charged than I had anticipated. Many of the managers told me deeply disturbing and distressing stories about older adults who reportedly died in pain and/or distress. They told me about care home staff feeling *"abandoned"* and left to deal with often very sick and vulnerable older adults without any significant NHS support. Unfortunately, the same themes emerged again and again as I taught five rounds of an interactive *Introduction to Palliative Care* course to over one hundred care home staff during my first year in post[3]. Again, I felt perplexed and troubled about how the circumstances staff described came about. I was also unclear about how some care homes had come to be called nursing care homes (NCHs) and others residential care homes (RCH), as from the descriptions staff gave me they seemed to be caring for people with similar needs – but RCHs had no nurses on-site.

1.4 Care Homes: Funding and a two tier system

Since the 1990s many long-term NHS hospital beds for older adults have closed. Bed closures, along with moves to promote earlier hospital discharge for older adults, meant older people could no longer rely on the NHS for long-

---

[3] One of my responsibilities was to develop and deliver palliative care education courses for care home staff. Two courses were offered, a four day course for registered nurses and a three day course for other care staff. These courses were delivered in the education centre of the hospice I worked for.

term care. This generated a gap between what older adults needed and what they could access from the NHS – which resulted in many more community based care homes being built.

Care homes are costly communal residential settings, where people who require a sustained level of care and support that cannot be offered in domestic, acute or other care settings live. Care homes are also complex care settings that cross many care boundaries due to the wide range of needs of older adults living in care homes. For example, older adults in care homes have needs ranging from requiring help and support with intimate personal care such as washing and dressing to requiring help and support to access the appropriate level of NHS healthcare support that is required when a resident is unwell and/or dying (Froggatt *et al*. 2009).

The UK care home sector is large and diverse in terms of ownership. Care home services are provided by Local Authorities and by private and voluntary sectors (Royal College of Nursing 2010). Similar to many countries of the world, Scotland operates institutional care for older adults along a two tier system. A system that differentiates between settings that used to be called “residential care homes” (RCH) and settings that used to be called “nursing care homes” (NCH)[4]. Most people who live in care homes make some contribution toward the cost of their care. The rules surrounding care home fees in Scotland and the other parts of the UK are complex. The level of

---

[4] In this thesis when I refer to both types of care home, I will use the generic term *care home*. When I refer to what used to be called residential care homes I will keep that term and use the abbreviation RCH. When I refer to what used to be called nursing care homes I will keep that term and use the abbreviation NCH.

contribution required is dependent upon a Local Authority financial assessment into how much capital is available to the person needing care.

Capital includes money held in financial institutions, stocks and shares, National Savings Certificates, Premium Bonds, cash, trusts, land and property. There are some circumstances under which property is disregarded from the financial assessment, such as the value of a family home when a spouse is still resident in that home. From 7th April 2014, those assessed as having £26,000 of capital receive no financial help from the Local Authority with care home fees – this group are classified as self-funded. Those with less than £16,000 receive financial support with care home fees – this group is classified as publicly funded. Those with capital between the bands of £16,000 and £26,000 are assessed as having *tariff income* of £1 for every £250 or part of £250 between £16,000 and £26,000. They are then charged for their care accordingly (Care Information Scotland 2014).

From June 2014 the standard rates set by the Local Authority for the publicly funded group was £499.38 per week for RCHs (around £26,000 a year) and £587.00 per week for NCHs (around £30,500 a year). Those who are publicly funded can opt to choose a care home which charges above the Local Authority's standard rate – but either they, or a third party must pay the difference (Care Information Scotland 2014). In reality, many of the publicly funded group will still need to make some contribution toward the cost of their care. This is because, according to Laing and Buisson's UK Market report for 2013-2014 (Laing and Buisson 2014), most people in Scotland can expect to pay around £600 per week for a RCH (approx. £31,000 a year rather than the £26,000 allocated by the Local Authority) and £750 per week for a NCH (approx. £39,000 a year rather than the £30,500 allocated by the Local Authority). Costs can be considerably higher depending on the quality of the accommodation, and other services that are offered. It is worth noting the difference in cost between RCHs and NCHs. RCHs cost the Local Authority approximately £4,500 less than NCHs per resident per year, and RCHs cost older adults (or a third party) approximately £8000 less per year than NCHs. In other words, RCHs cost less than NCHs per resident per year.

Before the closure of NHS beds for older adults in need of long term care the cost of care would have been met by the tax-payer, making it free to the person in need of care at the point of delivery. While care has never been cost neutral, the situation since the 1990s demonstrates a significant shift in financial responsibility for funding long term care, from the tax-payer to the person needing care, or a third party acting on behalf of that person. This has produced a financial burden to the majority of older people who require ongoing care; care which does not extend to the level of regular medical and nursing support this group would have received in long-term NHS care settings. It has also produced businesses that can only remain viable to the extent that they continue to generate capital by maintaining a high occupancy rate.

RCHs provide services classified as personal or social care, this includes aspects of care such assistance with washing and dressing. NCHs also provide personal care but in addition to this they also offer many elements of care classified as *“nursing care”* to meet specific needs described as *“healthcare needs”* (Seymour *et al.* 2011). The care that each setting is registered with the Care Inspectorate to provide, either personal/social care or nursing/health care, dictates the grade and expertise of staffing that is required to operate and manage it. There are moves toward compulsory registration with the Scottish Social Services Council for care staff working in care homes. This will require the compulsory attainment of Scottish Vocational Qualifications (SVQ) during the first period of their registration. The compulsory registration process was in progress at the beginning of this study in 2010. It is still ongoing as the study comes to an end in 2016. Therefore, it is not possible to say how many people with or without formal health and/or social care qualifications, are currently working in Scotland's care homes (Scottish Social Services Council 2009).

The Care Inspectorate regulates and inspects care services in Scotland to make sure that they meet the *right* standards.

After the *National Care Standards for Care Homes for Older People* (Scottish Executive 2001) was published, the statutory distinction between NCH and RCH was abolished in Scotland. As a result these two distinct care settings were reclassified (and their services inspected) under the generic title of *"care home"*. Additionally, RCH staff were encouraged to make their care setting a "*home for life"* rather than risk further *disruptions* by moving residents from the RCH to a NCH as their health inevitably declined. RCH staff informed me that it was less and less common for residents to be transferred out of their care for matters related to declining health, although they may be transferred out if their *"behaviour"* became difficult to manage. While I was getting to know the care homes in my catchment area I found this generic title confusing and misleading. In line with my own observations and the reports of care home staff, I was aware of a range of research studies suggesting that residents in both RCH and NCHs were becoming increasingly frail and disabled, with complex co-morbidities, and often high levels of cognitive impairment (Bowman *et al*. 2004; Froggatt *et al*. 2009; Laing and Buisson 2009). Indeed, a study of six RCHs in England published early in 2010 highlighted that, unlike the past when RCH residents were significantly less debilitated than NCH residents RCH residents now had a range of conditions, treatments and functional disabilities which produced needs broadly equivalent to residents more traditionally cared for in NCH (Goodman *et al*. 2010). The RCH staff I was working with confirmed that their client group *had* changed over recent years. They also confirmed that residents in their RCHs *did* need more help and support that they had in the recent past. This included needing more help and support from doctors and nurses. As vignette 1 demonstrates, and as the RCH workers knew, the availability of NHS healthcare support from doctors and nurses was variable. I will discuss this further in Chapter Five.

What I was reading in the research literature to inform my professional work, combined with what I was consistently hearing from RCH staff during educational courses made me increasingly concerned for the welfare of residents and staff who were living/working in that setting. I began to wonder how to improve the co-ordination of care for residents in RCHs as they were dying.

1.5 Palliative Care in RCHs: The SPAR (Supportive and Palliative Action) Project

Towards the end of my second year in post, in 2010, I was invited to work on a project with a local doctor working as a GP. The project aimed to improve the organisation of care for those who were dying in three RCHs in the area and was called the SPAR (Supportive and Palliative Action) Project

(Appendices 1 - 4). At the beginning of this project work I was influenced by a number of factors. Firstly, I was influenced by classroom based discussions about the need for improvement in RCHs and NCHs. Care home staff from both settings told me that they thought organisational improvements were needed within their care homes, and also between the care home and the NHS healthcare teams that they relied on for support. Secondly, I was influenced by the recently completed PhD research and publications of Jo Hockley, a specialist palliative care nurse. Hockley had introduced a range of documents, known as *palliative care tools*, into eight NCHs in the Lothian district of Scotland. She claimed implementation of these tools supported a more co-ordinated and process driven approach to care of people who were sick and dying in those homes (Hockley 2006). One tool used in Hockley's work was The Gold Standards Framework for Care Homes (GSFCH) (2005)[5]. GSFCH is an adapted form of the original Gold Standards Framework (GSF) which was developed to guide the practice of palliative care in GP practices. I will say more about the GSF and other palliative care tools in Chapter Four (Section 4.3). Thirdly, I was influenced by the policy document published by the Scottish Executive, *Living and Dying Well*, the national action plan for palliative and end-of-life care (Scottish Executive 2008). This document not only influenced my thinking, but it also influenced the direction my management team wanted me to take during the fixed-term post. Therefore, fourthly, I was influenced by the direction set by my management team.

1.5.1 Opportunities and financial challenges

My management team had expectations about what should be achieved as a result of investing in a fixed-term educational outreach post. Those

---

[5] Jo Hockley's research and palliative care tools will be discussed more fully in Chapter Four.

organisational expectations were increasingly influenced by external pressures and priorities as a result of the publication of the first national action plan for palliative and end-of-life care in Scotland: *Living and Dying Well* (Scottish Executive 2008). The national action plan promoted the implementation of *palliative care tools* as the **primary** means of improving the quality of palliative care in all care settings. At the beginning of the SPAR *Project* I had explored the feasibility of using the tools used by Jo Hockley - the Gold Standards Framework for Care Homes –GSFCH. However any care home wishing to adopt the GSFCH process had to follow an expensive *Quality Hallmark Accreditation Process*. Unfortunately, cost made adopting GSFCH prohibitive for the project I was co-leading. This is because there was no formal budget allocated to the project - beyond funding for the project leaders time and the care homes could not/would not commit to paying the expensive accreditation fees. In addition to budgetary constraints, the project team also recognised that many of the documents used in the GSFCH were complex documents developed **for** healthcare staff **by** healthcare staff. Therefore we thought it would be unfair to expect RCH staff to use them. In the process of looking for a workable alternative we were drawn to a new locally developed document called the Supportive and Palliative Action Register (SPAR) (Chaplin and Patterson 2010) (Appendices 1 - 4). SPAR was developed by a highly qualified senior palliative care nurse and an experienced GP with a special interest in palliative care. It was developed to meet the need to promote palliative care tools in all care settings - mandated in *Living and Dying Well* – as a low cost substitute to GSFCH when the senior nurse was the *project manager for palliative care projects for people with non-malignant conditions* in the NHS health-board we both worked in. This project management role was a fixed-term post in which the post-holder had specific targets to meet within a relatively short time-frame. She held considerable influence over what was deemed important work at that time. The GP was partly funded to promote palliative care projects by a leading cancer support charity. He also held a position of influence about what was deemed important work at that time.

SPAR is a document that uses a traffic light coding system (green, amber, red) in conjunction with a numeric scoring system, to assess, gauge and chart patients'/residents' level of function and rate of decline. Assessments are made on a monthly, weekly or daily basis depending on the coding, numerical score and general condition of the resident. The combination of the colour and numeric coding aimed to help staff recognise which residents may be coming towards the end of their life. It also offered a range of suggested actions to be taken - in conjunction with the residents' GP. Actions included: discussing the change with the family, thinking ahead to what may happen in the near future and commencing or updating an Advance Care Plan (ACP). The aim of commencing and/or updating an advance care planning was to improve the likelihood of well-planned and well-organised care being delivered at the end-of-life. The advance care planning also aimed to minimise the potential for reactive care that may result in what were classified, or conceptualised, as *inappropriate emergency hospital admissions*, *insufficient symptom management* or *inappropriate cardiopulmonary resuscitation (CPR) attempts*.

SPAR had been successfully piloted in a number of NCH in the neighbouring area and there was local interest in developing the pilot further

- to include RCHs. I, along with my project colleagues, (mistakenly) thought the SPAR document seemed relatively simple to use. After discussion with its developers the project team agreed to pilot and evaluate the usefulness of SPAR in the RCH setting as the focus of our project work.

There were four work streams to this year long project. Phase One involved writing to all the medical practices to raise awareness of the SPAR documentation and the actions it suggested, it also included speaking at a conference for GPs and District Nurses (DNs) – which many GPs were paid and obliged to attend. Phase Two included a programme of education aimed at the participating RCH staff and their management teams. Phase Three included the supported implementation of the SPAR documentation into three RCHs. Finally, Phase Four included a series of evaluation meetings and survey questionnaires to evaluate the project from the care home staffs' perspective.

The *SPAR Project* team hoped that implementing this document and process would improve RCH staffs' ability to notice the often subtle deterioration in residents' condition as they were dying. We also hoped it would improve their ability to raise awareness of that deterioration with families and with their NHS healthcare support teams.

During Phase three of this project the incident in vignette 1 occurred. It is not my intention to criticise individual practitioners in any of the vignettes included in this thesis. I recognise that everyone involved was working within the constraints of a complex health and social care system. Nevertheless vignette 1 highlights that a significant gap existed between what Mr. A, his family and the RCH staff attempting to care for him needed in terms of medical and nursing support and what they actually got. As a result of what had happened to Mr. A, the SPAR *Project* team became even more convinced that there was a need for a more co-ordinated approach to care for RCH residents. This incident strengthened our resolve to drive and support the implementation of SPAR in care homes because we wanted incidents like this to become a thing of the past and naïvely thought that implementing this document was the means of achieving that end.

1.6 My academic entre to the study

I was asked to present on the work I had been doing with SPAR at a special interest group hosted by the University of the West of Scotland (UWS). This led to an opportunity to apply for a studentship on a postgraduate research programme. As a result of all that is reported above, I applied for and was granted a level of funding that made it feasible for me to embark on this part-time study.

I had heard many disturbing stories about care home residents' experiences at the end-of-life and many stories about how RCH staff were left feeling unsupported. I wanted to shed light on the issues faced by staff working in RCHs as they attempted to care for older adults with dementia who were dying. I also wanted to suggest concrete changes so RCH staff could tell stories that had more peaceful endings in the future.

During the first year of this part-time academic programme, and before I made a final decision on IE as the method of inquiry, I was required to begin a formal process of immersion in the professional and academic literature. This was to orientate my knowing towards what already had been written about work that was categorised as *palliative care in care homes*. It was also to meet one of the criteria built into the assessment processes within the institution of the University - to produce a publication. In my case this was a publication about the organisation of palliative care in Scottish care homes (Reid *et al.* 2012) (Appendix 5). This publication was not generated from the knowledge I gained from the care home staff who told me about their difficult experiences of caring for older people who were dying (classified as *"anecdotal evidence"* within the academic world I had learned to navigate throughout my undergraduate degree programme). Rather it was produced from the knowledge of researchers, policy makers, auditors, regulators and others who in some way had the power to rule over how care homes were represented or organised, without being present as workers within them. I, like those I worked with in my professional role, took it for granted that these *"authoritative ways of knowing"* (Campbell and Gregor 202:17) were the right way of knowing about how things actually worked in care homes. I present the following section as a snapshot of how my knowing was socially organised by that professional and academic literature.

1.6.1. Palliative care and care homes

Most Europeans are not expected to die before they reach late adulthood. - late adulthood is typically categorised as being aged 65 and older (Leon 2011). In the UK, the majority of older adults continue living in their own homes as they grow older (Joseph Rowntree Foundation 2012), however some older adults with complex long term care needs will require the additional support offered by a care home. People enter care homes for many reasons, including the need for support with physical, psychological, social and personal care needs (Steves *et al.* 2009). People also enter care homes because they have ongoing care needs that no longer fit the criteria to remain in cure focussed acute settings such as hospitals, or intervention focussed specialist settings such as hospices. This is despite care homes having limited expertise in managing the level of care that those patients require (Seymour *et al*. 2011). The combination of these and other factors (more fully explored in Chapter Six, Section 6.3.2) means that many of those who move into care homes are frail and living and dying with complex needs (Bowman *et al*. 2004, Seymour *et al*. 2011). Most people admitted to a care home will not be discharged home but will die in the care home – or die after being transferred from the care home to hospital. Before they die many older people experience a range of distressing and uncomfortable symptoms such as pain, breathlessness, fatigue, anxiety and depression (Royal College of Physicians 2007). In order to promote the best possible quality of living and dying, it is important to be intentional about seeking effective measures to ease the suffering that these symptoms produce.

A significant number of older people who will die from complex life-limiting illness experiences such as cancer, circulatory and respiratory conditions also have dementia (Froggatt and Parker 2010, Goodman *et al*. 2010, National Council for Palliative care 2006). According to the Mental Welfare Commission, up to 70% of care home residents in Scotland may have a degree of cognitive impairment from dementia (Care Commission, Mental Welfare Commission 2009). This means that people with dementia make up a significant percentage of the Scottish care home population. There is a growing trend in the healthcare literature to classify dementia as a *terminal* condition that could benefit from the application of *palliative care* (Sampson 2010). Palliative care is the term that is used to describe all aspects of care of people whose disease cannot be cured, and who by implication will most likely die as a result. Dementia has a prolonged terminal phase that tends to progress slowly (Hennings *et al.* 2010). Deterioration is typically punctuated by periods of illness which arise as a result of problems such as pneumonia (Hicks *et al.* 2010). Deterioration is also associated with problems that follow sustaining a fracture (Sachs *et al.* 2004). Despite the significant challenges that advancing dementia brings, effectively identifying and managing those challenges becomes increasingly problematic as the disease, and the associated communication difficulties, progress (Social Care Institute for Excellence 2013). The challenges around identifying problems pose particular difficulties for those attempting to support older people with dementia to both live and die well (Froggatt and Parker 2010, Goodman *et al.* 2010, National Council for Palliative care 2006).

In the UK, the most recent studies put the number of deaths in care homes at between 16-20% of the total number of UK deaths (Ahmad and O'Mahony 2005, Gomes and Higginson 2008, Leadbeater and Garbe 2010). According to a report commissioned by one of the largest private care home providers in the UK, the average (adjusted) length of stay in their care homes, from admission to death, was around fifteen months - between 2009 and 2010 when the data was collected (Forder and Fenandez 2011). This makes care homes an important setting when thinking about where and how people die. Although it is difficult to say exactly how many deaths in care homes are specifically attributable to dementia, the prediction that one person in three over the age of 60 will have dementia when they die, by the year 2025 (Brayne *et al.* 2006) suggests that this group will continue to represent a significant proportion of those who live and die in care homes in the UK.

1.6.2 The clinical challenge of caring for people who die in care homes

The professional experiences I have cited in this chapter are congruent with the findings of other researchers who suggest that there is an imbalance between the ideal and actual provision of care for older people who are living and dying in some of the UK's care homes. This raises concern that some of the most vulnerable members of our society could be receiving sub-optimal care in the final phase of their life (Hall *et al.* 2002; Hockley 2006, Seymour *et al.* 2011). Therefore, the task of improving care for those who die in care homes could be considered as a clinical challenge. The blame for poor quality care is often laid at the feet of specific practitioners or individual care homes, and inadequacies tend to be attributed to lack of knowledge and/or training of care home staff (Froggatt 2001, Froggatt *et al.* 2009, Katz and Peace 2003). However, attributing the problem of suffering in death and dying in care homes to gaps in training is too simplistic an explanation for understanding the full extent of the complexity of the current situation (Seymour *et al.* 2011) as this study will demonstrate.

1.6.3 Understanding how older people die in Scotland's RCH: an academic challenge

Understanding how older people die in Scotland's care homes could also be considered an academic challenge. This is particularly the case for people who die in RCHs because while there are some studies that focus on general care in RCH (Joseph Rowntree Foundation 2008, Gage *et al.* 2010), few focus on care of the dying in RCHs specifically meaning there is minimal knowledge about this topic (Ellis-Smith 2014, Froggatt *et al.* 2002). The majority of UK studies since the 1990s which have focused on care of the dying have been carried out in NCHs rather than RCHs (Froggatt 2001, Froggatt *et al*. 2009, Goodman *et al*. 2013, Hennings *et al*. 2013, Hockley 2006, Katz and Peace 2003, Seymour *et al*. 2011, Turner *et al*. 2009). Furthermore, most UK studies about care of the dying in care homes have been conducted in England (Froggatt 2001, Froggatt and Payne 2006, Froggatt *et al*. 2009, .Goodman *et al*. 2010, Goodman *et al*. 2013, Hennings *et al*. 2013, Seymour *et al*. 2011, Turner *et al*. 2009). England has different policies and practices to guide and support care of those deemed as having palliative care needs including: different regulatory bodies, different funding streams and different national policy initiatives. Differences in statutory and regulatory practices between England and Scotland, along with the differences in setting, mean that the knowledge generated from studies about what is classified as palliative care in English *NCHs* is not transferable to understanding how care of people dying with dementia is organised in *RCHs* in Scotland.

As a result of all that is detailed in this chapter, I considered inquiring into how care is organised for older adults who are dying from/with dementia in RCHs as being both important and necessary.

1.7 Chapter summary and introduction to subsequent chapters

This chapter has introduced me, as the researcher, including why I decided to undertake this research project. It has also introduced the reader to the way my knowledge about care of people who are dying in RCHs was organised by the professional and academic discourse of palliative care.

I will now outline a brief introduction to the content of each subsequent chapter of this thesis.

Chapter Two: Finding a place to begin, finding a way to proceed: Institutional Ethnography: This chapter introduces the method of inquiry I adopted to use for my study, giving a rationale for my choices. It introduces the group whose standpoint/subject position I adopted for this study - Senior Social Care Workers (SSCWs) and the care setting – a RCH in Scotland. It also describes the approach I took to data collection and data analysis.

Chapter Three: Presenting and analysing data from within the research site: This chapter presents and analyses the data I gathered from the research site. It recounts how SSCWs were drawn into work that granted frailer residents admission into the care home than had been the case in the recent past to *"keep beds filled"*. SSCWs described how conversations about the DNACPR form arose from the *"serious illness"* category in the resident's personal file/care plan - to meet the RCH management's expectations. From my interviews I learned how the RCH managers work was articulated to the Care Inspectorate processes as a means of managing *"standards"* in the care home and managing the reputation of the care home as a business.

Chapter Four: Reviewing key literature to trace, analyse and discuss the development of an authorised version of *palliative care*: This chapter explores the evolution of the term palliative care. It also traces and maps the development of an authorised version of the conceptual palliative care practice as that concept was embedded in palliative care tools and frameworks mandated by the Scottish Government.

Chapter Five: Chapter Five: *"Difficult visits…to difficult patients….at the expense of your other paperwork…and meetings"* and *"they are a social care setting and - and we only cover nursing care homes":* factors

influencing the social organisation of medical and nursing work in the RCH: This chapter presents an outline of the data I gathered from a GP participant and from a documentary analysis of one aspect of GP remuneration. It demonstrates the way in which GPs were not remunerated for work associated with the DNACPR form for most RCH residents but were pulled into other forms of income generating work for the GP practice. This chapter also draws on my own knowledge about how the NHS Care Home Liaison (Nursing) Team was socially organised to exclude RCH residents from their caseload.

Chapter Six: “*Trying to prevent hospital admissions by re-structuring care*” and “*our expectations are the same*”: factors influencing conversations about “*serious illness*” in the RCH. This chapter presents data gathered from a palliative care facilitator who was socially organised to promote advance care planning in care homes through the *My Thinking Ahead and Making Plans* document as part of a larger Scottish Government initiative to reduce NHS spending on those over 75. It also presents a review of the authorised literature on advance care planning, CPR and data gathered from a Care Inspectorate Health Advisor (CIHA). The CIHA was socially organised to classify the presence of the DNACPR form and staff attendance at educational events about the DNACPR policy as evidence of *quality palliative care* being delivered in care homes – through textual practices associated with advance care planning work and other activities. The inspection criteria was the same, no matter the staff group working in the care home or the level of external support from NHS doctors and nurses available to the care home staff and residents. The work of both participants influenced the topics SSCWs discussed with family members at routine care review meetings, and drew SSCWs into work that met the needs of the care home company – to maintain a high quality grading – and the needs of the Scottish Government - to reduce NHS spending – but did not meet the SSCWs need for medical support with what is classified in the DNACPR policy as a *medical decision*.

Chapter Seven: Putting it all together: ruling concepts and practices, explanations and conclusions: This chapter weaves the threads uncovered in this research together to demonstrate how RCH staff and others took up ruling concepts and practices without reference to what was actually happening. In so doing they (intentionally but unknowingly) took up the very tools of oppression that dominated and overpowered their own and others lives. The study concludes that the contribution to knowledge generated by this research will be to show SSCWs and others how they unknowingly participate in taking up actions that are not in their own or others interests. It is hoped that this will be the basis of changing the conditions of SSCWs and others lives - thereby advancing anti-oppressive work.

Chapter Two: Finding a place to begin, and finding a way to proceed: Institutional Ethnography

2.1 Introduction

In relation to nursing research in the UK, I have chosen a relatively new method of inquiry to answer my research question: Institutional Ethnography (IE) (Smith 1987, 1990, 2002, 2005, 2006). IE could be described as a process of empirically exploring and mapping powerful ruling knowledge practices which are always present but typically *unseen* in relation to understanding how and why things happen as they do in everyday working life.

IE begins in the everyday working lives of those whose standpoint/subject position has been adopted. Therefore to root the writing of this chapter in that subject position, Part One of Chapter Two includes two more vignettes. The vignettes are constructed from stories reported to me by Senior Social Care Workers (SSCWs) working in RCHs. I will use the first vignette to explain and discuss the fundamental aspects and terminology of IE and also explain why I decided to adopt the standpoint/subject position of SSCWs working in a RCH. I will use the second vignette to outline how I came to my research question – which is focused on uncovering the way in which SSCWs knowledge and experience was subordinated to official or authorised knowledge practices about death and dying. The entry point into this inquiry concerned the requirement to have a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) form in residents' care files to prevent CPR automatically being carried out when s/he died. I chose to follow the thread of CPR and the DNACPR form in this research because I felt it represented an extreme example of important but under-represented problems and contradictions present in the work of SSCWs. The key objectives of this research were firstly to treat the SSCWs as expert knowers of their world – in that they knew their way around that world and knew how work was done within it – and secondly to explore and explain how the world of the SSCWs was tied into specific forms of knowledge that authorised, categorised and directed work in the RCH in ways which did not meet SSCWs needs for medical (and nursing) support.

Part Two of this chapter goes on to describe and discuss the specific principles of procedure I adopted for this study. This includes detailing: the problematic (or point of tension) identified for this study; how the research question was finalised; how the data collection and analysis proceeded; and why I chose to include vignettes and maps in this thesis. Part two ends with a brief discussion of challenges encountered during the research process.

2.2 Part one: Choosing the method of inquiry

As outlined in Chapter One, I was concerned about the lack of support that RCH staff told me they experienced from doctors (and nurses) as residents with dementia became sick and died.

My research question at the beginning of this study, before I settled on IE as the method of inquiry, was very broad, and conceptual: *how is palliative care organised for RCH residents with dementia in Scotland*? To answer this question I first considered using Action Research or Case Study Research, but then I listened to two online lectures. The first was given by sociology professor Dorothy Smith, the original theorist of IE. She explained how IE could be used to explore how and why troubling experiences occurred as they did (University of Oregon 2010). The second was given by Dr Janet Rankin (British Columbia Nurses Union 2010) a nurse researcher who used IE to uncover how powerful management systems had overtaken nursing work and negatively affected patient care (Rankin and Campbell 2006). After further reading about how IE had been used to investigate other healthcare issues and inequalities (Campbell 1984, 1988, Campbell and Gregor 2002, Diamond 1992, 2006, Mykhalovskiy 2001, 2003, Mykhalovskiy *et al*. 2004, Lane *et al*. 2010) I was persuaded that IE could offer a means of understanding how institutional practices were impacting the (dis)organisation of care for people who were sick and dying in RCHs. It also offered a means of empirically mapping the problems that characteristically arose as a result of those institutional practices. This meant the research could be useful and productive in terms of: raising awareness about the problems facing the staff group whose standpoint/subject position I took; pinpointing how and why those problems had arisen; and offering recommendations for change.

2.2.1 Philosophical assumptions of IE

Like all methods of inquiry, IE comes with a history and underpinning philosophy. This history and philosophy commit the researcher to a particular stance in relation to what she *can* see and know during the research process. They also commit the researcher to adopting a position about who she is vis-a-vis research participants.

The historical backdrop to IE originated in Dorothy Smith's consciousness raising experiences in the North American women's movement of the 1970s:

> *As women we came together to talk, knowing only that we had something to talk about, much to talk about; but what we would talk about was, at the outset, without a name…Within the consciousness raising we practiced in many forms…the transformative step became*

> *naming our experiences and constituting thus an inter-individual territory among us as subjects who could now speak our experiences; our spoken or written experiences could thus become the bases of political organisation and activity. We became subjects for each other in a new way. (Smith 2005:78-79)*

From this starting point of consciousness raising and naming, Smith developed IE as a systematic and scholarly method of inquiring into women's experiences of power and/or oppression by uncovering the always powerfully present but usually unrecognised institutional practices that influenced and directed their lives (Smith 1987)[6]. By focusing on institutional practices, and how knowledge about those practices is socially organised, IE rejects theoretical constructs such as race, gender, sexuality or socio-economic status as the primary explanations for how everyday experiences happen as they do (Campbell and Manicom 1995, mith 2005). Instead, it aims to explore, discover and illuminate how troubling episodes are often unintentionally but systematically, administratively and institutionally (dis)organised. Its purpose is to raise awareness of how troubling episodes are experienced in people's lives and how they result in oppression and/or negative outcomes: such knowledge may lead to recommendations for change.

As a sociologist, Smith was influenced by the work of a range of scholars such as Karl Marx (1954), George Herbert Mead (1938) and Mikhail Bakhtin (1981). She took Marx's ideas about materialism, the economy and relations of exchange; Mead's ideas about symbolic interactionism as co-ordinating features of people's actions; and Bakhtin's ideas about conversational

---

[6] Smith has since broadened the applicability of IE as a method of inquiry into any situation where any *person* faces any kind of oppression (Smith 2005).

analysis. She then constructed a conceptual framework for understanding how the social world is organised. Although the philosophical underpinnings of IE are constructed from scholarly theories and concepts, the practice of IE is always firmly grounded in the embodied day-to-day happenings of everyday life. Therefore an IE does not begin in the library or in the conceptual world of theories and/or ideas, such as the conceptual practices that are categorised as *"palliative care"*; nor does a literature review carry the framing authority for a study that a conventional literature review does – although a review of the authorised literature (found in Chapter Four) is both important and necessary. Rather, IE's analysis begins (and remains) in the embodied experience of people who are involved in a fairly routine, but somehow puzzling or troubling activity. By never substituting theory for analytic interest in people's talk, activities and work with texts, it aims to uncover how that group's knowing has been socially organised - by what authority and using what methods.

IE is an inquiry into *social relations and the social organisation of knowledge and power*, however in IE the social is not defined in terms of personal relationships. Rather, the social is described as any activity that people are doing with purpose and intent which coordinates and is directly linked with the activities of others. This co-ordinating function is often achieved through the use of a variety of internal and external texts. Therefore, there are two sites of significance to the institutional ethnographer. Firstly, she is interested in the local setting (with local texts) where the issue under investigation has arisen and the inquiry begins and secondly, she is interested in the extra-local setting (with extra-local texts) where the investigation leads. Extra-local settings are any settings outside the local setting, but which influence and direct how everyday life in the local setting can proceed. For example, everyday care home work is influenced and directed by the everyday work of regulators and educators. The regulators' and educators' work is influenced by researchers', legislators' and policy makers' work, and so on. Each person within these groups is considered as an expert knower of their own work, including how it is mediated through the use of particular texts relevant to their work, such as policies, procedures and protocols. Despite the influence each group of workers has on the experience of others, what one group knows about what actually happens does not extend very far into the (textually mediated) work of others in the wider group. IE was designed to bridge that gap. Investigating an issue from local and extra-local sites means that IE is not confined to what can be observed directly, nor is it restricted to what research participants have directly experienced. Rather IE is a method of inquiry that can be used to uncover the extended bureaucratic, legislative, professional and economic relations impacting and directing the production of local events and local activities – as those activities have been mediated through the use of texts. In IE administrative and governance texts such as protocols, pathways and policies are known as *relations of ruling* because they co-ordinate peoples thinking and people's acting at work (Smith 1987, 1990, 2002, 2005, 2006). Finding, following and mapping the specific relations of ruling that come to bear on the experience under inquiry is a major part of the work of IE. In this way:

> *The ethnographer is not looking for agreement among different informants, but for the intersections and commentaries of their*

> *different accounts in the (social) relations that coordinate their work (Smith 2005:63).*

The aim is to discover, highlight, and map the particular work processes, intersections and discourses that have coordinated and produced the experience under inquiry. Smith states:

> *The investigation of textual practices makes visible many phases of the organisational discursive processes that are otherwise inaccessible. In particular, the formality, the designed, planned and organised character of formal organisation depends heavily on textural practices, which coordinate, order, provide continuity, monitor, and organise relations between different segments and phases of organisational courses of action etc. (Smith 1990:217).*

While IE seeks to track and discover how experiences have been socially organised to happen as they do, its aim is not to find or expose *"villains"* - people who have set out to produce negative outcomes with malicious forethought and intent. This is because the production of negative outcomes in modern institutional settings is a complex matter, typically produced inadvertently by people who view themselves as helping others in some way, and who are going about their everyday accountable working practices in good faith (Smith 2005).

2.2.2 Learning to notice the relations of ruling

As is typical in studies using IE, the process of refining exactly what I was going to investigate, and exactly what I was going to look into involved a prolonged period of *"stumbling about"* (Diamond 2006: 47). DeVault and McCoy (2002:755) describe this phase of the IE research process as:

> *rather like grabbing a ball of string, finding a thread, and then pulling it out; that is why it is difficult to specify in advance exactly what the*

> *research will consist of. IE researchers know what they want to explain, but only step by step do they know who they need to interview, or what texts and discourses they need to examine.*

To *grab the ball of string and find a thread,* Campbell and Gregor recommend beginning an IE by writing up an account that contains a puzzling event and then noticing the organising features, or relations of ruling, embedded in that account. Beginning with actual events gives an entry point into the inquiry, and gives the researcher an opportunity to start learning about the topic under investigation *"as those who live it know it"* (Campbell and Gregor 2002:47).

To follow this protocol I constructed vignette 2. This vignette also demonstrates the importance of my decision to adopt the standpoint of SSCWs from RCHs - an important but typically under-represented and under-researched group of workers.

The events described in vignette 2 were reported to me during the course of my everyday work (to discuss and promote the implementation of the SPAR register in care homes) by three different people over an eight week period. I constructed the vignette shortly after those conversations took place. I have highlighted some of the relations of ruling embedded in vignette 2 in bold text. This is to draw the reader's attention to the varied and complex aspects of the institution that powerfully entered into, directed, and at times restricted, the range of actions that were open to the SSCWs. I also wanted to highlight some aspects of the institutional discourse used in describing events at work. Institutional discourse does not name people as the individuals that they are in actuality, but rather defines them in terms of the pre-given categories that they occupy within the world they describe (e.g. resident rather than older adult with needs, care home staff rather than person who offers another person support, power of attorney rather than person who speaks on behalf of someone unable to speak on behalf of themselves etc.). I have also highlighted other forms of institutional discourse such as diagnostic labels and care settings because it is important to begin to see how these pre-given categories determine (and restrict) the functions and activities that could take place within the context of this RCH. Constructing these vignettes built my capacity to notice the social organisation of ruling and ruling practices as they were embedded in everyday care work in the RCH. They also directed me to the next stages of data collection.

2.2.2.1 Vignette 2

Resident B is an 84 year old woman with **advanced dementia**. She is cared for in RCH B, which is staffed entirely by **social care staff.**

A **bowel screening kit** had arrived to screen Resident B for **bowel cancer**. Staff followed the usual **protocol** when making decisions for **Adults with Incapacity**: they discussed the test with Resident B's (elderly and well-intentioned) husband because he was her **welfare power of attorney. Resident B**'s husband felt that *"everything should be done"* for his wife, and in his role as **welfare power of attorney** he said that he wanted **care home staff** to carry out the test as soon as possible. The perspective that *"everything should be done"* had also led this man to refuse **a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) form** for his wife.

Staff had difficulty obtaining a bowel sample to complete the test because the resident had recently become constipated. The constipation was discussed with **Resident** B's **GP** over the telephone. The **GP prescribed**

two sachets of a mild laxative per day over the week-end. **Care staff** felt uneasy about the **prescribed treatment** for constipation and the **bowel screening** test. They thought both were *"too much for Resident B to cope with"*. However, they said they had *"no option"* about how to act in this instance because they had received direct instruction from **Resident** B's **welfare power of attorney** and had a specific medical order to follow and **prescription to administer**.

The **prescribed laxative** needed to be dissolved in at least 125mls water. **Resident** B had difficulty swallowing this volume of thick and unpleasant tasting liquid. She refused to eat her evening meal, breakfast, or lunch the following day. She experienced frequent episodes of loose bowel movements over the next three days. This meant she required more frequent assistance with personal hygiene which was uncomfortable because her limbs were stiff and contracted. Increased bowel activity also quickly resulted in red and painfully excoriated skin.

Resident B seemed to be experiencing abdominal discomfort from the laxative and pain from her excoriated skin. This was discussed with the **GP** over the telephone. The **laxative** was discontinued, and **an anti-spasmodic medication** was **prescribed** along with **medicated lotion.** However, she had become weak and dehydrated, and after another telephone discussion with her GP she was hospitalised for a short period. She was discharged from hospital within two days of admission with a DNACPR **Form** in her notes and a recommendation from the hospital consultant that she not be admitted to hospital again but cared for in the RCH till she died. The form and the recommendation produced tension in the relationship between care home staff and the family. However, the SSCW assigned to this woman's care said by returning from hospital with a DNACPR form the issue of CPR had *"thankfully been taken out of her husband's hands"*.

These events marked the beginning of **Resident** B's final period of deterioration. She **died** in the **care home** few weeks later - with occasional telephone support from the resident's GP and a brief daily visit from a district nurse who was assigned to look after a syringe pump that helped to manage Resident B's pain in the last week of her life.

2.2.2.2 The social organisation of Vignette 2

The expert knowledge of the SSCW related to this account is at the forefront of how I use this vignette as data.

RCH staff said they felt pressured into taking actions that were not in the best interests of the resident they were employed to care for. They knew about what it meant to carry out a test for bowel cancer and what an appropriate dose of laxative was. They also knew that making a DNACPR decision for this woman was a medical rather than a family matter. In their view: the test and the dose of medication were *"too much"* for Resident B; and her husband did not understand what CPR would involve for his wife. They knew that being without a DNACPR form placed the care home staff and the resident in a vulnerable position when she inevitably died at the end of a long illness (they knew this from previous experience: see vignette 3 – 2.2.3.1). Writing this vignette from the standpoint of those who were involved in an actual situation helped me recognise the SSCWs knowledgeable work of caring for older adults with needs. It also helped me recognise that they had knowledge about being unable to reliably access a sufficient level of support from doctors (and nurses) when they needed it. In the account in vignette 2, this meant that RCH staff knew they were expected to manage the care of a woman with dementia, who was only a few weeks from death and experiencing difficult symptoms, only with occasional telephone support from her GP – typically initiated by RCH staff rather than the GP. They also knew that nurses were routinely absent in such cases – unless the person had a *"nursing"* need, such as setting up and managing a syringe pump (vignette 2) or delivering mouth care supplies (vignette 1). As in vignette 1, my professional nursing view was critical that there was not direct nursing input to guide or support this woman's care other than as it related to a specific task.

Writing and analysing this vignette, also helped me recognise that RCH staffs' complaint of having little in the way of control in this situation was more than a feeling. This is because their work knowledge was systematically subordinated to institutional and professional dictates. Their actions had to be co-ordinated with specific internal care home policies (e.g. gaining consent for treatment and administration of prescribed medications etc.), specific external laws (e.g. The Adults with Incapacity Scotland (2000) Act), a range of governance and legislation processes around the licencing, prescribing and dispensing of medication, national guidelines on CPR and the DNACPR form, and the specific medical instructions of the resident's GP. The care home staff, as expert knowers of their world, understood that they were accountable for gaining consent to carry out the screening test from the resident's welfare power of attorney, they were accountable for discussing the topic of DNACPR forms at review meetings and they were accountable for administering the prescribed medical treatment – even although they understood that the test, CPR and the dose of medication were inappropriate based on this woman's overall condition. The SSCWs knowledge was not taken up by doctors, who had expertise related to a) discovering the cause of this woman's constipation and prescribing an appropriate treatment and b) deciding on the (in)appropriateness of the screening test for bowel cancer and CPR as an intervention for an elderly woman with advanced dementia who was in the final weeks of her life. Neither was the SSCWs knowledge taken up by nurses who had expertise related to a) managing constipation and other common problems experienced by a person who is dying and b) knowing how to access specific support from doctors – and other members of the health care team.

In this instance, the SSCWs had knowledge and experience which could have been useful in planning the care this woman actually needed, but the range of actions open to them and other RCH staff was largely determined and co-ordinated by people else-where and else-when. Critically the people with ruling power in this situation were people who did not visit and assess the resident. Rather they worked variously in in a distribution centre which posted tests based on computer generated lists, in a GP surgery where GPs time was carefully managed, in a community healthcare office, where district nurses time was also carefully managed, and in a lawyer's office where powers to act on behalf of another were recorded and authorised. In this way powerful relations of ruling that co-ordinated what happened in this account were produced. If SSCWs, or any other RCH workers, had chosen not follow the actions they were directed to take by the doctor, the legally appointed proxy decision maker, or the management systems organising the work of doctors and nurses, their behaviour could have been categorised as incompetent or even illegal.

Constructing vignette 2 and identifying some of the ways the relations of ruling organised what actually happened helped me begin to recognise the powerful but mostly unrecognised forces at work in this episode of care. Rather than looking to the RCH staff to understand the way this case developed I considered these happenings as clues about the possible (dis)connecting of people's practices – practices that, as a result of this research, I have come to recognise as drawing RCH staff into external policies and agendas that are not unfolding in the best interests of residents or staff.

What is notable, regarding the IE method of inquiry, is recognising that the staff who described the events cited in this research *participated* in activating the relations of ruling and bringing the circumstances about by their actions. In vignette 2 participation included speaking to Resident B's husband about the bowel screening kit and CPR as an intervention, and administering the medication prescribed by the GP. They activated the relations of ruling, taking them for granted, as they went about their everyday working lives. Indeed their actions complied with their professional standards and organisational structures. Despite complying with these standards and structures, the outcome in this instance was an episode of prolonged pain and discomfort for a woman with advanced dementia who was in the final weeks of her life.

There is a significant gap in our understanding about *how* episodes such as those in vignette 1 and 2 are produced - and re-produced. Understanding such gaps is the aim of this study using IE.

2.2.2.3 Adopting a standpoint

Smith first identified her method of inquiry as a *"sociology for women"* (1987). Important to this sociology, or method of inquiry, is establishing a standpoint. Establishing a standpoint, or subject position, provides the researcher with a starting place for an inquiry rather than being a *"means of identifying any socially determined position or category of position in society"* (Smith 2005: 10). In adopting a subject position, or standpoint, the researcher is not interested in favouring the knowledge of one group over another, but in rooting the study in the social location of a group experiencing a problem. The purpose of adopting this subject position is to look out and empirically discover the social relations that connect and co-ordinate the standpoint group's activities with the activities of others in a way that acts to *produce* the experience under investigation. Smith has since broadened the language she uses to identify IE from a sociology for women to a "*sociology for people"* (2005) in recognition that it is not only women who are organised in ways that subordinate and over-rule their knowledge about what is actually happening.

Smith identifies IE as a method of inquiry into how local experiences are organised and coordinated in ways that do not make sense in the context of people's everyday lives (Smith 1987). For example, it did not make sense to the SSCWs in vignette 2 that an elderly woman with advanced dementia be tested for bowel cancer when they knew she was too frail to undergo further testing for that condition, or the medical or surgical procedures available as treatments. Additionally, RCH staff in vignette 1 and 2 knew they needed medical support to provide care for residents who were sick and dying. They attempted to get help from doctors (and sometimes nurses) and it did not make sense that the level of help and support available was focussed on single symptoms in isolation of the context - and the knowledge of the RCH workers.

SSCWs are a group of RCH workers caring for a group of older people in need of care and support. Both groups are predominantly female. The work and experiences of SSCWs are important, but knowledge about their work and knowledge about the problems that they face are not well known or understood, partly because they have received little research attention – even though their work has undergone massive changes since the 1990s. Therefore, I decided it was important to adopt the standpoint of SSCWs to understand why that group are expected to manage sick and dying residents with minimal support from doctors and nurses – as described in vignette 1 and 2. I also felt it was important to adopt their standpoint to disrupt the taken for grantedness of the work processes that were problematic for the SSCW by studying the social organisation of those work processes (Campbell and Gregor 2002).

2.2.2.3.1 Regulating care work and care workers

To work as a SSCW a person must register with the Scottish Social Services Council as a *Supervisor in a Care Home Service for Adults*. The SSSC is a body created by the *Regulation of Care (*Scotland) Act 2001 (Scottish Government 2001) and established on 1 October 2001. The *Regulation of Care* (Scotland) Act 2001 (Scottish Government 2001) charged the SSSC to deliver on five main tasks:

1. To establish registers of key groups of social service workers.
2. To create and publish codes of practice for all social services staff and their employers.

3. To regulate the conduct of all registered workers.
4. To regulate the training and education of the workforce.
5. To undertake the functions of the National Training Organisation for the Personal Social Services (Scottish Government 2007).

Establishing a compulsory register to include all social services workers has been a significant undertaking for the SSSC, therefore compulsory registration has been a long-term project that has been phased in on a staff group by staff group basis. Registration began 2003 with the registration of all Social Workers. It is due to end in 2020 with the registration of the final group to join the register, Home Care Workers (Scottish Social Services Council 2014).

At the research site, registering as a supervisor meant that SSCWs had to agree to work toward attainment of a Scottish Vocational Qualification (SVQ) 3 in *Social Services and Healthcare w*ithin the first five years of registration. Workers were authorised by the SSSC to *"act up"* in a role that they were not registered to practice/perform for a maximum period of six months – such as a Social Care Worker (SCW) *"acting up"* as a SSCW. After appointment to a new permanent position – such as promotion from SCW to SSCW - workers have a six month period to update their registration with the SSSC. Care workers at the research site were not required to possess any formal qualification ***before*** taking up their posts. The SSSC state that:

> *…the Register for social service workers is* ***function based, rather than qualification based****. This means that an applicant must be carrying out the relevant duties in a service registered by the Care Inspectorate , rather than holding specific qualification (Scottish Social Services Council: MySSSC guidance 2014:10)*

It is worth noting that despite the increased responsibility for managing the needs of frail older adults, the practice based qualification required for

Supervisors (called SSCWs at the research site) (Appendix 45) is no different than the qualification required to work as a Practitioner (called a Social Care Worker at the research site) (Appendix 46).

There are two parts to a Supervisor's qualification requirements. The first part is a practice qualification, the second part is a supervisory qualification. The practice qualification that participants at the research site were either working towards, or had already attained, was the SVQ 3 in *Social Services and Healthcare* (Award code GH60 23) (Appendix 47). The SVQ 3 in *Social Services and Healthcare* is designed to demonstrate occupational competence in the knowledge and skills needed to perform roles that are described as "*complex and non-routine" (*Scottish Qualifications Authority 2013:3). SVQ 3 qualifications are deemed appropriate for those with *"considerable responsibility and autonomy, and control or guidance of others"* (SQA 2013:3). It is classified as a vocational rather than an academic qualification. It has eight practice based and assessed modules built around the National Occupational Standards. According to the qualification structure (Appendix 47), there are four compulsory units in the qualification, and four elective units. The compulsory units include: (H5RY 04 (SCDHSC 0031) *Promote effective communication*. This unit is worth 9 credit points, where 1 credit point is considered equal to 10 hours of effort meaning this unit should take the average learner 90 hours to complete. Other compulsory units include: H5LD 04 (SCDHSC0032) *Promote health, safety and security in the work setting* (10 points and 100 hours); H5LE 04 (SCDHSC0033) *Develop your practice through reflection and learning* (9 points and 90 hours); and H5SO04 (SCDHSC0035) *Promote the safeguarding of individuals* (9 points and 90 hours). The four elective units have 93 options for candidates to choose from.

Elective unit topics cover a wide range of subjects such as: (H5S1 04 (SCDHSC0328)) *Contribute to the planning process with individuals*; (H5S5 04 (SCDHSC0332)) *Promote individuals' positive self-esteem and sense of identity*; (H5T1 04 (SCDHSC0385)) *Support individuals at the end-of-life*; and (H5TY 04 (SCDHSC3121)) *Promote the effectiveness of teams*. Candidates are encouraged to choose the units that most closely match their work role.

To achieve this qualification candidates must attain 69 and 84 credit points in total. Although there could be a potential difference of 150 hours study time between candidates depending on the units chosen, the assessment method for this qualification makes it difficult to know how many hours are required to complete it. This is because:

> *a simple activity can provide some evidence toward completing a significant number of units. Activities such as a care planning review or meeting with other carers can provide a considerable amount of evidence* (Morris and Hill 2007:140).

Therefore, the evidence generated from one episode of care, such as a care review meeting, can be used to gain credit points in more than one unit. While this makes practical sense, it leads to a lack of clarity about the actual hours needed to complete this qualification.

Participants at the research site had taken just over a year to work through eight units, which were assessed through a process of internal and external verification. Assessment methods included direct observation of working practices and discussion about what has been gathered and written in an *evidence folder*. The average cost for this qualification is £1300, some of which staff at the research site raised through government funding schemes and some of which the care home company paid on the condition that workers remained in the companies employ for a year post-qualification. If they left before this time, they became liable for repaying the employers contribution toward the qualification to the company.

2.2.3 Identifying the problematic and the research question

As I was teaching care home staff about how to care for people who were dying with/from conditions that could not be cured in the context of my professional role, it became clear that there was significant anxiety around the topic of Cardiopulmonary Resuscitation (CPR). Vignette 3 describes an example of why the topic of CPR produced anxiety among care home staff. It describes unsuccessful resuscitation attempt at the research site. It left all who needed to become involved feeling anxious and distressed. This vignette is followed with another preliminary explication of the events using IE. My aim is to continue to uncover what is typically unnoticed and unseen in such accounts.

2.2.3.1 Vignette 3

Ninety six year old Resident C, with a diagnosis of advanced dementia, was dying in RCH B. Her death was not unexpected by the care home staff or her family. She died peacefully at 9pm, with a care home staff member holding her hand as her family made their way to the care home.

Shortly after the death, the staff member followed the care home protocol and legal requirements and called the call centre taking calls for the out-of-hours service, NHS 24. She did this because she wanted a doctor to come and verify the death. Verification of death includes a clinical examination by a qualified healthcare professional to confirm that a person is clinically dead. It was important that verification of death was carried out in a timely fashion. Firstly, and most importantly to minimise delays in communicating sensitive information about the resident's death to her family members. Secondly, to begin the process of having Resident C's body removed from the home by the funeral director appointed by her family.

As the RCH staff member was social carer rather than a qualified healthcare professional, she was not permitted to say that the resident had *died*. So she reported that the resident was pulseless and not breathing, despite actually knowing that the resident had died a number of minutes beforehand.

The call centre at NHS 24 had its own policies procedures and legal requirements. As such the call handler's questions and responses were not her own but prompts and algorhythms on her computer screen. The NHS 24 call handler said she had to clarify the situation and asked the care home staff member to confirm if the resident she was calling about was breathing and had a pulse. The resident did not. The next question asked was: **did the resident have a "Do Not Attempt Cardiopulmonary Resuscitation" (DNACPR) form?** Resident C did not. The next instruction given was to commence cardio pulmonary resuscitation (CPR) and continue until the paramedics arrived.

The care home staff member stated that she was uncomfortable about commencing CPR on this resident. The NHS 24 call handler acknowledged the difficulty of the situation, but repeated the instruction to commence CPR and continue till the paramedics arrived.

Against her best judgment the care home staff member commenced CPR.

Ten - fifteen minutes later the paramedics arrived.

The paramedics followed their protocol for responding to the (reported emergency) situation of a person (now classified as a patient rather than a resident) in cardiac and respiratory arrest. In this case that included: arriving at the care home in an ambulance with a blue flashing light and siren; running through the home to reach the patient as quickly as possible; removing the patient from the soft surface of her bed to the hard surface of the floor to facilitate more effective CPR; cutting her nightclothes to expose her chest; re-commencing chest compressions and rescue breaths; and administering electric shocks with a defibrillator in an attempt to restart the patient's heart. Care home staff reported that this procedure continued for a further 5 -10 minutes.

The attempted resuscitation was unsuccessful.

After the paramedics confirmed that the patient was dead, the care home staff had to find a way to get the Resident C's body off the floor and back into the bed. They wanted to "*tidy her up*", before telling the family she had died, or allowing them to see her. They were unsure about what to tell the family about the failed resuscitation attempt.

Care home staff reported that they felt traumatised by this experience, which they said they had little control over *("had to follow procedures")*. They stated their belief that it violated Resident C's dignity in a number of ways and as a result they felt they had let the resident and her family down. They also reported it had distressed residents in nearby rooms who were in bed for the night and were frightened by all the noise and commotion.

Paramedic staff told the care home staff that they too felt disturbed by this experience, which they said they had little control over *("had to follow procedures")*. They agreed that it had violated the patient's dignity and distressed other residents.

2.2.3.2 Noticing the social organisation in vignette 3 and formulating a problematic

This is another disturbing and puzzling account of an incident that deeply affected all the people who were involved in it, not least Resident C's family. This story was reported to me by the SSCW involved in the incident, the care home manager and two other members of the care homes' staff. I wrote the vignette from my memory of those conversations and from my knowledge of the institutional processes they describe.

As in vignette 2, it would be easy to blame this outcome on the level of competence or incompetence of any of the individuals involved. However, this was not the only such case reported to me by RCH and NCH staff. When staff working for a variety of organisations report similar happenings over a period of time, attributing those happenings to individual behaviour becomes an insufficient analysis. Looking at the situation described in vignette 3 through the lens of IE, and from the standpoint of the SSCW, I began to see specific (dis)junctures within this situation – (dis)junctures where the SSCWS embodied knowing of the situation – which was that an elderly woman had died peacefully in their care, and that her death was expected – had been overruled and subordinated by other more dominant knowledge. Rather than responding to this event as a peaceful and expected death it was abstracted into a medical emergency that required the immediate application of CPR and subsequent attendance of paramedic staff to continue that intervention and assess for further action. That this SSCWs work knowledge - gained from on the job experience - was over-ruled made sense to someone somewhere, but make no sense to the SSCW or the bereaved family. This is the point of tension in this account. It is also the point at which dominant knowledge organises subsequent actions without reference to what is actually happening at the scene. The death needed to be verified by a doctor. To get a doctor out of hours required a call to NHS 24. The NHS 24 call handler's work at the call centre was organised to activate a predetermined algorithm on a computer screen and direct CPR from afar. These events could have been avoided if the resident had a DNACPR form issued by her medical practitioner. This sequence of actions are organised by specific ruling practices. They compelled the SSCW to become involved in a procedure she felt was both inappropriate and out of alignment with her wish to treat the resident's body with respect, and to support the resident's family to sit peacefully with their recently deceased relative to say goodbye. In the process of carrying out her accountable work she activated a complex and interlinked web of ruling relations involved her in producing a traumatic and distressing episode for all who were involved.

In the language of IE, the care home staff and the paramedics were:

> *built into a specialized complex of objectified forms of organisation and consciousness that organise and co-ordinate people's everyday lives (Smith 2005:18).*

As a result, the staff were not free to influence or respond to the situation in front of them in the way they thought best because they had to "*follow procedures*" Textually mediated *"procedures"* positioned them:

> *Outside…her or his own experience of an event of which she or he had been part. (Smith 2005:28).*

In IE, accounts like those in vignettes 1-3 are used as data to explicate the disjuncture between the experience and work knowledge of those who are physically present in a situation and the ruling institutional practices.

Writing and reflecting on vignette 2 and 3 supported me in formulating a research problematic. A problematic is created from the actual material conditions of people's lives. It is focussed on the way in which those whose standpoint has been adopted are organised to participate in particular institutional practices. The problematic for this study was to explicate how SSCWs had come to stand at a difficult juncture between having responsibility to care for older people with dementia - whose overall condition would inevitably deteriorate and result in death – within the bureaucratic and legal practices that surrounded death and dying in the RCH. The bureaucratic and legal practices included the routine application of CPR in the absence of a DNACPR form. I felt this was an important area on which to focus my research because staff told me no one who had been subject to CPR in the RCH had ever survived it – which ties in with research describing the survival rates for care home residents as being *"consistently abysmal"* (Lannon and O'Keeffe 2010:20). Happenings in vignette 3 were also out of alignment with the *Do Not Attempt Cardiopulmonary Resuscitation (DNACPR): Integrated Adult Policy* (Scottish Government 2010:10) (Appendix 7) which states that:

> *In the situation where death is expected as an inevitable result of an underlying disease, and the clinical team is as certain as they can be that CPR would fail (i.e. realistically not have a medically successful outcome in terms of sustainable life), it should not be attempted.*

Resident C had died peacefully in the care home as an inevitable result of old age and underlying disease. Her death was expected by the staff. The care home staff were certain that CPR would fail in this instance – because she was already dead – but their knowledge was overruled and subordinated by the processes surrounding the verification of death, NHS 24 algorhythms, CPR processes and procedures and paramedics' policies and practices.

I felt it was important to understand how institutional practices related to death, dying and CPR in RCHs, because while individual staff members may come and go institutional work processes remain (Lane *et al.* 2010). This means that the social organisation of knowledge within institutions operates across times, locations and people. Therefore, even if ***all*** the practitioners in vignette 3 were removed and replaced by other practitioners the events would be organised to unfold in the same way. The SSCW would still have needed a doctor to verify the death; NHS 24 would have been called; and the directions to commence CPR would have been given in the absence of a DNACPR form. Indeed, if the SSCW, the NHS call handler or the paramedics had acted differently they may well have faced disciplinary action for being incompetent, because competence at work is directly related to employees adhering to policies and protocols.

2.2.3.3 Finalising the research question

The preliminary analysis of vignette 2 and 3, and my work knowledge about educational initiatives being implemented in the geographic area drew my interest to: a) the *Do Not Attempt Cardiopulmonary Resuscitation (DNACPR): Integrated Adult Policy* (Scottish Government 2010); b) the focus of palliative care education initiatives (of which I was a part) and c) discussion of the DNACPR form in the RCH where SSCWs had been drawn into conversations about the DNACPR form with family members – to ask them for permission to obtain a DNACPR form from the resident's GP. Although it had become routine practice in the RCH for SSCWs to discuss the DNACPR form with family members at care review meetings they told me they had been *"pushed"* into having this conversation *"as a result of recent trainings and things"*. They also said that they thought that a doctor, rather than themselves, should discuss DNACPR; that families were often surprised to be asked about the DNACPR form; and that families were often unhappy discussing the DNACPR form with SSCWs because they said they would have *expected* to discuss such things with a doctor. I knew that in my own care setting, a hospice, conversations that included discussion of the DNACPR form were initiated by senior medics. I also knew that, according to the DNACPR policy, discussions and decisions about DNACPR were the responsibility of senior doctors (or under certain circumstances senior nurses), so I was surprised that SSCWs were routinely involved in asking family members about the DNACPR form. As SSCWs described the process surrounding the DNACPR form as a point of tension I identified the DNACPR form and conversation as being of analytic importance in this study.

The final research question became:

How has SSCWs work become tied into the medical, legal and bureaucratic practices that rule death, dying and DNACPR decision making in Scotland's RCHs?

In this study, rather than focussing on value judgements about the rightness or wrongness of individual workers actions, I focussed on identifying the powerful relations of ruling that influenced how SSCWs (and others) were coordinated to participate in the wider institutional processes.

2.3 Part Two: Unravelling the ball of string and following the threads

Part two will detail the procedures and processes followed during this study and the key challenges that influenced its progression. It concludes with key challenges faced during the research process.

2.3.1 Principles and processes of data collection

This study draws on two main research methods: interviewing and textual analysis. To learn about SSCWs work of caring for people with dementia who would inevitably deteriorate and die I conducted ten open-ended interviews between March 2014 and March 2015. I conducted interviews with two groups of participants from within the local site of the care home, SSCWs (n=4) (Semi-structured interview schedule used with SSCWs: Appendix 6) and care home managers (n=3). I also conducted interviews with three participants whose work was extra-local but inter-related to work in the RCH. Extra-local research participants included: one GP with a joint role to provide medical care and lead palliative care initiatives in the community; one Care Inspectorate advisor with responsibility for advising on how to inspect the quality of palliative care provision within the care home; and one consultant physician with input to the national DNACPR policy making process.

All of the SSCWs at the research site were sent to education sessions on how to care for people with incurable conditions they would die from/with. This included awareness raising sessions on the *Do Not Attempt Cardiopulmonary Resuscitation (DNACPR): Integrated Adult Policy* (Scottish Government 2010) that I organised in the context of my professional work. Therefore, my own work knowledge is included as data. Within the distinctive IE formulation of the social organisation of knowledge, my professional location in relation to the standpoint location is used both as a source of data – in that I know what happens; and I know how death and dying can be handled differently to produce less suffering – and also as a point of interrogation.

Within the ontology of IE, my presence and the record of my work knowledge are not considered a problem of bias that need to be overcome. Rather the organisation of my own knowledge is interrogated in the thesis as a way of understanding how knowing is organised, by whom and for what purposes (Campbell and Gregor 2002). Interrogating my work knowledge was challenging and frustrating at times because that knowledge is co-ordinated within powerful concepts and ideologies that often obscured what I could see and understand about what was actually happening. However, by maintaining a commitment to the standpoint of SSCWs I was able to bring key aspects of my work and knowledge into the analysis and mapping of the social organisation of the SSCWs experience (Section 4.3.3 and Maps 4 -6).

The second method of data collection in this study is the use of key texts. Texts were given or indicated to me by research participants. I also used publically accessible material, including health and social care policy and guidance documents, health and social care reports and research, and articles from academic journals. Textual analysis was an important feature of this project because, according to Smith (1987: 17):

> *Texts are the primary medium (though not the substance) of power. The work of administration, of management, of government is a communicative work. Organizational and political processes are a form of action coordinated textually and getting done in words. It is an ideologically structured mode of action - images, vocabularies, concepts, abstract terms of knowledge are integral to the practice of power, to getting things done.*

The data collection process I followed is outlined below.

1. **Start with a social experience that produces a (dis)juncture for the group whose standpoint is being taken. Ensure that the social experience chosen is grounded in an experience of work (Smith 2006)[7].**

   The (dis)juncture identified for this research was those times and places when SSCWs knowledge about what was happening in the RCH when older people with dementia inevitably deteriorated and died was abstracted into institutional policies and practices that overruled what SSCWs knew about family members and residents and overruled what was needed to support a peaceful and dignified death.

2. **Gather data about the (dis)juncture through formal and informal conversations/interviews (Smith 2005).**

   Ethics: to gain authorisation to conduct formal and informal conversations as a means of gathering data for this study, I applied and was granted ethical approval to proceed from the University Ethics Committee

---

[7] According to Smith, work is any activity that *"people do that requires some effort that they mean to do, and that involves some acquired competence"* (Smith 1987:165).

(Appendices 9-11). In the second year of my study I had an unanticipated break in studies due to a prolonged period of ill health. After my return, the University Ethics Committee reviewed my application a second time and again granted permission to proceed (Appendix 12). There were tensions between attempting to treat research participants fairly at the same time as satisfying and complying with the relations of ruling that governed the ethics committee of the university. One reason this produced tension was that the ethics procedures required that I adopt a top down approach to gain access to the research site and recruit participants (Appendix 10: E-mail dated 24th Aug 2011 (12.53): *"You need to ensure permission…has been granted from….those responsible for the staff taking part in the study"*). This need to ensure permission from the care home manager responsible for the SSCWs left some of them feeling that they were obliged to speak with me (which I explained was not the case as detailed in the section on recruiting below). The ethics procedures also required that I describe my research in detail before I found a thread of inquiry to follow (as highlighted in section 2.2.2 above) which made it difficult to complete the necessary application forms to gain approval.

Access: To gain access to the research site I made telephone calls and arranged meetings with the manager of a RCH known to me from previous work-based projects. I introduced the broad topic of the research (which before I found a thread of inquiry to follow was: *How is palliative care organised in RCHs?*) and gained her consent to approach staff in the care home. I chose this home as the research site for a variety of reasons, the most important of which was the good working relationship I had already built with the care home staff and management team making access to the site relatively straightforward and unproblematic[8].

Recruiting: I had already established trust and rapport with a number of the staff at the research site as a result of my professional role. To recruit SSCWs from this group an introductory poster (Appendix 13) was displayed in the staff area of the care home. At the same time information leaflets (Appendix 14) with response cards (Appendix 15) were given to SSCWs and the care home management team. Four appointments with SSCWs were made by a care home manager during work time, and I interviewed staff in a room in the RCH. At the beginning of the interview I explained my reasons for wanting to carry out the research – to understand how care was organised for RCH residents with dementia who were at the end of their lives. I also explained that I was interested in finding out about the work they did in a typical day, particularly as that related to: the work of admitting a resident to the care home; the work of caring for a person whose health was failing; and the work of caring for a person who was dying (Appendix 14). After hearing that they were not obliged to participate and that they could withdraw at any time all four SSCWs

---

[8] Ease of access was particularly important for the progression of this particular project due to the competing demands of employment workload, family commitments and the ongoing health issues that I experienced throughout this study. As research is carried out by human beings it will always inevitably face challenges and constraints. The particular challenges and constraints impacting this particular study are not intended to be read as complaints, but as reflexive declarations of the specific influences surrounding this particular study. However, although there were factors influencing the choice of research site I do not consider that limitation as troubling in this instance. This is because the setting was viewed through the lens of IE where the activities taking place in a specific location are seen as *"a step or moment in a sequence that hooks back into the institutions"* (Smith 2006:136) that influences and co-ordinates the activity taking place in all settings of this type. This method of inquiry suggests that no matter where I would have started, the relations of ruling would have tied the local work of any SSCWs in any RCH to the regional/national/international work of those beyond their own institutions. This means that, no matter where it began, the inquiry would lead to the same end point.

volunteered to participate. In the first interviews I asked SSCWs to tell me about their work and how it was organised. This led staff to talk about care plans, specifically the *"in the event of serious illness"* section of the care plan, which led on to discussions about their concerns regarding the DNACPR form. As a result I focussed subsequent interviews with SSCWs on their knowledgeable work as it related to the DNACPR form, including the conversations they initiated with family members and the texts they were required to use.

Each research interview pointed toward what I needed to ask in the next interview to begin the process of joining the dots in an ever wider and more complex web of interconnected extra-local processes (Smith 2005) related to sickness, death and dying in the RCH. After speaking to the SSCWs I followed the clues embedded in those interviews. This led me to the RCH management team who audited the SSCWs work and were accountable for gathering and reporting on specific data to the Care Inspectorate and sending staff to educational sessions on *"palliative care"*. Talking with the care home management led me to a Care Inspectorate Health advisor who was accountable for advising on how care of those who were at the end of life should be inspected in care homes. It also led me to the leader of an educational initiative to *"improve"* the process of thinking and planning ahead for residents' death and dying in care homes. This participant was a GP who spoke to me about her medical work and also her palliative care facilitation work. My own work knowledge, the knowledge of the palliative care facilitator the knowledge of the Care Inspectorate advisor led me to interview a Consultant Physician with responsibility for developing a national policy on DNACPR. Shifting sites from the RCH did not involve a shift in standpoint. The research always remained rooted in the SSCWs standpoint.

After each person approached for inclusion in the study had: read the information leaflet, listened to the pre-interview information contained in the information sheet (Appendix 14) and heard an explanation of the process of consent, all agreed to speak with me about their work based practices and signed the consent form (Appendix 16). None of the participants recruited for this study, within or beyond the RCH, subsequently opted to withdraw.

This research, like all research, was restricted by the data that was accessible. For example, I could only recruit one (recently retired) GP to the study, other GPs approached declined to participate because they were *"too busy"*. However, the term *"too busy"* in relation to GPs became a common thread in various participants' accounts of work and so became of analytic interest – I was curious to discover what GPs were *"too busy"* doing.

Working with textual data mentioned by the GP, the Care Inspectorate worker and the Consultant Physician enabled me to find, follow and write about the conceptual links contained as traces within that data. These conceptual links were not made on the basis of theories, but on the basis of the materiality of the data, often in relation to ruling ideas and practices about *"advance care planning"* and *"palliative care"* work. In this way I explored how certain knowledge became authoritative and other knowledge became subordinated. In sticking closely with the data, *"the* *data held (me) the researcher accountable to "their" account"* (Campbell and Gregor 2002).

It is important to emphasise that I did not view any of the research participants as a representative sample of workers either within or beyond the RCH. In drawing on IE as a guiding framework I aimed to investigate the social organisation of knowledge that shaped SSCWs experiences and contributed to the aspects of those experiences that they shared in common. According to Smith (1987: 176):

> *The experience of one individual proposes, or can propose, a problematic directing our inquiry to a set of social relations. Exploring those social relations requires that we understand them as generating various actual experiences, in characteristic ways. A grasp of a set of interlinked institutional relations will explicate the generalizing relations determining its characteristic and diverse bases of experience. … **The explication of institutional relations brings to light not only common bases of experience but also bases of experience that are not in common but are grounded in the same set of social relations***

This meant it was not necessary to conduct a large number of interviews with SSCWs, or any other participant because the identification and explication of ruling practices in (and beyond) the RCH would uncover that the social relations themselves were the ground of common experiences.

Open Ended Interviews: I wanted to develop a clear understanding of how DNACPR forms organised the work of SSCWs. To do this I needed to talk with SSCWs in their work setting. The interview procedure was open ended, and the research participants were all treated as experts who were knowledgeable about how work was carried out in their local setting. The focus of the interviews was to gather information about what research participants knew they did, and then use that knowledge as a data resource to illustrate the knowledge, skills and experiences involved in acting as they did - including the difficulties that had to be overcome and the tensions that had to be absorbed (Campbell and Gregor 2002). Interviews with care home managers and other participants were also open-ended.

In IE interviews are used as a means of finding windows into the relations of ruling that shape accounts of everyday work to discover how that work is mediated and controlled through the use of texts (DeVault and McCoy 2006). Therefore, I needed to hear what the experience of everyday work involved and to see and understand the particular documents that organised and shaped that work. I also needed to obtain blank copies of the most relevant documents for analysis during subsequent stages of the research process. At the beginning of each interview with SSCWs, they seemed anxious and guarded about answering questions related to their working practices. I wondered if they felt uneasy because they thought they were under scrutiny and so needed to be careful in case they said something “wrong” or were somehow “caught out”. However, once they realised that I considered them to be experts in the work they did and that I was trying to understand their working practices they were more than happy to show me the various forms relating to the aspect of work I was investigating - even if they were bemused about why I would be interested in such (supposedly) mundane matters as how forms were used. As the SSCWs knew that permission for the research had been granted by the RCH management they were happy to show me these documents and supply blank copies where possible.

The sequence of questions asked during each interview followed the common format of: introduction, warm-up, main- body, cool off and close (Robson (2002). Cooling off was particularly important in this study due to the emotive nature of the subject matter and the distress staff witnessed and experienced as a result of their work.

In addition to these formal conversations I also had informal conversations with the SSCWs and their managers to clarify how texts were used. This information was used to build ethnographic maps of the texts and work influencing practice in the RCH. The ethnographic maps in Chapter Three were eventually shown to RCH workers who confirmed their accuracy. I also had informal conversations with various work colleagues, including a GP, education colleagues, and a nurse from the Care Home Liaison Team. This extended my own work knowledge and has made its way into the research (and ethnographic maps) through my own accounts of work within the wider institution.

2.3.2 Principles and processes of data analysis

A number of approaches can be implemented when analysing data in IE. The level of flexibility that exists within this method of inquiry is highlighted in the introduction to the only text on the practice of IE (Smith 2006) - edited by its original theorist Dorothy Smith, who writes:

> *This book is not a manual: it is not a how-to-do-it collection that will…tell you exactly how to produce a piece of research that others can recognise as institutional ethnography…though there are certainly*

> *some definite principles of procedure, there are many ways of realising them in practice (Smith 2006:1).*

This variety of "ways" meant there was no set protocol to follow, so I reviewed Campbell (2006), McCoy (2006), Griffith (2006) and Turners' (2006) writing on their projects using IE (Smith 2006) to construct a process to guide my study. To construct this guiding process I underlined the actions described by these authors, I also underlined the questions they asked of the data and which contributed to the analysis. I then transcribed and colour coded the actions and questions onto a large piece of flip-chart paper (Appendix 8), before synthesising the actions and questions into one overarching process, as outlined and described below. The principles guiding the process I followed are included below to offer the reader insight into what is considered important when conducting a study using IE and to offer signposts as to how the rest of the thesis should be read.

1 **Treat the experience of work as data.**

2 **Examine the data closely to discover the following:**

- **What the experience of work is, in other words, what it is called or classified as; what the experience of work involves for workers, in terms of actions; what skills or working knowledge is required or assumed to carry it out; what it feels like to be doing this work; what problems and/or successes that routinely arise for people doing this work; how the experience of work is connected and linked to the work of other people; what key texts make this particular social experience of work into a routine, standard, replicable and teachable procedure (or set of procedures) and how this specific episode of work**

is articulated to the wider institutional work processes and the wider institutional order.

This analytic process required that I pay attention to all of the work related to illness, death and dying that was carried out by SSCWs. To do this I reviewed the interview transcripts to discover the tensions, frustrations and contradictions that SSCWs, and other research participants, described.

The "work" of SSCWs included their work to assess and make a decision on resident's suitability for admission to the care home. After admission it included their work to organise a key worker to manage the day to day care needs of residents and arrange regular care review meetings to talk to family members about their loved one's needs and wishes. Care review meetings always included discussions about *serious illness*. This meant talking about wishes related to potential hospital admissions and the family members view on the DNACPR form. The SSCWs work also included efforts to contact GPs to negotiate support. In relation to the DNACPR form this meant asking the GP to supply a completed DNACPR form for the resident's care home files. SSCWs work also included: efforts to negotiate support from GPs as residents became unwell and developed needs related to being unwell and/or dying; efforts to negotiate support from district nurses with specific tasks; attending meetings with the care home management team to discuss resident's care files; attending palliative care education sessions; supervising the work of junior RCH staff and *"running the shift"* when on duty; and adhering to institutional requirements for managing resident's care files and records.

The SSCWs work related to death and dying in the RCH included knowledge about: the difficulty of accessing support from doctors and community nurses; the inevitable decline of an older adult with dementia being cared for in a RCH; and what would happen if the resident did not have a personalised DNACPR form signed by the GP when the s/he died. SSCWs also knew that speaking to family members about the DNACPR form tied their work in with discussions about emergency treatment. They knew this work was difficult for them and for the families they spoke with. They knew that: it created tensions between themselves and the family members and tensions between themselves and the GPs they relied on for support. They knew that that speaking to family members about the DNACPR form was linked with the auditing process of the care home management team; and not having completed DNACPR forms in resident's files created tension between themselves and the management team because it was somehow tied into the grading process of the Care Inspectorate.

There were a number of texts that made SSCWs work with death and dying in the RCH into standardised procedures. These linked the SSCWs work into institutional textual practices. Key texts included: Standardised Sharable Assessment Document; Certificate of Incapacity under Section 47 of the Adults with Incapacity (Scotland) 2000 Act; Schedule 1 Certificated granting decision making powers to a designated person(s); mobility assessment document; four week assessment document; admission checklist; care planning documents; care review documents; personal file (care plan) audit form; DNACPR form; *The Standards of Care for Dementia* (Scottish Government 2011); texts used to inspect the RCH by the Care Inspectorate ; texts used to inform the inspection documents; texts used to inform palliative care education projects; texts used to inform the *DNACPR Integrated Adult Policy* (Scottish Government 2010), including 1) the report on palliative care services by the National Audit Committee, 2) the national action plan for palliative care in Scotland and 3) documents related to the term *"palliative care"* produced by the World Health Organisation (WHO).

According to Campbell and Gregor (2002: 97) reading and writing about such texts analytically can provide a method of inquiry into the social relations that guide work in human services work. In this way:

> *Institutional ethnography acts as a kind of radiography of everyday life, making visible its skeletal underpinnings. Of course, the skeleton is comprised of people's actions that are co-ordinated somehow, including textually…making discoveries about who did what with regard to producing and using the text in question…by following the traces left in those same texts.*

3 **Identify the institutional discourse embedded in the key texts[9].**

The analytic process required that I follow the texts into the nested documents and practices that linked SSCWs work into national and international discourses about palliative care, advance care planning, and the DNACPR policy.

---

[9] In the same way that the social experience of work became data to discover and explore how that work was socially organised, the key texts were also treated as data, to discover and explore the institutional discourse(s) embedded within them. Institutional discourse is defined as any "widely shared professional, managerial, scientific or authoritative ways of knowing (measuring, naming, describing) states of affairs that render them actionable with institutional relations of purpose and accountability. Far more than jargon, these are conceptual systems, forms of knowledge that carry institutional purposes and reflect a standpoint within relations of ruling" (McCoy 2006: 118).

4 **Identify how the institutional discourse identified organises the thinking, talking and acting of the group whose standpoint is being taken by looking for how the discourse shapes the experience/behaviour/work of the group within their own institution.**

5 **Look for ways this experience/behaviour/work becomes linked to/with the work of others outside of their institution.**

This stage of the research process required that I pay attention to the following: the language, categories and certification procedures (etc.) being used by research participants; how groups become the text based object of professional attention; my own allegiance to the institutional discourse, including how that allegiance framed my own thinking, talking and writing throughout the research process; and the extent to which the requirements to think and act as an agent of the institution (an institutional functionary) impacted and influenced the disjuncture under inquiry.

6 **Gain further insight into how the social experience under investigation is *produced* and made *actionable* by extending the interview process beyond the original research site.**

Following principles four to six is the focus of the writing in Chapters Three to Six. These chapters will describe the way in which, to be deemed competent workers, SSCWs were drawn into work that met the needs of the care home as a business and the needs of the Scottish Government to increase access to *"palliative care"* in all care settings and decrease NHS spending – but did not meet their own needs for medical (and nursing) support.

7 **Produce an ethnographically based cartography of the key relations of ruling that have been identified.**

To produce an ethnographic cartography of the key texts organising SSCWs work with DNACPR forms I mapped the texts that produced actual sequences of work in, and beyond, the RCH. I based this aspect of my research on IE researcher Susan Turner's work and her technique of mapping institutions as work and texts (Turner 2006). The maps represent how taken for granted textual practices were located as *"sequences of action"* (Turner 2006:140) that co-ordinated individuals and groups throughout the institution to carry out particular activities in standard but complex sequences of inter-related work - discursively described as *"advance care planning"* and *"palliative care"* work. These complex sequences became the *"acts of the institution"* (Turner 2006: 140). To demonstrate the range of ruling relations coming to bear on SSCWs during this one conversation it was essential to retain the complexity within the maps – in other words I have not attempted to simplify them.

2.3.3 Principles and processes of writing

In IE analysis is done in the writing and as the researcher writes (Campbell and Gregor 2002). To begin the work of analysis, I have included a number of vignettes in this thesis. Vignettes 1-3 are the product of preliminary data collection, Vignettes 4-6 are the product of data gathered as a result of the problematic I decided to investigate.

To check the trustworthiness of the accounts constructed in vignettes 4-6, which were constructed from interviews with four SSCWs and on which this IE is hinged, I showed the vignettes to two research participants who had worked in the RCH as SSCWs (both had since resigned from the RCH as SSCWs because they told me that they found the role too stressful). They confirmed that the vignettes reliably represented the processes described within them. Indeed one participant asked me if a section of dialogue within vignette 5 was hers (it was not) because she said it accurately represented something she might have said about the process of discussing the DNACPR form with family members. Another participant commented that reading the vignettes made her realise the high expectation and level of pressure on SSCWs to perform complex tasks and do so with minimal support.

There are many threads contained within the vignettes that are analytically interesting and important. It was not feasible to follow them all. Therefore, what kept the research project manageable and focussed was using the data gathered within and beyond the RCH to answer the research question: How has SSCWs work become tied into the medical, legal and bureaucratic practices that rule death, dying and DNACPR decision making in Scotland's RCHs?

2.3.4 Challenges

This section outlines the main challenges that were faced during the research journey.

Two significant and unexpected events are worth mentioning at this point. Firstly, I developed a prolonged period of ill health as a result of a post viral syndrome 18 months into this study. Ill health resulted in a break in my studies. Unfortunately it also left me with prolonged health issues. As a result this project has taken place over a much longer period that originally intended. Secondly, shortly after my return to work and study, a media storm grew up around the use (and reported misuse) of the Liverpool Care Pathway (LCP) for the Dying Person (Section 4.3.2). At the beginning of my study the use of this document was advocated in a range of national and local policy documents to guide staff in what was considered *"best practice"* in care of a dying person (Department of Health 2008, Scottish Executive 2008). The chain of events surrounding the withdrawal of the LCP produced a period of shock and critical reflection within my local palliative care community. This mood was captured in a conference speech by a leading figure within the Scottish palliative care community as perhaps heralding *"the end of societies' unconditional positive regard for the practice of palliative care"* (Hazelwood 2013). I include this statement to highlight the level of dis-ease and flux around the topic of palliative care at the time of my return to work and study in 2013 - 2014.

2.4 Chapter Summary

This chapter has outlined the background, philosophy and underlying assumptions of IE as a method of inquiry. It has also detailed what led me to this particular disjuncture, these particular research participants and these particular writing strategies. As a result it has established the direction this inquiry took. Each subsequent chapter will now uncover different threads of social organisation that were the ground of SSCWs experience with DNACPR forms. In following these threads of social organisation I will uncover how that experience was produced and ruled.

I am hopeful that this study, and any publications produced from it, will bring a new perspective into the professional and academic discussion about the social organisation of care in RCHs. I am also hopeful that adding this new perspective into the more general healthcare literature base will raise awareness about the potential usefulness of IE as a method of inquiry for other nursing and healthcare studies.

As IE begins in experience, I will now go on to present SSCWs experience in the form of three vignettes.

Chapter Three: Presenting and analysing data from within the research site

3.1 Introduction

In this chapter I will present and discuss data gathered from within the RCH. It is presented in the form of three vignettes. These vignettes were constructed from interviews with four SSCWs. They recount the SSCWs knowledge of their accountable work – including discussing DNACPR forms with family members and then requesting completed DNACPR forms from residents' GPs. The vignettes are followed by maps of the texts and work that are described within them.

As before, the vignettes and the maps do not simply report experiential data – what participants said and/or what I saw with my own eyes – rather, they are the product of my analytic thinking and writing. The earlier analytic thinking (as discussed and described in Chapter Two) made it possible for me to identify and explicate the connections and ruling practices "in" SSCWs accounts of their everyday work.

This chapter also includes data gathered from talking with three RCH managers.

3.2 The everyday work of the SSCWs

The following vignettes and maps will demonstrate the way in which conversations about the DNACPR form were a systematic and routinized part of SSCWs' accountable workload within the RCH.

3.2.1The pre-admission process: Vignette 4

Vignette 4 describes the pre-admission process to the RCH. This process is part of the standard work of SSCWs in the research site, and is the official process followed to inform decision-making about offering (or not offering) a four-week assessment period in the care home. This four-week assessment period could be viewed as a trial period for the resident and the care home - although in practice staff said that few residents would not go on to subsequent admission for long term care. The vignette demonstrates the way in which the SSCWs and the family members came into a legal decision-making relationship over the person in need of long-term residential care.

3.2.2 Vignette 4

Karen works as a SSCW at RCH C. For the first three and a half years of her employment she worked as a Social Care Worker (SCW). Six months ago she started *"acting up as a senior"* (SSCW). Recently, she has been promoted to the position of SSCW on a permanent basis and has changed her registration status with the Scottish Social Service Council (SSSC) – the body who regulate *"social care"* workers.

One of Karen's responsibilities as a SSCW is to conduct pre-admission assessment visits. The aim of her visit is to assess the suitability of a person who has requested admission into RCH C, or who has been referred by a worker from the social services department of the local authority.

Karen's recent pre-admission assessment visits have been for/with people living in other care homes.

"So the past two residents in our care, I went and assessed in another care home, and brought them here."

Karen has a clear idea of the specific information she is looking to gather on this visit. If the potential resident meets the criteria for admission into RCH C, she is authorised to offer a formal four-week assessment period.

The first thing that Karen needs to confirm is: does the potential resident have a medical diagnosis of dementia? RCH C is registered with the Care Inspectorate under the categories of dementia and old age. It is also registered under the specialist care category of Alzheimer's. This means that the home only admits people who have a documented medical diagnosis of dementia that has progressed to such an extent that the person is deemed to have *"lost capacity"*.

"[I] might look at their file, see if they are suitable for us…they have to have dementia."

Karen looks for an Adult with Incapacity *"Section 47"* certificate, with a treatment plan, in the care home file of the potential resident (Appendix 18) to confirm the diagnosis and the lack of *"capacity"*.

Next, Karen speaks to the potential resident, asking her/him about their thoughts and feelings about coming to RCH C. She is assessing the potential resident for:

"their abilities and obviously asking them do they want to come, if they're able to tell me that, at that sort of stage they're usually quite able to converse and say their feelings."

"But when I'm going and speaking to them and I'm assessing them, it's just…having a conversation with them. I tell them about [RCH C], explain the things we do, ask them about their likes and dislikes, just to get a wee picture of the person really…"

The person Karen is assessing does have a dementia that has progressed to such an extent that she is deemed to have lost the capacity to make meaningful decisions. Many people with dementia have been advised soon after diagnosis to consult with a lawyer to appoint a family member – or other – to act as their Power of Attorney (POA) if/when they lose capacity to make decisions for themselves. At that point this person becomes their proxy decision-maker (*Schedule 1 Certificate*: Appendix 19).

As the POA powers have now come into effect, the potential resident has little legal influence over the decision about whether to be cared for at RCH C or not, so Karen is more interested to find out what "*the family*" have to say on the matter because:

"*they get the decision anyway…so, I will be speaking to them, speaking to their carers, or the senior at that home if that's the way that home runs. Might have a look at their file, see if they're suitable for us, if we would meet their needs. (J:00:01:39)*

The file includes a Single Shared (Care Needs) Assessment document which is a multi-agency, multi-disciplinary document completed before admission to the current care home – typically by a social worker assigned to this person's *"case"* (Appendix 20) It details the financial package that has been agreed with the finance committee of the Local Authority to help cover the cost of long term placement in a care home. The residents' file also contains the care plan that has been agreed for the resident at their current care home, and the *Schedule 1* and *Section 47* certificates.

Karen looks at the file for information about the potential residents' *"behaviours"* and *"mobility":*

"their behaviours would be quite important, but it's not to say that if they don't have this [suitable behaviour] *we're not suitable for them, right? It doesn't mean that if they come here they're going to behave like that, you*

know…we specialise in dementia…so, we've got more training…know how to handle and get around them and reassure them more maybe".

This means that behavioural issues will not automatically result in exclusion from admission to RCH C. Karen also knows that there is an official policy on mobility.

"they have to be mobile to come in the first instance".

Being *"mobile"* means being able to transfer from bed to chair independently, or with minimal assistance of one person (Appendix 21) However, the care home management is not as strict about mobility as they used to be due to financial pressures to *"keep beds filled."* And so mobility is not so much of a consideration as it once was.

If all of the conditions that make a person *"suitable"* are met, Karen is authorised (by the care home manager and care home admission process) to offer the potential resident a four-week assessment period in Care Home C, on a trial basis.

3.2.2.1 Pre-Admission: "The family get the decision"

On analysis of this vignette the specific relations of ruling that give family members, and care home staff, powers over important aspects of the life of the person being assessed for admission become clear. I noticed that the RCH's admission process, and SSCWs' work, were hooked into the legal and medical processes surrounding how a woman being assessed for admission became a *Person with Dementia* and then an *Adult with Incapacity*. This process set pre-determined legal agreements in motion and gave decision making powers to her daughter who became her Power of Attorney (*Schedule 1 form*). As a result Karen knew, *"the family get the decision anyway"*. The process of becoming an *Adult with Incapacity* also gave some powers to care home staff members assigned to care for her through the *"Section 47" form (*issued by a doctor to confirm a diagnosis of dementia and certify a person's "incapacity" to make decisions). For example, the Section 47 form authorised staff to administer prescribed medication (categorised as *medical treatment*) to this woman without the need to gain her consent as to whether or not she wanted that medication (or treatment). This form also brought the care home staff and the Power of Attorney (POA) into a legal relationship with each other because *medical treatments* needed to be discussed and agreed with the POA as proxy-decision maker. In this way the woman who became Resident C was removed from the decision-making processes about where she would live and what treatments she would accept or refuse, and those decision-making powers were granted to her daughter in consultation with the care home staff.

3.2.2.2 Pre-Admission: "who is suitable for us" and "keeping beds filled"

On analysis I also noticed how SSCWs were drawn into meeting the business needs of the RCH during the admission process.

SSCWs' work was textually mediated through the RCH's admission processes to determine a person's *"suitability"* for admission. Karen told me that the RCH management had become more flexible about the mobility section of the admission process as a result of financial pressures facing the RCH during the previous few years. Her analysis of this flexibility on mobility was that the home needed to *"keep beds filled":* a need which was more focussed on the needs of the RCH to remain viable as a business than on a *person with needs* being cared for in an appropriate setting. As a result of this move toward flexibility, Karen knew that she need not be so concerned about the residents' ability to move from chair to chair, or chair to bed without the help of another. She also knew that needing help with mobility would previously have excluded people from admission into the RCH.

What is hidden in this taken for granted flexibility about admitting people with a limited ability to move from place to place without help is the way in which this change resulted in people who were frailer and more disabled than had been the case in the recent past being admitted into the RCH. I was curious about the way Karen explained this change by abstracting a person with needs into a *"filling"* for a *"bed"*. This particular abstraction has resonance with Diamond's (1992) IE which uncovered how the work of tending to the everyday needs of older people in care homes in the United States of America was made into tasks that could be numbered, scaled and controlled by those in authority to make a financial bottom line for the care home operator – a process which he described as *Making Grey Gold*. Diamond writes:

> *This procedure had the consequence of moulding the formal records of resident's lives into a history of progressively separate and isolated individuals: reduced to the status of those acted upon, from social relations to individuals, from individuals to patients, to sickness, to units of health service, and ultimately to objects. All these components went together to make up the "bed". The leap from person to bed was thus not direct. It followed an ideological pathway: from socially contextualised person to isolated individual, on to patient and disease categories, to bodies and behaviours, to tasks done to them, then on to the records to code them. "Beds" came into this logic at the end of this conceptual conveyer belt, fully accomplishing the fusion of person and bed, resident and commodity (*Diamond 1992: 210).

In vignette 4, textual practices reduced a mother into a person with dementia, a person with dementia into an adult with incapacity, an adult with incapacity into RCH Resident C (who would be charged a weekly rate to receive care), RCH Resident C into a person who needed help to move from bed to chair (from paid RCH employees), and finally from a person who needed a specific form of help into a *filling* for a *bed*. The *bed* needed to remain *filled* so the business of the RCH could remain viable.

In the course of my professional work many care home managers had mentioned this need to *keep beds filled*. This topic became more prevalent after the demise of the largest provider of care homes and long term care facilities in the UK in 2011 – the Southern Cross Group. The demise of this group had arisen as a result of public spending cuts leading to fewer referrals and a drop in occupancy rates. The care home management at the research site knew that way the RCH could avoid a similar fate was to maintain a high occupancy rate. This could only be achieved by admitting people who could meet the cost of care from their own resources or by admitting people who had both been assessed and granted state financial assistance through the work of a Social Worker - using the Shared Assessment Document.

The hidden descent from person to commodity is concerning, not least because people with dementia who are admitted into RCHs will inevitably become even frailer, more disabled and will die during the period of their admission. This means it is also inevitable that the RCH staff will need more support from doctors and nurses to manage that care even though no doctors and nurses work in the RCH and accessing sufficient support from NHS doctors and nurses can be difficult (as was seen in vignette 1 and 2 and will be discussed further in Chapter Five).

The SSCWs were working to assess *"who is suitable for us"* and the RCH management was working to *"keep beds filled"* and both knew accessing medical and nursing support could be challenging, but admitted people who were more frail and disabled into the RCH nevertheless. *Keeping beds filled* was related to *"what makes a person suitable for us"* and it is important to recognise that what made a person with needs *"suitable"* as a *"filling"* for a bed was not the same as what made that person *"suitable"* for admission into care setting with no nurses on-site. As demonstrated in vignette 1 - 3, the RCH staff could not manage the needs of residents without regularly calling for help from NHS doctors and nurses and NHS doctors and nurses were not routinely available to provide the level of support that staff and residents needed (as further discussed in Chapter Five).

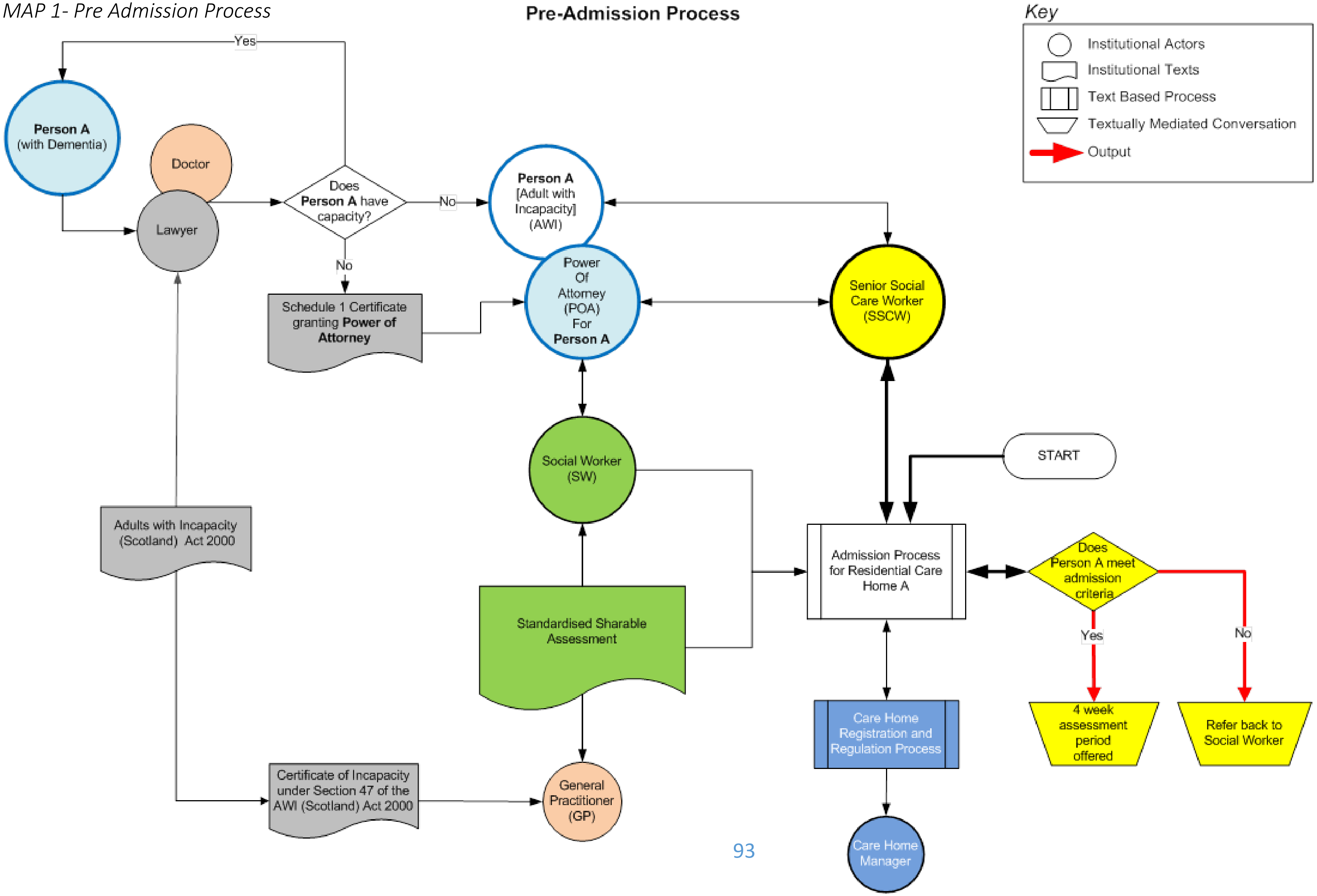
3.2.2.3 Ethnographic Map 1

The institutional actors, texts, process and textually mediated conversations that shaped the SSCW's work processes in this vignette are now represented in the form of an ethnographic map. This begins with the SSCWs knowledge of the admission process, or what made a person *"suitable for us"*, it is shaped by the legal and bureaucratic processes that surround a person with dementia becoming a Person with Incapacity who has been assessed for their eligibility for financial support with the cost of long-term care by a Social Worker using the *Single Shared Assessment Document*. The output of this process is that the SSCW is authorised by the care home management to either offer – or deny - the family (acting on behalf of their relative) a place at the RCH for a four-week assessment period. Few who enter this pre-admission process are not offered a 4 week assessment for long-term admission.

I knew from discussions with many care home managers that the pre-admission work and processes are linked to the work of the Care Inspectorate's registration processes and that compliance with the Care Inspectorate's registration and inspection processes was the responsibility of care home management teams.

Map 1, and all the maps that follow, are included to illustrate the way in which the texts and talk of all the groups included in this study were put together and so became the *"acts of the institution"* (Turner 2006: 140).

MAP 1- Pre Admission Process



3.2.3 Admission after the four-week assessment: vignette 5

Vignette 5 picks up the next strand of work for SSCWs guiding the care of people who have entered the admission process: admitting a resident for long-term care during a care review meeting.

3.2.4 Vignette 5

Steven is the *acting* SSCW on shift. (Karen should have been on duty to take a family meeting today but she has been called away to another home owned by their company to cover sickness absence.) Steven has reviewed the documents that record Resident D's care and progress during the four-week assessment period.

The paper work for the assessment period includes a respite care plan, the four-week assessment sheets and the dependency rating scale. Resident D's key worker has used these documents to:

"…make up a shortened care plan with the family just getting as much information down as we can, but it's not an official this is "The" Care Plan because…it's someone you don't know yet".

During the four-week assessment period the key worker (and other care staff) have gathered and documented information on care needs such as personal needs around support with washing, dressing and continence. They have also gathered and recorded information on participation in activities and interests, physical health, including nutritional needs and mobility issues, and communication skills and interaction with others (Appendix 22)

"because we are trying to build up a better knowledge about them…just trying to build the picture, as much information as we can get from the social worker, from the family, from the resident themselves. Because, obviously, we want to be meeting the needs."

Steven finalises the paperwork for the first review meeting by completing a four week review document.

"By that point we'll have decided if the person's suitable for here or not. In my experience…we've always said we'll offer them a place. And then a review in six months"

The people typically invited to this meeting include the resident's social worker, the key worker, the SSCW, and a representative from the resident's family – usually the residents' POA.

"When I first came here you always had to invite the resident, which we still do, that hasn't changed…but it became upsetting for some people…so we would do the review when we discuss things [with the POA/family member] …and then go and see them [the resident] in their room, in their own environment and do like a second part of it…residents still come to the review…but some are distressed at it."

Stephen has a lot of ground to cover during this meeting, with subjects ranging from when a person usually gets up in the morning to company policies and procedures on issues such as visiting, payment and complaints, to personal wishes around burial arrangements and sometimes the DNACPR form.

Steven and the social worker co-lead the meeting. They give the POA feedback on how the resident has been during the four-week assessment period. Resident D is considered *"suitable"* for RCH C, so Steven is authorised to offer a long term place, which Resident D's POA accepts - on her relative's behalf.

“and then [we discuss] anything that’s maybe been brought up by the family or the social worker if they feel that there’s anything that might be relevant to that person. We would document it and then work on it. So one of the things was that a lady did not like to sit in the lounge with other residents in her nightwear…its communal living…it’s not ideal, but sometimes it has to happen, but this lady didn’t want to do it…so we wouldn’t do it and the night shift would assist her for bed…so she never came through in her nightwear…and she still doesn’t. So, that was agreed…She’s got two hearing aids but she doesn’t want to wear them, so the daughter said that’s fine, however…she’s finding it quite hard to hear…so I’m going to keep one in place…we’re going to try her to see if she’ll keep it in because I think it’s helping her. So different things we agreed.”

At this point Steven moves to the admission checklist to make sure he discusses all that is considered relevant to discuss at this meeting with Resident D’s daughter (Appendix 23)

“At the review we talk about the National Care Standards (Appendix 24), *the Dementia Standards* (Appendix 17) *the codes of practice* (Appendix 25) *the SSSC... We give them a wee feel for what we’re working in line with, because people don’t know anything about that when they bring their mum or dad to live here.”*

Typically Stephen will also discuss the contract between the care home and the resident. Two copies of this must be agreed and signed, one for the POA and one for the care home. Other information discussed at this meeting includes the following list:

- the care home charges and the terms and conditions of the services that are offered;
- the arrangements that need to be made should private or top up fees run out;
- the philosophy of the home;
- the rules of the home;
- the complaints procedure;
- a statement of the rights and responsibilities of the resident during their residency in the care home;
- the Service User Charter;
- the role of the key worker;
- the Quality Assurance process;
- advocacy needs;
- communication systems;
- contact details and opportunities for involvement;
- visiting arrangements;
- the care review process;
- the meaning of private and public space;
- the service brochure.

Along with all of the above, Stephen must also discuss and agree the care plan also known as the personal plan (Appendix 26) This process includes discussing: aspects relating to personal care, spiritual needs, dietary requirements and arrangements, community activities, choices, preferences and requirements, medical records and information, gaining consent to take the resident's photograph for identification purposes on the care plan and for identification purposes on the resident's Marr Sheet (medication chart) and an explanation of the daily structure within the RCH. The final section of the care plan contains information *on the occasion of having a serious illness*. Unlike other sections of the care plan, there are no specific guidance notes at the bottom of the page to support Stephen with the topics that need to be discussed and documented under this section. However, he has been to *"palliative care training"* and so understands the information required for this section to mean anything that:

"required [a person] to go to hospital".

This section of the care plan may include statements such as:

"in the event of a serious illness I would like to stay in Care Home C and not go to hospital"; "if I'm ill, you need to contact…the relevant professional", whoever that may be, whether it's a doctor or an ambulance or whatever…"need to contact my family", if that's what the family want, if the family want to go with them to the hospital or do they not want to be contacted and things like that because some of them don't, but a lot do. Also if they have a DNACPR in place that'd be documented in there as well."

The DNACPR form is a *"difficult"* topic for Stephen to raise.

"I think with recent trainings and things we've been pushed to do this [talk about the DNACPR form]…people were scared to talk about it before…at the moment I would say it feels like it depends, like you gauge the family on how you think they would be if you approached them or not. Do you know what I mean?...But, that's probably not ideal. We should probably be just doing it at a set time with people so they know from the start".

Stephen finds it more difficult to raise this topic if the resident and family have not been using the care home for respite care and so are new to the home and the staff.

"We'll try and discuss a DNACPR form…we'll try and raise it…if I'm dead honest that is a procedure that sometimes doesn't become relevant…it becomes quite difficult depending on the person…but it's our policy that we should be doing that, and we'll work towards doing that…like I was able to do one, because the lady had been in for respite a lot and we got to know her daughter…we have to remember sometimes we only meet people once in four weeks, and you're discussing the DNACPR form at the end of this [review meeting]…and your know, that's a really hard thing to talk about at that time…and I know it's important, but it's also important not to be saying some stuff to people…we had one daughter…and she felt her mum still has a lot of life to live…and she's got some health issues but at that time it was a definite no to the form. What we said was we'll discuss it again in the future…what I did that day was explain how it [the DNACPR form] came about…I told her it was a really hard decision…that the doctor would take her views into consideration…but at that point she didn't want to be approached with the doctor…but it would be raised again at the six month review."

At the end of this meeting the care plan is agreed and signed by the resident's POA, who is offered a "quick guide" summary copy for her own records. A note about whether the care plan was offered, accepted and/or rejected by the individual (and/or the individual's advocate) is recorded and signed in the quick guide section of the plan.

The care plan forms part of the agreement between the care home, the resident and the resident's POA. This agreement is valid for six months, when a further meeting will be arranged and the care will be discussed and reviewed.

3.2.4.1 Admission into long-term care and the DNACPR form "A really hard thing to talk about at that time" and being "pushed to do this"

What is noteworthy in this vignette is the volume of information and range of topics that Steven must discuss at this hour long meeting. It is also important to notice who is present and who is absent. The RCH staff, the resident's family members and the assigned Social Worker are all in attendance. The person whose care is being discussed is not usually at the meeting nor are any doctors or nurses.

The precariousness of staffing in the RCH is also evident in this vignette – Karen has been called away to cover sickness absence and Steven has to step in for her. To do his work as the *"acting SSCW on shift"* he must read the authorised accounts of Resident' D's case as that case has been written up by her key worker using the four week assessment documents – to *"decide if the person's suitable for here or not"* although he knows that it is rare for *"a place"* not to be offered at this point.

Although Steven is dealing with *"someone you don't know yet"*, he is an expert knower about the wide range of institutional issues that need to be discussed at this meeting. These issues range from when a person likes to get ready for bed in the evening, to information about how to complain, and how to prevent a traumatic death by getting a signed DNACPR form into the resident's file. He understand that although the issues he has been tasked to discuss are *"important"* (to someone, if not to himself or the family members) it was also *"important"* (to him) that he have the freedom to *"gauge"* how family members *"would be if you approached them"* about the DNACPR form. As a result, it was *"important"* (to him) *"not to be saying some stuff"* at decision-making meetings based on his knowledge/relationship (or lack of knowledge/relationship) of the family member. Stephen knew that the conversation about the DNACPR form was discretionary at the admission meeting **and** he knew that it would come up again at the six-month review meeting (as will be described in the next vignette).

What made the conversation about the DNACPR form *"a hard thing to talk about at that time"* was a) the number and range of topics that needed to be covered at the time-limited admission meeting, b) the need to discuss the DNACPR form with *"a person you have only met once in four weeks"* and c) family members lack of understanding about why they are being *"approached"* with a conversation about the DNACPR form. This lack of understanding about the DNACPR form can be seen in the response given to Stephen by one daughter who said her mother *"had some health problems"* but also *"has a lot of life to live"*. This suggests that, like many other lay people, this daughter was not aware of: what CPR would entail for her mother; the typically poor outcome of CPR in older people with dementia; or the typically poor outcome of CPR in older people in care homes (which is discussed more fully in Section 6.2.4). It also suggests that this daughter understood the SSCWs conversation about the DNACPR form as a question about whether she wanted the RCH staff to attempt to save her mother's life by initiating CPR or to let her mother die by with-holding CPR. She did not understand what the SSCW was actually attempting to convey by telling her *"how it [the DNACPR form] came about"* which was that in order to ensure her mother would not be automatically subjected to an aggressive intervention that had not been successful for any previous RCH resident, and had prevented previous residents and family members from having a peaceful experience of death, the care home needed a completed DNACPR form that was signed by a doctor. To discuss the form with the doctor, the SSCW needed the consent of the daughter (in her role as Power of Attorney).

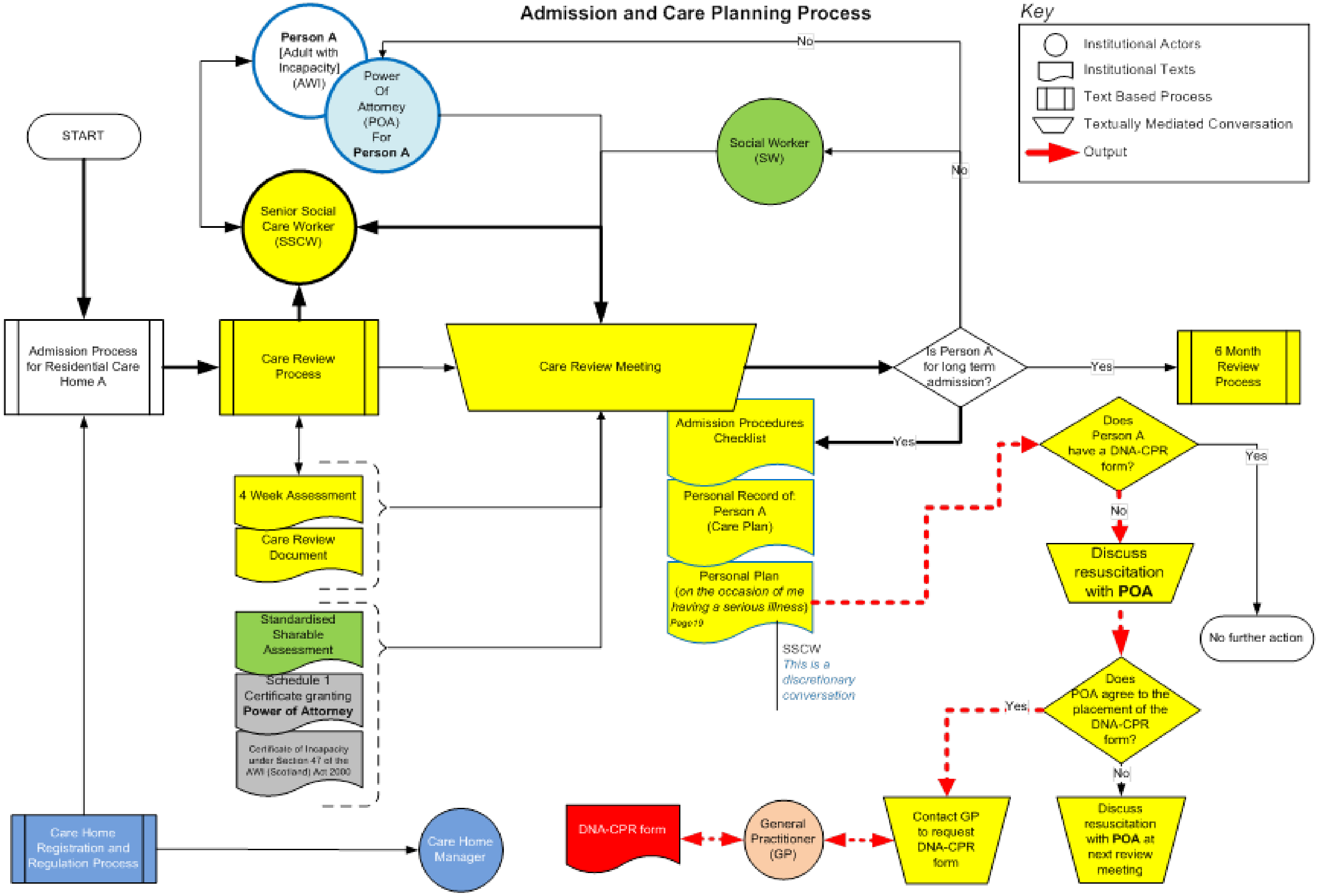
What also made the DNACPR form a *"hard thing to discuss"* was: being "*pushed"* into it as a result of *"recent trainings"* that SSCWs were assigned to attend by their management team (organised and facilitated by palliative care staff working for third sector organisations and discussed more fully in Section 4.3.3, and Section 6.2); knowing that although they were *"scared"* to ask family members about the DNACPR form it was now an institutional duty because it was the RCH's *"policy"* to discuss it when they came to the *"serious illness"* section of the care plan; and that if the family could not or would not agree to a DNACPR form the topic would be *"raised again"* at the six-monthly care review meeting - under the review of the *"serious illness"* section of the care plan. How SSCWs knew to discuss the DNACPR form at this point in the care plan will become clear in the next vignette (and why it had become the RCH "*policy*" to raise it at every care review meeting will become clear in Chapter Six).

3.2.4.2 Ethnographic Map 2

The work and texts organising how the admission meeting could proceed extends what was mapped in Map 1. It also pictorially represents what SSCWs knew, that in order to obtain a DNACPR form they had to contact and discuss the form with the resident’s doctor - after gaining the consent of the Power of Attorney.

The SSCW had knowledge about what would happen in the absence of a DNACPR form. He also knew that the RCH home was not issued with these forms and that SSCWs were not authorised to fill them out. The GP had knowledge about disease processes and viable (or non-viable) treatment options. The GP was the professional issued with blank DNACPR pad containing blank forms. The GP was the professional authorised to fill them out. The GP’s knowledge about disease processes and viable and non-viable treatment options could have been useful to the SSCW who recognised *“it was a really hard decision”* and the daughter who felt her mother had a *“lot of life to live”* and said a *“definite no”* to the DNACPR form when asked by the SSCW. However, GPs were routinely absent from meetings where this issue was discussed, and did not routinely prompt discussion about resuscitation status at any other time.

MAP 2: Admission and Care Planning Process



3.2.5 The Ongoing Care Review Process: Vignette 6

NV 6 describes a day that contains a six monthly care review meeting. This meeting is scheduled and offered every six months for the duration of the resident's stay. In most cases, this stay will be until death. Conversations about future care are regularly initiated during these six monthly care review meetings. They may also be initiated at any other time it seemed appropriate, such as if the resident's health declines, or if family members have any particular concerns they wish to discuss.

This vignette describes a typical day shift in the RCH when a six monthly review takes place. It details the range of work-strands SSCWs must keep on top of during any shift, and the range of priorities that compete for her/his attention. Because of the length of this vignette, it is sub-divided into three sections: morning work, afternoon work and the six monthly care review meeting. Also, to assist the reader, key analytic points are made within the vignette.

3.2.6 Vignette 6

Morning work

Karen is back at Care Home C after her secondment. At 07:15 she takes the handover report, and reads over the senior's diary for a list of list what she needs to get done by the end of her shift. Today, the list includes:

- arranging the collection of a urine sample for a suspected infection and calling Resident E's GP to discuss the same;
- forward planning for Resident Ds six-monthly review next month;
- meeting with one of the key workers on her team;

- overseeing the organisation and set up of a birthday party for one of the residents,
- calling another GP surgery about Resident G's test results,
- meeting with Resident F's daughter for a six-monthly review;
- calling a company to come and fix the projector.

At around 07:25 Karen gives a report and delegates work tasks for the staff this shift. Karen, as SSCW, is responsible for running the shift.

*"You would give the staff the report and you would read out the allocation of duties first. You would read out anything in the communication book, any points that need to be passed on. You would read anything that's in the diary. It could be something like an admission or if any samples are needed. And then lastly you would read the handover notes from the night shift; you have to read that just to let you know what's been happening during the night...."so you've taken the report and you're looking at all the different books [*general diary, care staff diary, seniors care staff diary, communications book, handover report sheets*] and you're allocating the duties." ..."nothing can be really set in stone, but you know, you have to have structure and certain timescales, you know and things like that."*.

While the care staff go to help residents get up and dressed, or start the work of administering medications, Karen goes to the dining area. She needs to make breakfast for any residents that are up and dressed early, then she needs to help those who require assistance to eat their meal.

"So you would make sure people are sat down, have got what they need - whether that's cereal, toast, tea, coffee, juice, yoghurt etc. And you're preparing breakfast for them. After the kitchen assistant comes in at 08:00

they take over preparing the breakfast, then I would just sit and assist people [to eat breakfast*].”*

As long as everything is running smoothly, at 09:00 Karen returns to the office. She can plan to work there till around 10:00. Today she asks one care staff member to set up the quiet lounge for the birthday party during the morning and another to collect a urine sample. She fills out all the necessary documentation that needs to accompany the sample, and she arranges for the handyman to take the sample to the surgery later that morning when he is out collecting a prescription for another resident from another surgery.

Once the sample has been collected and sent Karen writes a note in the senior staff diary to document that this action has been completed. She then writes a note, three days ahead, to remind the senior on duty that day to call the surgery for the result.

Next, she calls the surgery to speak to Resident E’s GP. She wants to discuss the suspected infection, the sample she is sending down, and the discomfort and increased level of confusion that Resident E is experiencing. The telephone line to the GP surgery has been busy for the past 20 minutes, as usual. She puts the phone on speaker and redial so she can talk to the people coming in and out of the office to ask questions and pass on information. When Karen eventually gets through to the surgery, she speaks to the receptionist who arranges for one of the GPs from the practice to call the care home back during any break in appointments, or after the morning surgery is finished sometime in the early afternoon. Karen knows that the doctor’s time is pressured and that the receptionist acts as a gatekeeper to guard that time. She also knows that her own time is pressured. Nevertheless, she has to put her duties on hold to try and make contact with the doctor according to the doctor's schedule rather than her own.

Next Karen phones the projector company, makes an appointment for a repair, documents her action in the senior staff diary, and makes a forward note of the appointment she arranged.

Next, Karen starts work on planning for Resident D's six monthly review.

"Basically the six monthly review is our review of the whole care plan" (J:00:28:03)

The *"care plan"* (discussed in detail in the six month review section of this vignette) is a document which charts how Resident D should be cared for in the RCH. This plan must be reviewed in consultation with the key decision maker six monthly to *"work in line"* with the regulatory process of the Care Inspectorate and so Karen sends an invitation to Resident D's husband, who is also her Welfare Power of Attorney. She also sends a:

"wee questionnaire" so she can: *"gather some feedback"* from him *"about the service and about their relative's care and if they're happy, not happy, anything they want us to fix…things like that…and then the idea is that they send it back before the review…we can look at that and try to have resolved any issues or talk about it."*

Next Karen invites Resident D's GP to input into this review. Typically this request will be answered by a telephone call reviewing the resident's medication chart (*Marr Sheet*), and discussing any changes to medication that are deemed necessary. The doctor will not generally come out to assess the resident for the six-month review, but she is familiar with Resident D's case.

"Most of our residents don't go very long periods without seeing a doctor….very rarely have I thought a doctor hasn't seen our residents for over two or three weeks to be honest. They're quite regular."

The reason that the doctors were *"quite regular"* was because the staff had to call on them regularly for support and advice. The reason they needed to call for support and advice is because the residents have multiple health problems and their general condition is fragile. It is the calls for help and the task specific response to those calls that is *"regular"*. Despite needing to be called out to consult on some matter relating to the resident's health every *"two or three weeks"* the doctor's contribution to the meeting will be the completion of a medication chart that has been reviewed on request prior to the meeting. S/he will not attend. The SSCW will discuss medication changes with the family member.

Karen makes a note in the senior staff diary to record the actions she has taken in organising the six-monthly review for Resident D. She then leaves the office and goes back out onto the floor to check that everything is going to plan and:

"check the standards that care staff are providing, like to make sure people are being assisted with personal hygiene properly… you're also checking the standards of the unit because the place has to be clean."

When she is satisfied that everything is as it should be, she takes a quick break but comes back before the *"teas go out" to* supervise care and to answer questions:

*"because a lot of things come up during that time…like the door handle's broke…or the community nurse just came up to change a dressing…or the GP's in…you know, things like that. So you have to respond to all these sorts of things…Then at 11:00 you start to check everybody's written up and then to write your own handover…we used to go through and read everything in the log sheets, but now we've condensed that into one handover sheet…one piece of paper with boxes in it …so you're going through the whole sheet and you read what the person [care worker] has written about, say Mr. Smith, that morning, and you just condense that into one box. Because we used to go through every folder [*at the handover report*] and it was very time consuming. So now it's condensed into one box…if there's too much information…[*or*] if the information that's written in the log sheets needs to be read, you would just write "see log sheet"."*

Karen knows that to "*run the shift*" she is responsible for: a) equipment including the "*door handle*" and the "*projector*"; b) "*standards*" including cleanliness of the building and cleanliness of the residents, and organising regular care reviews with decision-makers; c) supervising and participating in meeting the everyday needs of residents including making breakfast and organising parties; d) managing illness among the residents by "*regularly*" asking for help and support from doctors and nurses, this requires negotiation with doctor's receptionists and working around doctors and nurses schedules, and; d) managing and supervising the work of staff including the textual practices associated with handover reports. Time is at a premium in the care home. This has resulted in a truncation of what is reported when the next shift come on duty to "*one box*" in a single page handover report which makes the handover report less *"time consuming"*. In this way much of what happened during the morning shift becomes invisible and unknown to the next shift, but staff can be sent out onto *"the floor"* quicker to carry on with the afternoon work. Getting onto the floor is important because while the residents are frailer and have greater need of help and support the staff to resident ratio has remained the same in the RCH. This means more work needs to be done by the same number of people.

Afternoon work - including a six month review

The handover report is given to the SSCW on late shift, Michael, and to the late shift care staff. After the report the care staff leave the office to start work on their allocated duties for the afternoon. Michael goes with them to check everything is running smoothly on the floor. When he comes back to the office, Michael and Karen discuss any work that has been carried over from the morning, what needs to be done during the afternoon and who will carry out the daily duties that have been allocated for that day[10].

---

[10] Daily duties for each day of the week are as follows.

- On Monday, the medication cupboard needs to be re-organised and any unused or unwanted medications returned to the pharmacy.
- On Tuesday, all the receipts of items purchased from the petty cash box on residents' behalf needs to be checked, the money spent needs to be refunded into the petty cash box from resident's personal allowances, and the corresponding paperwork completed.
- On Wednesday, files are checked to ensure every resident has had a bath and that residents bowels are *"working properly"* .
- On Thursday, the files need to be checked (i.e. ensure the care plans are up to date, all the four weekly summary notes have been completed, residents have been weighed and all the risk assessment documents have been completed within the specified timeframe).
- On Friday, the diaries and books [general staff book, senior staff book, general diary and communications book] need to be checked and cross-referenced to make sure *"things add up"* (S:00:35:23).
- On Saturday, the food and fluid charts need to be checked and balanced so that if someone is losing weight their diet can be altered during the following week. General filing is also carried out on Saturday (items no longer needed are removed from the resident's care plan, and filed elsewhere.) Paperwork is generated during the course of every week, filing work aims to

As there is a review booked in for this afternoon, Karen's colleague agrees to run the shift, do the daily work task set for today, oversee the birthday party and call the GP surgery about Resident G's test results. This allows Karen to speak with Molly, Resident F's key worker, about the care plan before Resident F's family arrives at 14:00 for the care review meeting.

The full care plan, is a large folder that has the care plan plus many additional pages detailing financial and contractual information, healthcare information, and details of previous care review meetings – among other items. It has been decided that this folder is too large for care staff to use on an everyday basis so Molly has been referring to the full care plan to help her write a weekly work plan (Appendix 28), which is a condensed version of the care plan that only contains details of the work for the upcoming week. The weekly work plan is kept in Resident F's room, along with the daily logs (Appendix 29) where daily work has been recorded. At the end of each month Molly writes a monthly summary document (Appendix 30) based on the full care plan, the weekly work plan and the daily logs. She summarises details about Resident Fs progress in relation to what has been charted and discusses that progress with Karen.

In this way, although Karen is not directly involved in the regular everyday care of the residents assigned to her, she is kept updated about the residents whose care she has been assigned to supervise. In preparation for today's review meeting, Molly has completed the six monthly review section of the personal record document (Appendix 31) She has also discussed and

---

keep the size of the working care plan manageable. Then work rotas for staff need to be completed.

- On Sunday, the wages for relief staff need to be documented and faxed to the head office for payment.

agreed what she has written in this document with Karen. They will bring the full care plan to the care review meeting for reference, but the six monthly review document is what they will use to guide their conversation. What is clear in this account of the SSCWs afternoon work is the volume of paperwork that Karen and her colleagues have responsibility for completing, supervising and organising. There is paperwork relating to the allocation of spending money, the recording of what residents have eaten, what they weigh, what they excrete and when they last had a bath. In this way a person needing help and support is abstracted into a body with particular behaviours and needs. As Diamond (1992) has highlighted this is organisationally useful as it allows the allocation of specific tasks to care staff to complete and the documentation of those tasks as evidence of care being carried out. This was important because "*if you don't document it, it didn't happen as far as the Care Inspectorate is concerned.*" The care home relied on the grading of the Care Inspectorate to demonstrate to present and future residents/customers that the care home provided a high quality service.

The 6 monthly care review meeting

Resident F's daughter arrives, as scheduled at 14:00. Karen welcomes her into the meeting room, and asks if she would like a drink. After everyone is settled, Karen starts the formal part of the meeting. Resident F has been living in the care home for a year, so this is the third review meeting her daughter has attended. Karen discusses any issues from the questionnaire, then works her way through each section of the six monthly review document. This is complex work that requires a great deal of organisation, skill and sensitivity.

They discuss *social support issues* and talk about any outings Resident F may have been on, who has been to visit her and any matters arising about the use of her personal financial allowance.

They discuss *physical support issues* and talk about Resident F's ability to walk and manage to the toilet and any changes in her weight.

They discuss *intellectual support issues* and talk about the kind of activities Resident F has participated in and either liked or disliked.

They discuss *cultural support issues* and talk about any matters that are important to Resident F relating to her personal tastes and diet.

They discuss *emotional support issues* and talk about any fears and/or distress that have been experienced. They also talk about a friendship Resident F has recently developed with one of the other Residents in the care home, and what seems to be making Resident F happy at the moment.

They discuss *spiritual support issues* and talk about the visits Resident F has had from members of her faith community, and how much she has enjoyed being able to walk/sit in the garden during the summer months.

They discuss *health support issues* and talk about any changes in medication that have been ordered by the doctor, they also talk about a wound that is being treated by the nurse and the regular visits Resident F receives from the podiatrist. They discuss *personal hygiene support issues* and talk about how Resident F is finding it difficult to accept help with washing and dressing some days and what measures staff are taking to work with Resident F on this matter.

They discuss *nutrition and diet support issues* and talk about a change in Resident F's eating pattern and her increased need for prompting and help during meal times.

They discuss *night support issues* and talk about Resident F's restlessness some nights and what staff do to ease any discomfort and/or distress.

The last issue for discussion in the review document is support issues on the **occasion of serious illness** (Appendix 27). Karen knows what to discuss under this category because of *"recent trainings"* she has been sent to attend. This includes being nominated to become an Advance Care Planning champion as part of a community palliative care project. This involved participating in a series of training days focused on using a document called *My Thinking Ahead and Making Plans* (Appendix 50) and hearing why it was important to consider the topics of CPR and the DNACPR form with residents. The categories for discussion using the *My Thinking Ahead* document include: *important things to me just now (e.g. the things that really matter to me, what I like and what I value); planning ahead (e.g. important events coming up, things I want to do in the future, things that I want to carry on doing); looking after me well (e.g. where I would like to be cared for and any treatments I would or wouldn't want); my concerns (e.g. things that worry me now and any worries about what might happen in the future); other important things and things I want to know more about (e.g. benefits advice, Welfare Power of Attorney, a living will, attempting/not attempting to restart my heart – CPR)*. These are the topics that Karen (and her colleagues) now cover when talking through the "serious illness" section of the care plan. Although Karen knows that the DNACPR form has been raised and discussed at previous review meetings, she remembers that this was a *"difficult"* conversation for the previous SSCW in charge of supervising Resident F's care. Karen had heard from her colleague that during this part of the previous review Resident F's daughter was very distressed and tearful, saying she *"couldn't bear to think about all of that"*. She remembered how visibly distressed her colleague had been at the end of that meeting. No agreement had been made about a DNACPR form for this resident and they did not want to *"go behind the families back"* and discuss this matter with the GP directly.

Karen feels apprehensive and hesitant at this point in the meeting, but knows she needs to *"approach the family with the form"*. It is unsurprising that Karen feels apprehensive at this part of the meeting. She knows there is an institutional requirement to talk about an issue that in the past this relative has indicated that she can't *"bear to think about"* and may not fully understand -as discussed in section 3.2.4.1. So, Karen begins this part of the meeting by explaining what the procedure would be if Resident F *"collapsed"*. This is, that a 999 emergency call would be made, an ambulance with paramedics would come to carry out emergency treatment which may include CPR, and the ambulance would take the resident to hospital. She goes on to say that the family would be informed as soon as possible and that a member of staff would accompany the resident to hospital. At this point she wants to emphasise why it is important to think about a DNACPR form, so she relays a story about what can happen when the care home do not have a DNACPR form in the residents care home file. She does this by telling the story described in vignette 2. She goes on to explain how having a DNACPR form in place can protect residents. Karen says she knows this subject has been raised before and she knows it was *“hard to think”* about, but asks if Resident F’s daughter still has the same view as she had previously. Resident F’s daughter is quiet for a time, and seems troubled. Then she says that the topic has been:

“playing on her mind and that she had thought about it a lot, so she had decided it was probably a good idea.”.

Embedded in this part of the account is the care and consideration Karen demonstrates toward this relative. She also demonstrates her knowledge about the lack of success when CPR has been attempted in the past, why the care home needs a DNACPR form and what would happen if a 999 call was to be made. However, as Finucane *et al*. (1991) comment, when a care home resident is found pulseless one can describe that event as dying peacefully after a long illness in one’s own home (as was the case in vignette 3), or as a medical emergency that has taken place in a healthcare facility (as vignette 3 became as a result of the textual practices that entered directed proceedings in and to the RCH). By discussing the DNACPR form in relation to a *“collapse”* that could apparently be managed by a call to the paramedics and admission to hospital Karen links the inevitable death of an older adult with dementia with an emergency situation and a medical condition that has a potential medical treatment to reverse it – CPR. According to research (discussed in Section 4.3.1.2.1) an older person with dementia being cared for in a care home has minimal likelihood of achieving a successful outcome after CPR. The *Do Not Attempt Cardiopulmonary Resuscitation (DNACPR): Integrated Adult Policy* states that:

> *In the situation where death is expected as an inevitable result of an underlying disease, and the clinical team is as certain as they can be that CPR would fail (i.e. realistically not have a medically successful outcome in terms of sustainable life), it should not be attempted.* ***In this situation CPR is not a treatment that can be offered and it is an unnecessary and cruel burden to ask patients and relevant others to decide about CPR when it is not a treatment option*** *(Scottish Government 2010:10)*

The *Do Not Attempt Cardiopulmonary Resuscitation (DNACPR): Integrated Adult Policy* (Scottish Government 2010:11) also states that:

> *Discussions about resuscitation are sensitive and complex and should be undertaken by experienced healthcare staff. It is recommended that staff have formal communication skills training in preparation for this clinical responsibility.*

This clarifies the ruling perspective that DNACPR should be discussed (and the form completed) by the senior clinician. According to the DNACPR form, the senior clinician is:

> *The senior clinician assuming clinical responsibility for the patient during that care period who has the appropriate capability and knowledge (e.g. GP, Consultant, Staff Grade doctor, Associate Specialist, Nurse, Out of Hours Clinician).*

In the RCH the senior c*linician* is the resident's GP. Despite this ruling perspective on the role of a *senior clinician,* the SSCWs knew that the *senior clinician* was **not** the person initiating the conversation about DNACPR in the RCH. Karen knew that the doctor was only available to talk about DNACPR forms by telephone, and that the doctor would typically ask "*what do the family want*" when Karen asked for a DNACPR form for a resident.

This provides another explanation of why a DNACPR conversation is *"difficult"* conversation for SSCWs. To obtain a DNACPR form Karen needs to ask a family member to decide on something that, according to the research, is not a realistic treatment option for an older person with dementia - which, according to the DNACPR national policy, is placing a *"cruel burden"* on that family member – and herself as a SSCW.

Karen proceeds with the meeting by saying that she will call the surgery and speak with the GP about their conversation today. She explains to Resident F's daughter that the GP *might* call her for a chat and *might* invite her to go in to the surgery to talk things over some more, but s/he *might not*. This demonstrates the unpredictable level of support the family (and the SSCW) can expect with the DNACPR process.

Karen asks if there is anything else Resident F's daughter would like to talk about today. She says no, so they conclude the meeting by agreeing to go and give a brief summary of their meeting to Resident F. Karen and Resident F's daughter have agreed to keep this part of the meeting very short and only to relay the more neutral aspects of what has been agreed.

On returning to the office Karen calls the GP's surgery. She is fortunate and the GP is free to take her call on this occasion. She relays the conversation she had with Resident F's daughter, the GP agrees to complete the form, then instructs Karen to call the surgery in a few days to see if the form is ready. If it is ready when she calls someone from the care home can pick it up later in the week.

Karen dislikes the process of initiating conversations about the DNACPR form, but it has become part of her job, so she feels she has no option and just needs to get on with it. Karen also knows that the deputy manager will conduct an audit of resident's files in the next few weeks. One of the items on the audit checklist is the presence or absence of a DNACPR form, so she knows she also *"needs to get the form"* to comply with the audit. The audit is one of many topics that Karen's manager will discuss with her at her next supervision meeting.

3.2.6.1 Managing the Care Review Process: *"things are changing"* and *"we need the form"*

Research suggests that treatment decision-making conversations add to the experiences of pre-death grief and distress among family carers of people with dementia (Sampson *et al*. 2011). That SSCWs were socially organised to routinely ask family members to make a decision on the DNACPR form at review meetings - as a result of *"recent* [palliative care] *trainings"* and the RCH's *"policy"* to *"get the form"* - demonstrates that family members were required to engage in a decision-making conversation about death with SSCWs based on institutional requirements rather than individual assessments. Institutional requirements to *"get the form"* took precedence over relational concerns of the SSCWs – particularly when during the six month review when there was no longer an option for SSCWS *"not to be saying some stuff"* about the DNACPR form.

The care home manager (a person who had been promoted from SSCW to deputy manager to acting manager during the previous year as a result of unprecedented internal disruption in the home) said "*Mostly we (RCH staff) lead it. We get the ball rolling. We have the conversation with families. Only one time that I remember did a doctor lead the process…that was during the year when they came out to the reviews of all our residents to review their medications and look at their Section 47s and things…we deal with nine* *different doctors surgeries, and none of the doctors have raised the subject with us, other than that one time."*

That *"one time"* was a year during which GPs received a special payment for carrying out reviews of care home resident's care as part of a specific project initiated by the Community Health Partnership (CHP), a body with the power to influence how GPs work was organised and remunerated. This drew my attention to the social organisation of GP remuneration – a topic which will be explored further in Chapter Five.

The care home manager expressed a concern about the new SSCWs discussing the DNACPR form with families, saying it was "*a worry*". Nevertheless from her ruling standpoint as manager she knew that *"the SSCWs need to have the conversation…we need the form…but it's a concern with some of them…they need a lot of guidance"* The manager acknowledged that "*it's a very sensitive conversation…a hard topic"* and she knew that *"families are sometimes surprised when we bring it up…it's not something families have thought of on the whole"* As well as being something families have *"not thought of"* before, it was something RCH staff did not *"speak"* of before. "*I've worked in social care for twelve years and we never used to speak about these things – never. No-one. Not even the manager. But things are changing …and now we need to do it. The seniors (SSCWs) need to do it. But some of them struggle. It's a concern…some of them don't have the skill…some families can't bear to speak about it…but we raise it at every review…one man couldn't bear to speak about it…he just kept saying no – you need to do everything for her. Then she went to hospital and thankfully it was taken out of his hands. She came back with a DNACPR form in place. And that was that."*

*(*The man referred to in this instance is the man whose wife's case was described in vignette 2.)

The deputy manager also knew things had changed in the care home, "*when I first started here we carried out a dependency grading assessment…we didn't even have a hoist…as soon as a person was unable to walk they were moved to a nursing home…it was a regular occurrence ten years ago…then thinking changed. It's very rare to move someone now – it would be more for behaviour issues than anything to do with their health*" She also knew speaking with families about "*thinking ahead*" was "*difficult*" because staff were caught in the middle of a conversation that, according to the DNACPR policy and form, was the responsibility of the GP "*when we are speaking about thinking ahead to families they can be quite…they don't believe you…like, what do* ***you*** *know…some GPs are great…they offer to call the families and speak direct instead of us relaying messages back and forward…most are rubbish…they say I'm far too busy to speak to families*". The busyness of GPs will be explored further in Chapter Five.

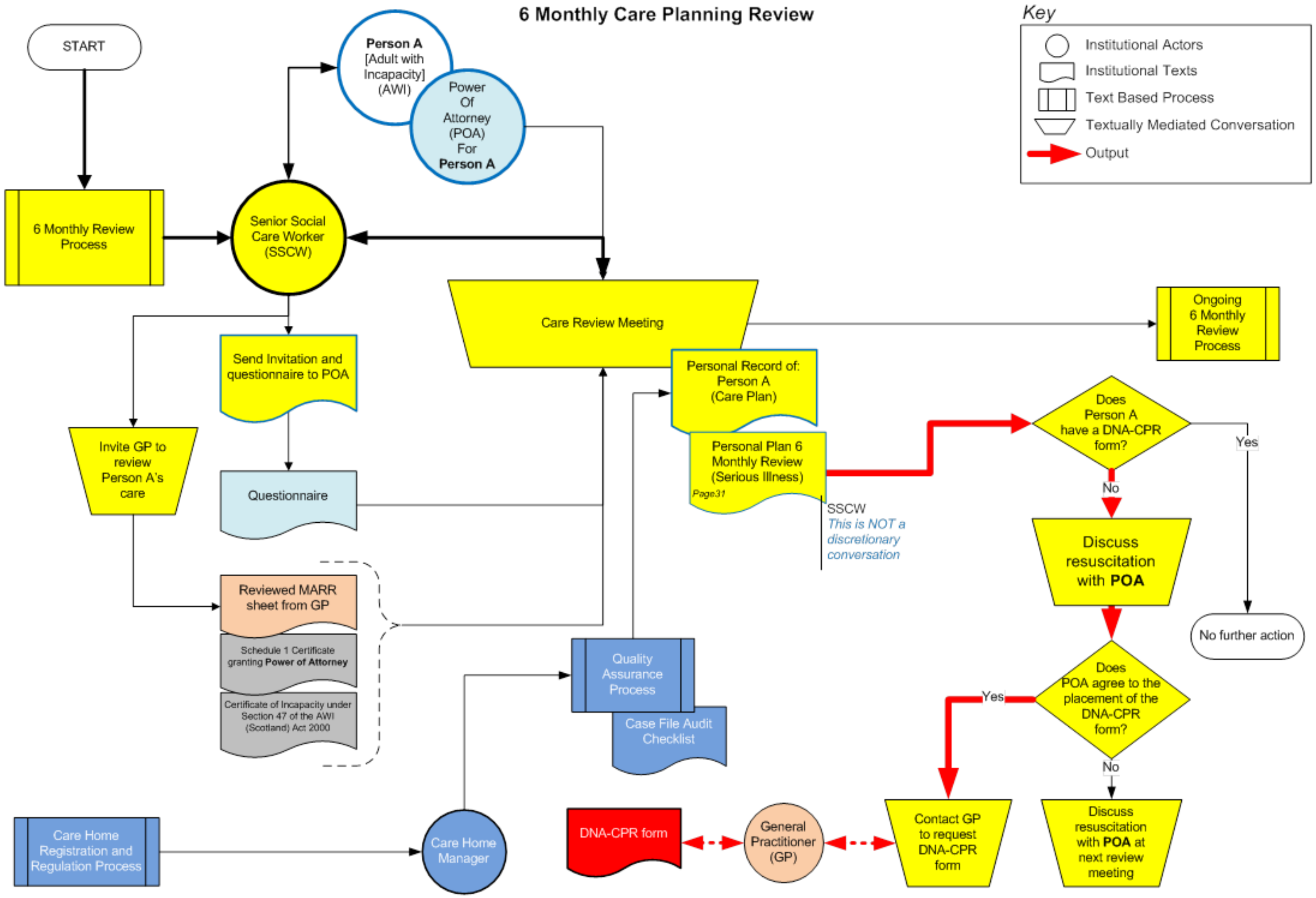
Embedded in these managerial accounts are directives placed on the SSCWs that "*they need to have the conversation* (because) *we need the form*". The managers own analysis of why this was important was "*because things are changing with the Care Inspectorate and trainings and everything*". Part of the "*everything*" that had changed was the increased "*dependency*" of the RCH population as a result of the flexibility about what made residents "*suitable for us*" and the recent lack of moving residents to a nursing care home "*as soon as they are unable to walk*". Something else that was "*changing*" was that the presence/absence of the DNACPR form was now being audited by the care home manager, and a conversation about DNACPR was now mandatory at the six month review meeting – *“we raise it at every review”*. The need to review care six monthly was linked the *National Care Standards* (2002, 2007: 26), which states:

> *Your personal plan will be reviewed with you every six months, or sooner if you want or if your needs change.*

Compliance with a six monthly review was a feature of care the manager told me would be inspected by the Care Inspectorate Inspector - on annual unannounced inspections. Accordingly, it had become the policy of the RCH to *“raise it* [the DNACPR form] *at every review”* despite knowing that: some SSCWs *“struggle”* with the conversation; and some family members *“can’t bear to speak about it”*. While some GPs were described as *“great”* by the care home manager, because they would *“offer to call and speak to families direct”*, most were not described as being *“great”*, rather they were reported as being *“far too busy”* to speak to families and *“rubbish”*. The unpredictable nature of GP support with the DNACPR decision-making process left the SSCWs with a *“difficult”* and *“very sensitive”* conversation about DNACPR regardless of the managers’ assessment of their *“skill”* or the help they could access from GPs.

Map 3 is a development of the work and texts included in Maps 1 and 2. The audit process is now included, and the conversation with the family is no longer discretionary.

MAP 3: The Care Review Process



3.2.6.2: Exclusion from *advance communication skills* training support

I have described care home manager's concerns about the skill of staff to undertake a conversation about DNACPR with family members, and I have described SSCWs discomfort at initiating this *"difficult"* conversation. I decided it was of interest to explore the communication unit within the qualification being pursued by the SSCWs at the research site. This unit was categorised as: *Promote Effective Communication* (Appendix 48). It included the following heading and topics:

- Establish understanding about individuals' communication
- Support individuals to interact through communication
- Communicate effectively about difficult, complex and sensitive issues
- Communicate using records and reports

Of greatest relevance to this study was: Communicate effectively about difficult, complex and sensitive issues. The course descriptor describes difficult, complex and sensitive communications as being likely to be:

> *distressing; traumatic; frightening; threatening; posing a risk to and/or having serious implications for the individuals and/or key people; communications that might be difficult to understand assimilate; about sensitive issues including those of a personal nature* (Appendix 48: 1).

This definition accurately describes SSCWs' work with proxy-decision-makers at the care review meeting. SSCWs' descriptions of their communication work suggested that it regularly included: handling anger; dealing with collusion, denial and uncertainty; dealing with unrealistic expectations around non-viable health interventions, negotiating with healthcare professionals and colleagues, working with loss, grief and guilt; breaking bad news; and discussing future care with proxy-decision makers including advance decisions on CPR. The authorised literature about effective communication skills in relation to interactions of this nature have been described as having:

> *the ability to elicit and identify…concerns, worries and information needs. It involves meeting those needs through tailoring information appropriately so that the person hears and understands*" (Scofield *et al*. 2015:4).

According to the recommended model of psychological assessment and support produced by the National Institute for Clinical Excellence (NICE) (NICE 2004), all levels of health and social care professionals should be able to recognise psychological needs and be effective in giving information, compassionate communication and general psychological support. Nevertheless government reports produced over the past 20 years consistently report negative findings in the areas of communication and psychological support (Calman and Hine 1995, Clwyd and Hart 2013, Department of Health 2008, Department of Health 2013, The Mid-Staffordshire NHS Foundation Trust 2013). At the same time, these documents agree that developing effective communication skills is a complex process, and competence in those skills cannot be assumed on the basis of seniority, role or experience. There is a suggestion in the authorised literature that this is because eliciting concerns and preferences with compassion and empathy, and then taking those concerns and preferences into account when making joint decisions about a person's health and treatment, is a skill that must be intentionally learned and practiced (Schofield *et al*. 2015). Communication skills research suggests that the most effective way of increasing facilitative communication skills (such as noticing and picking up patient cues, using open questions, showing empathy and acknowledging concerns) and decreasing inhibitory skills (such as using leading and closed questions or offering premature advice and/or reassurance) is to receive training over a number of days or weeks that uses a mixture of theoretical and experiential teaching methods (such as role play) with feedback (Ammentorp *et al*. 2007, Fallowfield *et al*. 1998, Maguire *et al*. 1996, Riess *et al*. 2012). This type of training is typically classified as *"Advanced Communication Skills Training"*. This was not the type of training in the SVQ 3 qualification – which was text-book based and basic, in my view. In the geographic area under investigation, *"Advanced Communication Skills Training"* is only available to particular grades of staff, such as senior nursing staff, senior allied health professional staff and medics. This means that *"Advanced Communication Skills Training"* courses, are not open to SSCWs on the basis of their grade rather than on the actuality of their work. Although I am not suggesting that SSCW should be *"pushed"* into discussing topics such as DNACPR decision-making, or that additional training would solve the problems I have highlighted to date, I wanted to draw attention to the current situation where there is both an institutional requirement for RCH SSCWs to participate in complex conversations and an institutional exclusion from access to the communication skills training which could support SSCWs to develop confidence and competence in managing difficult conversations. This exclusion leaves SSCWs in a vulnerable position – in relation to all types of difficult conversation.

3.3 Chapter summary

This chapter presented the first stage of my inquiry and analysis to find and map the work and texts that shaped SSCWs experience, and to find the clues in that experience that would lead on to the next stage of data collection. When I spoke with the SSCWs, they described how they followed internal processes to know what was expected of them in relation to admitting residents and organising and holding care plan review meetings where DNACPR forms are a feature. This work involved: knowing what to discuss at care review meetings - including raising the topic of the DNACPR form with proxy-decision makers; and understanding how to get the documentation the care home required (a DNACPR form) into resident's care home files through negotiation with the resident's GP by telephone.

This chapter highlights the work of getting a form in place was important to SSCWs for three reasons:

1. firstly, to prevent CPR attempts being made on residents when they died;
2. secondly, to satisfy the legal requirement to gain consent to give/with-hold treatments from the Power of Attorney of an Adult with Incapacity;
3. thirdly, to comply with internal policies and quality assurance processes which included regular care file audits on the presence/absence of specific documents;

To follow the thread of inquiry into why the care home now had a *“policy”* requiring that SSCWs discuss the DNACPR form at review meetings, when before no one in the RCH ever spoke about *“these things…not even the manager”*, it is important to explore the term *palliative care*. This is because *palliative care* is the organising institutional discourse leading SSCWs to initiate conversations about DNACPR forms. They did this under the heading of what to do *“on the occasion of serious illness”* and the content of what was discussed under that section was informed by *“recent trainings”* organised by palliative care facilitators and educators working for third sector organisations. Therefore, in the next chapter I trace how the discourse of *palliative care* organised the thinking, talking and acting of the SSCWs and the palliative care staff. It is also important to trace how this term influenced my own thinking, both as a palliative care nurse whose professional work influenced events in the RCH, and as a researcher attempting to map the social organisation of knowledge in (and about) the research site.

To begin this process I review key literature to trace and discuss the evolution of the term palliative care. I then trace how palliative care policy directives made *palliative care tools and frameworks* mandatory in all care settings and review and discuss the authorised knowledge about the taken for granted *correct way* to care for care home residents who will inevitably die. In this way I will uncover how knowledge about an authorised version of the conceptual practice of palliative care was socially organised in Scotland’s care homes - when the data for this study was collected between 2014 and 2015. This will demonstrate how dominant knowledge informed by the institutional discourse of palliative care made its way into the consciousness of the SSCWs as they attended palliative care *“trainings”* and were *“pushed”* into changing their working practices as a result.

Chapter Four: Reviewing key literature to trace, analyse and discuss the development of an authorised version of *Palliative Care*

4.1 Introduction

In the previous chapter I described and mapped a routine everyday aspect of SSCWs work – admitting frail residents who would inevitably die with or from dementia into the RCH and discussing and planning *care* at a care review meeting with family members. In constructing that chapter as vignettes and maps I positioned myself as an institutional ethnographer in the RCH paying attention to the issues the SSCWs were concerned about in the same way that SSCWs described those concerns – as being *"pushed"* into having a *"difficult"* conversation with family members about a DNACPR form for their loved one as a result of *"recent trainings"* and *"things"* while also *"keeping beds filled"* by making decisions on what made particular people *"suitable for us"*. I accepted their accounts as being true accounts of their experience. I checked the trustworthiness of the vignettes and the maps I constructed from those accounts by showing them to SSCWs. They were confirmed as a faithful account of a) what happened in the RCH; and b) how they (SSCWs) were involved.

In constructing this chapter I now turn my attention to how events described by the SSCWs were socially organised by authorised forms of knowledge. *"Recent* [palliative care] *trainings and things* [care home policy]*"* was the SSCWs own explanation of why they had been *"pushed"* into raising the topic of the DNACPR forms in the first instance. Knowledge influencing the *"training"* (organised by palliative care education facilitators such as myself) and the *"policy"* of RCH staff *"getting the* [DNACPR] *form"* (monitored by the RCH manager through an audit of resident's personal files/care plans) were both organised by the institutional discourse of palliative care. Therefore, I will now focus on the development of the institutional discourse of *palliative care*.

Institutional discourse is defined as any:

> *widely shared professional, managerial, scientific or authoritative ways of knowing (measuring, naming, describing) states of affairs that render them actionable with institutional relations of purpose and accountability. Far more than jargon, these are conceptual systems, forms of knowledge that carry institutional purposes and reflect a standpoint within relations of ruling (McCoy 2006: 118).*

The goals of this analytic chapter are to: to discover what is already written in the literature about palliative care, and to highlight:

> *how…institutional work processes are organised and how they shape the ground of people's everyday experiences…to glean good ethnographic understanding of the informants' lived experience and circumstances in a way that brings into view the institutional hooks and traces, identifying sites and processes for further investigation.* (McCoy 2006:123).

This required a sustained period of *detective* work as I followed threads from interviews with SSCWs (and others whose work influenced the SSCWs work, including my own), reviewed authorised knowledge in the literature, and identified the predominant institutional discourse(s) and textually mediated relations of ruling. As a result of that detective work, Chapter Four will first follow the threads which trace the development of the term *palliative care* and then follow the textually mediated relations of ruling which led to the promotion of *palliative care tools and frameworks* in all care settings by the Scottish Government. The promotion of palliative care tools and frameworks was a key part of my role as a palliative care education facilitator (Chapter One).

Uncovering the conceptual framework that socially organised SSCWs to initiate a *"difficult"* conversation about the DNACPR form with family members will begin to show how:

> *the issue of knowing emerges as a contested aspect of research – that in institutional ethnography is made explicit…* [it will also show how I, as a researcher and institutional ethnographer, attempted to]…*come to terms with the literature while delineating and maintaining her particular stance vis-à-vis discourses, authorised knowledge, and views that express a standpoint organised differently from the institutional ethnographer's stance in the everyday world.* (Campbell and Gregor 2002:51)

4.2 Part One: What are we talking about when we talk about palliative care?

Palliative care is typically described as a *model or philosophy of care* (WHO, 2003, 2004, 2011). However, as highlighted above, I am treating this term (and the phrases that were linked with it in the RCH documentation: *end-of-life care* and *on the occasion of serious illness*) as a form institutional discourse that organised the thinking, talking and acting of the research participants – including myself as a palliative care education facilitator/researcher.

In her explanation of IE as a *sociology for people*, Smith (2005) introduces IE as a:

> *theory of language…in which thoughts, ideas, ideologies, and so on are lifted out of the regions of people's heads and into the social, understood as the coordinating of people's doings…because…the distinctive forms of coordination that constitute institutions are* ***in language***. (Smith 2005:94).

Therefore, understanding how language was used was important to this study because categorising work as *palliative care* had a powerful co-ordinating function that could be seen in people's talk and actions when that term appeared in administrative documents and texts (Smith 2006).

The terminology relating to palliative care has undergone several transitions since it was coined in the 1970s. This has produced confusion about what is currently meant when that term is used. Adding to this confusion, there are now a range of different terms used in relation to care of people in the final phase of life, where the practice of palliative care is typically situated. These terms include: hospice care, end-of-life care, terminal care, care of the dying, continuing care and supportive care (Payne and Seymour 2008, Nicholson 2007). Although these terms are used interchangeably with palliative care they may or may not have the same aims or goals as each other. This leads to confusion about which group of workers should be doing what, when they should be doing it, and/or who is responsible for funding it. To unravel how this confusion became a practical rather than a conceptual problem for SSCWs who had become accountable for discussing the DNACPR form with family members, I will now trace where the term originated and how it has developed.

4.2.1 A new model of care emerges and develops

Dame Cicely Saunders is cited as being the pioneer of the modern hospice movement. Her work had significant influence on the development of the model of care later identified as *palliative care*. Trained initially in nursing and social work Saunders re-trained as a doctor in 1958 with the intent of dedicating her career to improving the care of people who were dying. Before this, dying was often viewed as something of a medical failure. According to

Krismann-Scott (2001), whose PhD thesis explored care of the dying person between 1944-1976, thinking of dying as a medical failure led to the marginalisation of those who were dying by sequestering them to a *“Room at the End of the Hall”* (Krisman-Scott 2001:1) in acute general hospitals. To reverse the tendency toward marginalisation and improve the experience of those who were dying (with cancer), Saunders founded St. Christopher’s Hospice (London, England) in 1967. As there was little enthusiasm for specialising in care of the dying within the state funded NHS at that time, this work had to be independently financed in its early stages. It took Saunders eight years to raise sufficient funds to build and open St. Christopher’s Hospice (Saunders and Clarke 2006). The aim of care at St. Christopher’s was to reduce people’s suffering by promoting the best possible quality of living, and the best possible quality of dying (Pace, Treloar and Scott 2011, Saunders and Clarke 2006). To achieve this, care was focussed on the following principles:

1. The inevitability of death must be discussed and prepared for – but neither hastened nor hindered.
2. The patient must be viewed as a whole person with a complex interplay of physical, psychological, social and spiritual dimensions at work in their experience of pain and illness.
3. Common symptoms, especially pain, should be effectively managed and controlled.
4. The *family* rather than the *individual* should be the unit of care because when one member of the family suffers every member suffers.

5. Family pain and distress does not end with the death of the patient, therefore an active programme of bereavement support and care should be developed.
6. Research and education should be ongoing (Saunders 1993)

Operating as a small charity with independent funding streams meant that senior staff at St. Christopher's had freedom to pursue this vision of care (Saunders and Clarke 2006; Pace *et al.* 2011). When St. Christopher's opened, it was clear who care was intended for – namely, people with a terminal cancer diagnosis and their family members. It was also clear that, under normal circumstances, focussed care would only be needed for a relatively short time period – weeks or months rather than years - because of the progressive nature of advanced cancer, and the lack of effective cancer treatments available at that time (Saunders and Clarke 2006).

Saunders ideas and approach were revolutionary at the time, most notably her ideas about continuous pain management for continuous pain, and open acknowledgement of and discussion with patients about diagnosis, prognosis and the inevitability of death. Thanks to the guidance based on Saunders approach now being set in World Health Organisation's analgesic ladder (WHO 1996)[11] continuous pain management for people who are experiencing continuous pain is common practice. However, in the 1960s and 70s there was hesitancy around prescribing regular doses of strong analgesia out of fear that patients may develop an opiate addiction. In addition to challenging ideas about pain management, Saunders challenged the ethic that

---

[11] When this guidance is followed it is reported to be 80-90% effective in managing cancer pain.

it was acceptable - and even desirable - to conceal a cancer diagnosis and prognosis from patients[12]. This may have come from a well-intentioned desire to protect sick and vulnerable people from additional distress. However, counter culturally, Saunders advocated that healthcare professionals should more openly recognise the point at which life may be coming to a close, and then have open and honest conversations about patients' likely prognosis - including the treatment options that were now viable/non-viable as a result. This was important for cancer patients who were often receiving chemotherapy and radiotherapy up to the point of death. These can be difficult and demanding interventions for patients to tolerate under the best of circumstances. As they have minimal clinical benefit for terminally ill people, Saunders believed that open recognition of the terminal phase would minimise the use of burdensome but ineffective interventions in favour of promoting comfort instead (Saunders and Clarke 2006). Saunders also believed this level of openness would assist people with the process of actively preparing for the inevitability of death.

Inspired by the principles and techniques being employed at St. Christopher's, Balfour Mount - a Canadian physician - opened a hospital ward in 1973 to offer the same kind of care to Canadian cancer patients. However, he decided not to adopt the word "hospice" to describe this ward, because that term was already in use in Canada to describe a care setting for *the poor and destitute*. He introduced the term *palliative care unit* instead. He did this for a number of reasons: partly to minimise potential stigma associated

---

[12] This debate was still going on in the mid-1980s when I first entered healthcare work.

with the term *hospice;* partly because he was drawn to the word's etymology which means to cover, protect, alleviate and improve the quality of something; and partly to intimate that a specialised type of care was being delivered (a device employed by other medical specialities, such as cardiac care in a coronary care *unit*) (Pastrana *et al.* 2008). Although the terminology Mount adopted was different, the target patient group, terminally ill cancer patients, and the overall philosophy of care was largely the same as that of the St. Christopher's model. One crucial difference between Saunders' hospice and Mounts' ward was how they were financed and operated. Mount chose to set the palliative care unit up within the hospital building. He did this to progress the work of integrating care of the dying into the administrative and funding structures of Canada's healthcare system - rather than operating as an adjunct to that system as was the case with hospice care in the UK. He also did this because he did not feel the independent hospice model was financially viable or sustainable in Montreal where he worked (Scott *et al.* 2015).

Funding care of the dying has been an ongoing challenge for UK hospice care. In the early days the media played a significant role through informing and shaping the national (public) consciousness about the way terminally ill cancer patients were cared for at St. Christopher's. This consciousness shaping work began in 1978 after journalist Victor Zorza and his wife published a personal account in the Guardian newspaper called *Death of a Daughter* which was about their experiences of care at the hospice (Zorza and Zorza 1978). They subsequently expanded their article into a book (Zorza and Zorza 1981) at a time when the hospice/palliative care movement was still relatively young and unknown by the general public. (A movement is defined as a group of people working together to advance their shared political, social, or artistic ideas.) This book made Saunders into something of a folk hero. It also raised public awareness about the potential of this new model of care for terminally ill cancer patients, and generated much needed public interest in fundraising to build and finance the operation of more charitable hospices in a number of communities throughout the UK (Richmond 2005)[13].

Over time, the philosophy behind Saunders model of care spread to many other areas of the world. The term *palliative care* rather than terminal care or hospice care was adopted in 1990 by The World Health Organisation (WHO 1990). Adoption of this term was not universally welcomed. Indeed, some criticised it as a euphemistic devise to create distance from the bolder, and arguably clearer, label of terminal care (Pastrana *et al*. 2008). Around the same time, in 1987, the practice of *palliative* medicine became a distinct medical speciality in the UK (Hiller 1988) and the term *palliative care* was accepted and adopted by the international community.

The following section will demonstrate some of the challenges that have arisen in relation to defining the term palliative care.

4.2.2 Defining Palliative care: The WHO

Palliative care has been defined twice by the WHO, a powerful partner in determining the shape and direction of the palliative care movement (WHO 1990, WHO 2002). Their first definition was published in 1990 when palliative care was defined as:

> *The active total care of patients whose disease is not responsive to curative treatment. Control of pain, other symptoms, and of*

---

[13] Funding remains an issue for UK hospice based care, which is coming under increasing scrutiny to demonstrate value for money from NHS funding bodies who negotiate levels of financial support on a hospice by hospice basis.

> *psychological, social, and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with* ***anti-cancer treatment*** *(WHO 1990:11).*

It is obvious from this definition that palliative care was originally intended for cancer patients and was an extension of oncology, a branch of medicine that deals with the prevention, diagnosis and treatment of cancer. However, during the late 1990s a greater emphasis started being placed on applying palliative care to diseases other than cancer and in settings other than specialist units (National Council for Hospice and Palliative Care Services 1997). The case for this wider remit tended to be made on ethical grounds around equity of access and resulted in a move towards advocating that palliative care should be available to everyone who was affected by diseases that were *not responsive to curative treatment* (Addington-Hall *et al*. 1998). In other words, it should not be for people affected by cancer alone. This led to an updated definition of palliative care being published by the WHO in 2002 (WHO 2002). The 2002 definition is the current definition on the WHO web-site. It states that palliative care is:

> *An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO 2016: online).*

It is important to recognise that these subtle changes in wording have had considerable practical implications. Broadening who palliative care was aimed at presented national Governments with a significant political challenge of how to fund, organise, deliver and monitor palliative care for a much wider group. It is also important to emphasise that the culture of palliative care, and the subsequent development and delivery of palliative care services, was shaped around the care of people who are dying from cancer (Hockley 2006), which tends to follow a relatively predictable disease trajectory. For example, once a cancer disease trajectory reaches the point of producing permanently reduced functional status, there is a relatively recognisable and short dying trajectory. This short and recognisable dying phase makes cancer a distinctive disease process. Dying from non-cancer diseases tends to be more prolonged and more difficult to predict, both in terms of how the disease is likely to progress and in relation to when the irreversible end point and dying phase might be reached. This means the care needs of each group are different.

The different patterns of dying will be outlined further in the following section.

4.2.3 Dying trajectories

Dying trajectories, the time between the onset of the dying process and the arrival of death (Glaser and Strauss 1965), have become an important concept in the palliative care literature. In 2003, Lunney *et al*. (2003) proposed the following patterns of functional decline from the most commonly occurring diseases. These dying trajectories were corroborated by Scottish palliative care researchers in 2005 (Murray *et al*. 2005) and are used in the first national action plan on palliative and end-of-life care in Scotland, *Living and Dying Well* in 2008 (Scottish Executive 2008). They have become powerful drivers for those planning and delivering palliative care services for people living and dying with diseases that are no longer responsive to curative treatment. The four dying trajectories are:

1. Sudden death where there was little prior warning.
2. Death following a *terminal illness*, typically cancer, where people tend to remain in relatively good health until their functional status begins to deteriorate. This permanent reduction in function is an important prognostic indicator. It often occurs around 12 weeks prior to death, and is a timeframe which tends to be consistent across all age groups (Costantini *et al*. 2008).
3. Death from organ failure where there is a gradual decline in functional status that tends to be punctuated with acute episodes of deterioration and recovery - after aggressive treatment in hospital. However, even with aggressive treatment every acute episode poses a serious and immediate threat to life because recovery is not always possible, and any acute episode could end in death. The end-stage of this disease trajectory is longer than a cancer trajectory – typically between two – five years. Lack of predictability makes it challenging to plan ahead for this group (Gott *et al*. 2007).
4. Death following gradual and progressive decline typically from conditions such as frailty, stroke and dementia - often referred to as a period of prolonged dwindling before death (Murray *et al*. 2005). This group has sometimes been categorised as the disadvantaged dying, because until around 2006 they received less attention from policy makers than people dying from other conditions (Abbey *et al*. 2006, National Institute for Health and Clinical Excellence 2006). People with frailty and dementia

tend to have a protracted and uncertain journey toward death that lasts between four - eight years. This journey is often compounded by multiple difficult and uncomfortable co-morbidities - any of which could also result in death (Payne and Froggatt 2006).

These disease trajectories are often represented pictorially, as follows:

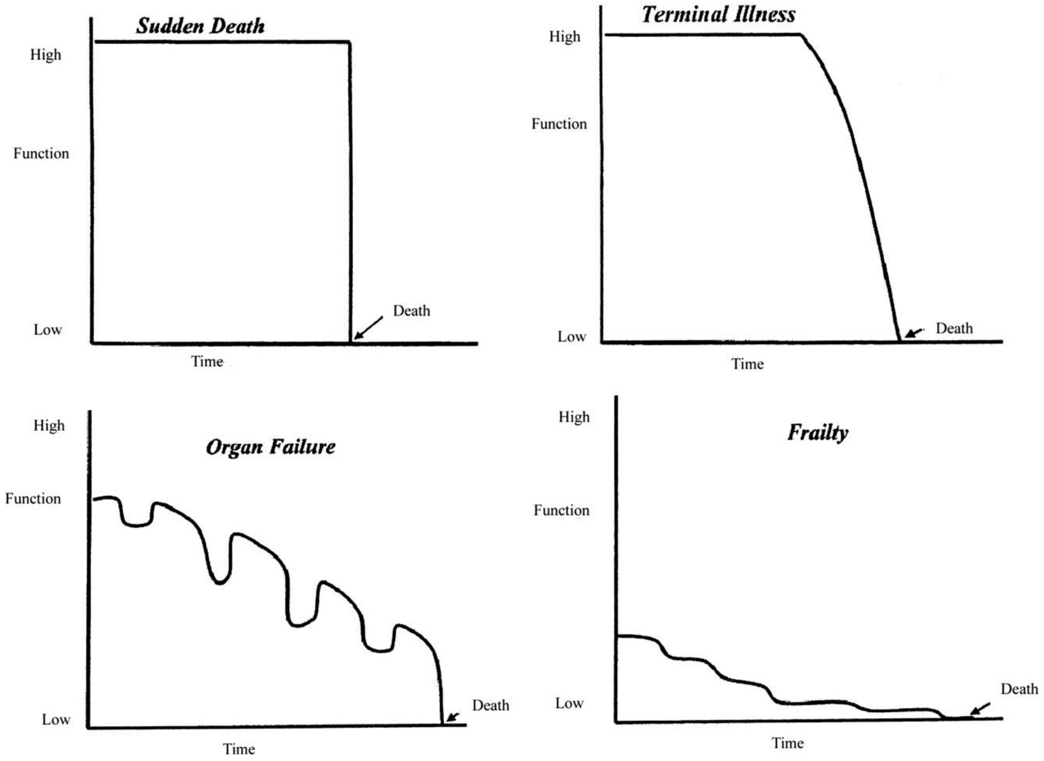


Figure 1. The 4 main disease trajectories (Lunney *et al.* 2003)

These diagrams and descriptions highlight that there are significant differences between the typical clinical progression (predictable/uncertain, rapid/prolonged) and the timescale of decline (ranging from 12 weeks – 8 years respectively) between each of these dying trajectories. As previously highlighted, the original model of palliative care was designed to respond to the needs of those affected by cancer at the point where curative treatment was no longer possible, and who were by implication in the terminal phase of illness (WHO 1990). Predicting how and when a person with organ failure, frailty and/or dementia (non-cancer disease processes) will enter the terminal phase, or succumb to the effects of their disease, is much more challenging and problematic in clinical practice. This suggests that the tasks and timings of interventions categorised as *palliative care* for people facing the problems associated with non-cancer disease processes will not be the same as the tasks and timings of those with a terminal cancer diagnosis.

This study focussed on SSCWs work to organise care for RCH residents with dementia who will inevitably die with or from dementia. As highlighted in Chapter One, there is a growing trend in the healthcare literature to classify dementia as a *terminal* condition that could benefit from the application of *palliative care* (Sampson 2010). People with dementia are often categorised as following the frailty dying trajectory (Murray *et al*. 2005). The level of uncertainty that surrounds the progression of dementia, including when and how death may occur, makes supporting the family unit and planning ahead a difficult and demanding experience for professional care staff (Sampson 2010). Lack of awareness among patients and families that non-cancer diseases are classified as terminal conditions means that the topics of planning ahead for illness and death are not only unexpected they are also often unwelcome among that group (Kendall *et al.*2015). This makes knowing if, how and when to begin the process of talking to people about death and dying a complex and confusing process for people organising care for people with *non-cancer* diseases (WHO 2011).

The following section outlines a further brief analysis of recent definitions of palliative care - which seem to be moving away from death and dying as the central principle of practice.

4.2.4 Moving away from *death and dying* as central themes in recent definitions

In 2001, Cairns commented that that no other area of healthcare seems to have gone to the lengths to define itself as has the practice of palliative care. Lack of consensus about what the term palliative care currently means, who it is for, who is equipped to provide it, and who should pay for it, has led to the term being defined, and re-defined, by a succession of national and international groups. In 2003 Doyle commented that no sooner *“is a new service started anywhere in the world, or a new professional palliative association formed, then people sit down a write a new definition...”* (Doyle 2003: 9). The search for consensus was ongoing in 2008 when Pastrana *et al.* published their discourse analysis of the term palliative care. They identified 37 English and 26 German definitions of the term. Their analysis suggested that the continued debate and activity around trying to produce a definitive description of what palliative care entails signified that discussion about this terminology was likely to go on for some time to come – which the most recent publication on palliative care from the Scottish Government suggests is problematic (Scottish Government 2015).

Some writers have argued that, in order to have wider applicability, many of the newer and broader definitions of palliative care have moved away from Saunders’ dual focus of offering holistic symptom management while also supporting people to prepare for the inevitability of death (Krakowski 2006, Payne and Seymour 2008). These writers have come to this conclusion because many of the more recent definitions seem to concentrate primarily on issues of symptom management and quality of life. Important as good symptom management and quality of life are, this narrower focus has resulted in Pastrana *et al.* (2008) noting that the words *death* and *dying* are used less frequently in more recent definitions of the term. They submit that this tendency to omit the words *death* and *dying* demonstrates a conceptual shift away from the care of the imminently dying. Indeed Pastrana *et al.* (2008) suggest that the relationship between newer definitions of palliative care and the issues around death and care of the dying are becoming increasingly *"strained"* (Pastrana *et al.* 2008:229) as time goes on.

This conceptual problem has practical implications in relation to the terms that are used to describe (and then mandate and measure) work that is categorised as palliative care in care settings – such as RCHs (Scottish Government 2015). It also has practical implications in relation to the current lack of knowledge about the experiences of people with different life limiting conditions (and their families) as they die. Worryingly, research into care of the dying published in palliative care journals is becoming less and less common as time goes on (Nobel and Winslow, 2015). This leaves those mandating, organising, delivering and regulating care dependent on current knowledge about death and dying – which is predominantly based on the experiences of those who are living/dying with cancer. This cancer based knowledge is of limited usefulness to those who will die from other conditions, such as RCH residents with dementia. It is also of limited usefulness to those who will care for that group – such as RCH and community based support staff. For a variety of reasons, Moore and Hanratty have described care home residents as being systematically out of sight and out of mind (Moore and Hanratty 2013). Lack of research into how people with dementia die in care homes keeps this group out of sight and out of mind and could be described as a further example of staff and residents from this setting being *"abandoned"* by the wider community as knowledge of residents and happenings in the care home is routinely subordinated to the authorised, but limited, cancer-based knowledge about death and dying.

The following section outlines how revised definitions of the term palliative care have developed further, so that complex work with people who are dying is now classified as *"routine"*.

4.2.5 Reclassifying palliative care as *"routine"* work

In 2008, building on the WHOs updated definition of palliative care (WHO 2002), the term palliative care started being used in influential UK policy documents to describe a model of care that was expected to straddle *all* care settings and be available to those affected by *all* types of life limiting illness (Department of Health 2008, Scottish Executive 2008). Furthermore, palliative care was to be available from the time of diagnosis of life-threatening illness, up to, through and beyond death into bereavement for those who were left behind. While these developments may be both appropriate and welcome, widening both the target patient group and the length of time that input is required has produced a blurring of what were once fairly clearly recognised service and manpower related boundaries. In the process it has created a significantly increased demand for activities associated with palliative care. Meeting such an expanded commitment has posed the Scottish Government with significant challenges, including how to upskill existing staff groups to be deemed competent in performing activities categorised as *palliative care*.

Perhaps as one means of responding to the challenges posed by expanding the remit and applicability of palliative care, it has increasingly been proposed that palliative care should be thought of as a spectrum or continuum of care rather than as a distinctly specialist activity (Scottish Executive 2008, WHO 2011).

According to this view, at one end of the spectrum palliative care should include the general knowledge and skills that staff in all health and social care settings have a duty to provide and which is described as *general* palliative care or *routine care*. This authorised knowledge about care of the dying person as *routine* care is demonstrated in the definition of *general* palliative care in the Audit Scotland (2008) report:

> *General palliative care forms part of the routine care of patients and support for carers. It can be provided in the patient's home, a care home, in GP practices or as part of the general care provided in community or acute hospitals. It may be part of the work of a range of health and social care workers including GPs and district nurses, social workers or care assistants, as well as hospital staff.* (Audit Scotland 2008: 3).

At the other end of the spectrum, *specialist* palliative care is thought to include the more detailed knowledge and skills provided by specialists whose main work is with people at the end of life, who have recognised palliative care qualifications, and often work in distinct physical locations such as a hospice or palliative care ward. This is described as specialist palliative care for people with specialist palliative care needs. Specialist palliative care needs are categorised as being needs which are particularly challenging and/or complex to manage (Audit Scotland 2008, WHO 2011). According to this spectrum, or continuum, of care, generalists should be able to manage on their own with the occasional back up of specialists, on whom they can call for help and support - when patients have (specialist) palliative care needs.

This was not the case in the *general care setting* of the RCH where general medical (and nursing) support was unpredictable, and specialist support could only be accessed by GP referral.

This additional change in wording and thinking altered what had previously been taken for granted, that the term palliative care described the specialised activities of experienced and qualified healthcare staff working with a distinct patient group for a relatively short period of time, into something much broader - and now the accountable business of all staff caring for everyone with a life-limiting illness in any care setting.

Part two of this chapter will continue to explore the institutional use of the term palliative care to uncover how an authorised and mandated set of tasks and activities, categorised as palliative care, has emerged in Scotland. This changed what was expected, and then measured, as palliative care work in the general care setting of the RCH under study. It also directly influenced the social organisation of my own knowledge as a palliative care education facilitator who offered training opportunities to staff at that site.

4.3 Part Two: Palliative care in care homes: policy and palliative care tools

This section traces how the conceptual practice of palliative care was promoted in all care settings – including care homes - through the mandated use of palliative care tools such as the Gold Standards Framework (GSF) (Table 1 below), and the Liverpool Care Pathway (LCP) (Table 2 below).

4.3.1 Policy, research and caring for dying people in RCHs

From 2000 onwards, the term palliative care started making its way into a range of Scottish Executive policy statements. These documents include: *Our National Health, A Plan for Action A Plan for Change* (2000) - which stated that palliative care should be available on the basis of need not diagnosis; *Cancer in Scotland: action for change* (2001) - which also acknowledged the need for wider application of palliative care beyond cancer care; and *Coronary Heart Disease and Stroke Strategy for Scotland* (2002) - which indicated that palliative care should be available to all with end stage heart failure.

In 2006 the Scottish Partnership for Palliative Care (SPPC) published *Joined up Thinking, Joined Up Care* (SPPC 2006). The SPPC describes itself as:

> *…an umbrella and representative organisation which, through a collaborative approach, supports and contributes to the development and strategic direction of palliative care in Scotland."* (Scottish Partnership for Palliative Care 2015: online)

Joined up Thinking, Joined Up Care (SPPC 2006) was a report on a three year project funded by the Big Lottery Fund to increase access to palliative care for people with conditions other than cancer. Around the same time, increased interest about the practice of palliative care in care homes led to the publication of *Making Good Care Better* which detailed national practice statements to guide the practice of general palliative care in adult care homes (Scottish Executive, Scottish Partnership for Palliative Care. 2006). This document was designed to raise awareness among care home staff about what was considered *best practice* in general palliative care in care homes at the time of its publication. It was developed at the request of the Scottish Executive (Scottish Executive, Scottish Partnership for Palliative Care 2006) and produced by an *expert* working group set up by the SPPC, who appointed twelve members to the national practice statements working party. It is interesting to note that the majority of this group were from the specialist palliative care community. Only two members came from the care home sector. This suggests that the knowledge and experience gained by specialists caring for people dying with cancer was the primary knowledge base used to inform how palliative care should be organised for older people being cared for in care homes. These practice statements were then used by the Care Commission (now the Care Inspectorate) – the body responsible for inspecting and grading care homes in Scotland at that time – to evaluate the quality of palliative care in care homes (as is further discussed in Chapter Six). A report based on this inspection was published in 2009 which claimed that while there were examples of excellent care across Scotland, 43% of care homes for adults and older people did not recognise or support the palliative care needs of residents (Care Commission 2009). This report was published shortly after Audit Scotland's report *Review of palliative care services in Scotland* (Audit Scotland 2008) which also highlighted that palliative needs were not always well recognised or supported in general care settings such as care homes. Understandably, these documents created a heightened level of concern about the welfare of people who were (living and) dying in those settings.

In 2008, the first Scottish national action plan for palliative and end-of-life care was published: *Living and Dying Well* (Scottish Executive 2008). This policy document also stated that palliative care provision was to be based on need rather than diagnosis. To improve *palliative care provision*, the Scottish Government had to rely on the knowledge, skills (and bodies) of a diverse staff group across diverse care settings. The staff groups and settings included: NHS hospital and community staff working in hospital and community settings; non-NHS hospice staff working charitable hospices; and non-NHS care home staff working in care homes (RCHs and NCHs). These staff groups and these care settings are neither inevitably nor completely under the control of the Scottish Government, or other any other national body. Therefore, one challenge of the government setting specific expectations around palliative care provision was how to standardise and make the work of palliative care knowable to those not previously socialised into its practice. A second challenge was how to administer, manage and audit the application of that knowledge. To address these challenges, the Scottish Government mandated that standardised texts, or palliative care tools, should be used to guide care in all care settings.

> *"NHS Boards – through palliative care networks and Community Health Partnerships – should* ***ensure*** *that recognised palliative care tools are used across all care settings by 2010" (*Scottish Executive 2008:10).

Palliative care tools are texts that focus the attention of staff: firstly, on identification and assessment of needs categorised as *palliative care needs*; secondly, on planning, delivering and co-ordinating particular activities to meet those needs; and thirdly on generating further texts to share identified palliative care needs, plans and actions with other staff groups in other care settings (as deemed appropriate). Textually mediated work using palliative care tools (such as the Gold Standards Framework (described in Table 1 below) became the basis of national standardised, authorised and accountable actions and activities in relation to palliative care work in *general* settings such as hospitals, patient's own home and care homes. Improving knowledge, skills and processes about palliative care was considered particularly important in general settings, because research produced around the same time as the tools were developed and the action plan was published suggested that general settings were where most people actually died (Gomes and Higginson 2008).

It was thought the implementation of palliative care tools would provide a consistent and fair approach to the delivery of palliative and end-of-life care across Scotland so the documents and processes of Gold Standards Framework, Advance Care Planning, DNACPR and the Liverpool Care Pathway became the key texts used to organise knowledge and practice in a variety of settings, including care homes.

The topic of *palliative care* in relation to care homes came to the fore as a result of the first research projects into living and dying in UK care homes and early research suggested that: approximately 20% of all deaths in the over 65 age group took place in a care home (Froggatt 2004; Social Care Institute for Excellence (SCIE) 2004); that the majority of residents in care homes died within two years of admission (Hockley and Clarke 2002); and that there were reasons to be concerned about the quality of living and dying among care home residents (Hockley and Clark 2002, Katz 2003, Sidell and Komaromy 2003). As a result there was a steady increase of writing and advocacy in the professional literature actively promoting a *palliative approach to care* in the care home setting. Promoting this approach was considered important because of its focus on comfort and improved quality of living, and because of its focus on the active preparation for the inevitability of death. It was believed that increasing the focus on death and dying would raise awareness that death and dying were central, significant and important events/experiences that regularly happened in care homes - as opposed being peripheral or rare events (Aoun *et al.* 2005 , Kayser-Jones *et al* 2005). Patient advocates and researchers hoped that increasing awareness of death as a fundamental and common happenings that took place in care homes would place a greater value and emphasis on attending to the quality of dying that was experienced in that setting (Brazil *et al.* 2004, Hockley and Clark 2002, Katz and Peace 2003). According to research carried out by Jo Hockley - the first specialist palliative care nurse to carry out doctorate level research into death and dying in Scottish **nursing** care homes - open discussion of these topics was **not** common in care homes at that time (Hockley *et al.* 2004, Hockley *et al.* 2005, Hockley 2006). Indeed, she described death and dying as *taboo subjects* which were not routinely discussed or planned for leading to increased suffering as a result of *"inappropriate"* transfers to hospital as older people were dying (Hockley 2006) To improve this situation Hockley carried out ground-breaking research into the use of palliative care tools in Scotland's nursing care homes. In Section 4.3.3 I will describe the significant influence Hockley's work has had on the development (and management) of my own professional role and thinking. I will also describe how, as a result of taking the standpoint of those having their working lives restructured by the institutional discourse embedded in palliative care tools, my thinking has changed during the course of this research.

To first understand the significance of Hockley's influence on the way palliative care in care homes has developed in Scotland it is important to have some understanding of Hockley's background and the institutional discourse that shaped her work in care homes.

4.3.1.1 Jo Hockley: Background and research focus

Jo Hockley's palliative care career began in 1979 as a ward sister in St. Christopher's Hospice, London, working alongside Dame Cicely Saunders. Recognising the potential of this model of care and wanting to see it more widely available, Hockley went on to set up two hospital based palliative care teams, one in London and one in Edinburgh. In 2000 she turned her attention to care homes when she was offered the opportunity to carry out a five year participatory action research study, in association with Edinburgh University, to evaluate the effectiveness of two palliative care tools - the Gold Standards Framework (GSF 2005), and the Liverpool Care Pathway for the Dying Person (LCP) (Ellershaw and Wilkinson 2002, 2010) - in eight NCHs in Lothian, Scotland. Previous research into the quality of palliative care available to care home residents (Brazil *et al*. 2004, Hockley and Clark 2002, Katz and Peace 2003) made those settings a prime target for those wishing to implement a more structured approach to the management of what was considered a *failing* aspect of care home work.

Hockley carried out her PhD study while working jointly as a hospice based palliative care clinical nurse specialist with a remit to care homes, and as a research fellow at Edinburgh University (Hockley 2006). After completing her study, Hockley accepted a 5 year fixed-term appointment as Nurse Consultant back at St. Christopher's in London, where in 2009 she set up the first hospice based research and practice project team researching and supporting the implementation of palliative care tools to develop palliative care practice in care homes. In 2013 she was awarded the OBE for her services to palliative care nursing. This brief biography highlights Hockley's professional commitment to improving the experience of dying for care home residents, it also demonstrates the level of respect that she holds within and beyond the discipline of nursing.

Hockley's action research study focused on implementing and evaluating two established palliative care tools and frameworks, the Gold Standards Framework for Care Homes (GSFCH) and the Liverpool Care Pathway for the dying person (LCP). The process of developing those tools was the work of teams who had observed and recorded, or captured, the complex and skilled range of processes and activities carried out by palliative care specialists. These specialists usually worked in hospices with cancer patients. Their activities were considered *best practice* at the time the tools were developed. After capture, the processes and activities were textually reconfigured in a variety of interlinked local and national documents. These documents were reviewed and updated by professional bodies on a regular basis. The documents used in the GFCH include: a *prognostic indicator tool* - developed to alert clinicians to those patients who may have advanced disease, be in the final year of life and/or need palliative/supportive/hospice care (Gold Standards Framework 2015) (Appendix 32); *a holistic assessment tool* to help guide an exploration and discussion of current and future needs and wishes about treatment and care (Gold Standards Framework 2015) (Appendix 4); an *end-of-life tool* to guide care of the dying person, usually the LCP (Ellershaw and Wilkinson 2002,2010); and guidance about *palliative symptom management and prescribing* (the most recent version of this guidance for Scotland was published by Health Improvement Scotland NHS Scotland in 2015).

The process of implementing the GSF was organised around seven key tasks – the 7 Cs of the GSF (Thomas 2003)

Table 1: The Gold Standards Framework (GSF)

1. ***Communication***

   - set up a palliative care register to highlight patients who have palliative and end-of-life care needs (as identified by the prognostic indicator tool),
   - meet regularly as a team to discuss the care needs of that group,
   - ensure patients and families have the information they need and want,
   - talk to patients and families about their wishes around future care so those wishes are known and taken into account.

2. ***Co-ordination***

   - appoint a clinical lead within the GP practice to co-ordinate care.

3. ***Control of symptoms***

   - use holistic assessment tools to identify and assess symptoms (Appendix 4)
   - promote joint working between professional groups to effectively manage symptoms identified

4. ***Continuity of care 24/7***

- develop systems to inform out of hours services about key information regarding patient care
- work with secondary care teams to promote continuity of care for palliative care patients

5. ***Continued learning and process improvement***
   - use audit, significant event and after death analysis in the development of practice protocols and to aid reflection on practice at GSF meetings.
6. ***Carer support***
   - assess and work toward meeting the needs of those caring for the patient up to and beyond bereavement.
7. ***Care in the dying phase***
   - use an end-of-life care pathway in association with local health board guidance about care of the dying person.

(Thomas 2003)

To achieve these goals all residents in Hockley's study were placed on a ***supportive/palliative care register*** (Appendix 33) and then coded as: **A**, years to live; **B**, months to live; **C**, weeks to live; **D**, days to live; or ***aftercare*** for the period following a death. After coding people into standardised categories specific tasks were assigned to workers, including:

1. Clarify resuscitation status.

2. Complete an *Advance Care Plan*.
3. Identify problems and concerns such as pain, depression and/or family difficulties.
4. Decide if other healthcare specialists need to be involved.
5. Send an out-of-hours form to the out-of-hours medical service (NHS 24)
6. Complete an *After Death Analysis* form (Appendix 34).

The supportive/palliative care register was also used to prompt discussions about the care of residents at *case management meetings*. This ensured that the focus of care in the care home was maintained on each of the designated work items above. In this way staff were organised to do work aimed at: the performance of specific tasks; contacting and discussing work items with GPs and other healthcare professionals; and taking pre-emptive action to reduce *unscheduled* hospital admissions in the final stages of life.

Hockley's work was the authorised knowledge that informed my own thinking about how care of those who were sick and dying should be organised in care homes. It also informed the development of the SPAR document and processes (Appendix 1-4) that I promoted in the research site as a palliative care education facilitator (Chapter One). Although organisationally useful, I now recognise that coding people in this way objectifies a human being in need of care into standardised categories for the purpose of allocating and tracking work – in this case, filtered through the lens of how long a person may have left to live.

As discussed in Part One of this chapter, predicting the likely prognosis of a person with a non-cancer diagnosis such as dementia is difficult – for example, although he was frail before his condition deteriorated, until the last few weeks of his life Resident A (Vignette 1) had been able to wash, eat and dress with assistance, so staff told me that they had not expected him to die when he did. Furthermore, the complexity of the work listed in *the supportive/palliative care register* above is not reflected in the associated textual practices of briefly recording those activities as dates and/or ticks on a chart (Hockley's research: Appendix 33; SPAR Project Work Appendices 1-4). For example, clarifying the resuscitation status of Resident B (Vignette 2) was challenging because, even when she was unwell, her GP conducted medical consultations by phone rather than in person. Furthermore, her elderly husband did not understand the implications of medical tests and interventions and told staff to *"do everything for her"*. It was not until this woman was admitted to hospital, in pain and distress that the decision about CPR was *"taken out of his hands"* – meaning a medical assessment of her resuscitation status was carried out and she returned to the RCH with a DNACPR form. The work of advance care planning in the *"serious illness"* category of the personal file/care plan was driven by institutional requirements to conduct a time limited six-month review where SSCWs had to cover topics from who had been to visit the resident, to what she had spent her allowance on, to what family members wanted staff to do when her heart and breathing stopped. Staff knew that no previous resident had ever survived a CPR attempt, and they knew that some family members *"couldn't bear to think about all of that"* [death, dying and the DNACPR form] and they knew that talking about death, dying and the DNACPR form was something they *"never used to speak about"* because residents who were sick were transferred out of the RCH. Nevertheless, they also knew that things had changed, and now family members had to be asked about death, dying and the DNACPR form. Another challenge hidden from view in tick, number and colour based palliative care tools, such as the SPAR register is that the work of identifying problems and deciding if other professionals needed to be involved did not always meet with a satisfactory response (e.g.: when nurses were asked for support with a dying man in Vignette 1 they delivered mouth-care supplies but did not offer any other help or support; when the GP was asked for support with a distressed woman in Vignette 2 he did not assess her in person but told staff to call an ambulance and send the woman to hospital). Finally, *"out-of-hours forms"* are tied in to the electronic patient management systems of GPs - which I knew from conversations with care home staff during education sessions to raise awareness of the DNACPR form, that GPs often resisted completing for care home residents. Staff said GPs refused to do this because *"out of hours forms"* were only for cancer patients "*on the palliative care register*" of the GP practice (the GPs palliative care register is discussed further in Section 5.3.2). These issues demonstrate that successful completion of the tasks and processes embedded in Hockley's research, and my professional work with the SPAR documents, is dependent on a level of external support from doctors (and nurses) that was not reliable. And, none of the actual complexity of the *palliative care* work recommended in the mandated tools is evident in a chart with ticks, numbers, colours and dates.

At the time of Hockley's study, task seven in the GSF process - care in the dying phase - was guided by the alerts and guidance contained within the LCP (Ellershaw and Wilkinson 2010). The LCP was a goal based integrated care pathway which was developed at the Marie Curie Hospice in Liverpool in the late 1990s for terminally ill cancer patients thought to be in the last days of life. Until 2013, when a phased process of withdrawal began (Department of Health 2013), the LCP was widely promoted as a model of good practice by a variety of powerful local and national bodies (General Medical Council 2010, National Institute for Clinical Excellence 2011, Scottish Executive 2008).

Seventeen goals were included in the LCP. Goals included aspects of care such as: the patient is pain free; the patient receives fluids to support their individual needs; and the wellbeing of the relative or carer attending the patient is maintained. Again, the LCP was a document which captured and textually reconfigured the activities of specialists working with cancer patients.

The key tasks of the LCP were:

Table 2: The Key Tasks of the Liverpool Care Pathway for the Dying Patient

1. **Diagnose dying:** Before admission onto the pathway, dying was diagnosed by the patient's multi-disciplinary team. The process of diagnosing dying was supported by a decision-making algorithm. The algorithm promoted the use of clinical judgment, particularly around considering if there were any alternative and potentially reversible reasons for the patient's current symptoms. Only after all potentially reversible reasons for the patients' symptoms were ruled out, and it was the clinical judgment of the healthcare team that the patient was likely to die in the next hours or days, should the patient be deemed eligible for admission onto the pathway.

2. **Initial holistic assessment** to inform care. There was a joint focus on the anticipation of needs and symptoms and the promotion of comfort as the person was dying. The process of assessment included: clinical decision-making about the risk/benefit of continuing to administer the currently prescribed medication; the risk/benefit of commencing or continuing *artificial* nutrition and hydration; and clarifying the person's current resuscitation status. This section of the LCP also included prompts for staff to speak to families to ensure they were aware that relative/friend was dying and assessment tasks to draw attention to families' needs.
3. **Regular ongoing assessment** to task staff with regular times for attending to the comfort oriented goals of care for the patient and for the family.
4. **Care after death** including verification of (expected) death, supporting families with information about what they should do next, last offices and communicating with other health and social care professionals about the patient's death.

(Ellershaw and Wilkinson 2002, 2010)

The tasks and processes contained within the LCP were considered *best practice* in care of the person who was dying until 2013 - 2014 when it was withdrawn (as discussed in Section 4.3.4 below). All of the above are complex tasks which require staff to: make (difficult) judgements about the likely dying trajectory of people with every category of life-limiting illness; engage in (difficult) conversations about resuscitation and people's hopes and fears about their future care; *diagnose* dying (in consultation with a doctor); make a (medical) decision on the need to with-hold and/or withdraw treatments as a person is dying; make a (medical) treatment plan to prescribe and administer medication to manage common symptoms; and initiate (sensitive) conversations with family members about the (suspected) imminent death of their loved one.

4.3.1.2 The findings of Hockley's research and data from this study

Hockley reported the following *gains* from implementing the GSFCH and LCP (Hockley 2006, Hockley *et al*. 2008, Hockley *et al*. 2010):

1. Fifty percent fewer deaths in hospital - which reduced from 15 – 8% when compared with the preceding 12 months.
2. A 40% reduction in *inappropriate* hospital admissions - admission was categorised as *inappropriate* when residents died within two days of admission to hospital.
3. Advance care planning and decision-making in end-of-life care rising from 4 – 55%.
4. DNAR status increased from 8 – 71% - resulting in fewer CPR attempts and fewer emergency ambulances being called out.
5. Relatives perceiving the quality of palliative care available in participating homes as better at the end of the research project than it had been at the beginning.

Increased quality, effectiveness, efficiency and equity of access to palliative care tend to be highlighted as key areas for attention in care homes. While Watson, Hockley and Murray (2010) have emphasised that:

> *…care should be taken when considering simple end points such as a reduction in hospital admissions as it cannot be assumed that all hospital admissions are inappropriate and that a reduction in them necessarily reflects better clinical decision-making…*

There has also been a concurrent drive to reduce the cost and number of what are classified as *avoidable*, *inappropriate* and *unplanned/unscheduled emergency hospital admission(s)* among the older population generally (COSLA, The Scottish Government and NHS Scotland 2010). *Avoidable*, *inappropriate* and/or *unplanned/unscheduled emergency admissions* are an area of concern for government officials, NHS managers and NHS administrators because they are not considered to be a good use of expensive, limited and publicly funded institutional resources. By far the largest group of emergency hospital admissions is among the over 75 age group, with 35,101 admissions per 100,000 of the population being admitted in 2014/2015. This figure was approximately 20,000 greater than typically found among 65-74 age group and 30,000 greater than the 25-34 age group in 2013/2014 (Scottish Government 2015). While the figures for the under 75 age group have remained reasonably constant since 2006/2007, the over 75 group has seen a steady increase since that time (Scottish Government 2015). Georghiou and Bardsleym (2014) suggest: that hospital admission is the most expensive aspect of care in the final three months of life; that cost of care is related to emergency (*unplanned/unscheduled*) hospital admissions; and that such admissions increase rapidly in the final few weeks of life – at an average cost of £4,500 per person who died. They compared this to the cost of care in a NCH or RCH, which was averaged at £1000 per person who died during the last three months of life- demonstrating that it is considerably less expensive to the state funded NHS for people to die in non NHS care homes than it is for that group to die in NHS hospitals. This makes it unsurprising that the links between palliative care work using palliative care tools and reduced hospital admission among older adults have been considered positive by those with fiscal responsibilities, including NHS Boards and the Scottish Government.

The issue of hospital admission was a point of tension in Hockley's study and she reported that the process of implementing the GSFCH and the LCP was far from smooth as a result. She claimed this was because there were significant challenges and barriers to restructuring the care of older adults in care homes using *a palliative care model*. On the basis of her clinical work as a specialist palliative care nurse and her academic work as a PhD researcher, Hockley claimed that one of the most significant barriers to the provision of high quality palliative care in NCHs was the predominantly *rehabilitative culture* of care in that setting. By this she meant that the focus of care in the NCHs tended to be toward recovery, restoration of functional abilities and healthy aging. She recognised these aspects of care as good and necessary, but also argued that they did not take sufficient account of the inevitability of death and dying as a natural conclusion to life for aging NCH residents living with multiple health problems. Hockley found that staff working in this *rehabilitative* care home culture tended to view death of a resident as a medical failure, rather than an unavoidable part of life for older people with complex illness experiences. Lack of focus on the inevitability of death, and preparation for it, led to what she described as an active, persistent and sometimes inappropriate *"striving to keep alive"* (Watson *et al*. 2006: 236) which often resulted in people being sent to hospital as they were in the process of dying. The predominantly *rehabilitative culture* Hockley described in the NCHs was out of alignment with the *palliative approach* she valued as a result of her clinical background and experience. However, I suggest that any disjuncture between Hockley and the care home staff was not only due to conceptual disagreements. This is because she was attempting to implement palliative care tools with specific tasks embedded within them as part of her clinical and academic work. This means there were also practical reasons for the difficulties she encountered. For example, the activities associated with a *rehabilitative* approach, such as routinely sending people to hospital when their condition deteriorates, was not compatible with the activities associated with a *palliative* approach, which includes thinking ahead to discuss and plan end-of-life care so residents can *die peacefully* in the care home rather than being sent to hospital. (In Hockley's study, hospital admission often involved burdensome and futile tests and interventions and so produced rather than alleviated suffering.) However, dying in the care home rather than the hospital requires a different kind of knowledge and support, both from the care home staff and the community based healthcare team. Even with Hockley's expert support and mediation, this level of internal and external support was not always achievable during her study (Hockley 2006). Therefore, although transferring people who are actively dying to a busy accident and emergency department of an acute hospital should be avoided when possible – when staff cannot access the support they need to manage the symptoms of dying (such as in Vignette 1) it may be the only, and the most appropriate, means of support for care home residents – and staff.

4.3.1.2.1 Advance care planning for a peaceful death: DNAR forms and the authorised knowledge about CPR

Along with reduction in hospital admission, Hockley's research reported a 54% increase in advance care planning documents being used by the end of the project, and an increase from rare to 71% usage of DNAR forms (the fore-runner to DNACPR forms).

The declining health and the advancing age of the general care home population means that the length of stay tends to be relatively short - fifteen months (Forder and Fernadez 2011). This means that dying is an expected outcome of admission to a care home, so Hockley and other palliative care writers and researchers, advocated for greater engagement with *advance care planning* in care homes (Hockley 2006, Watson *et al*. 2006, Seymour *et al*. 2011). In Hockley's research report, DNA[CP]R forms were linked with the work of advance care planning for a peaceful death, because in the absence of a this form residents automatically became subject to (inappropriate and unsuccessful) CPR attempts.

There is considerable variation in DNACPR law, policy and ethical attitudes and beliefs among the international community. Most countries lack a clear legal and/or policy framework for CPR decision-making (Santonocito *et al*. 2013). In this way the UK is different from the rest of the world, because it has had explicit guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing since 2001 about making CPR decisions, the most recent revision of which was published in 2014 (BMA, Resuscitation Council (UK) and RCN 2014). These professional bodies state in their guidance that CPR is a highly invasive technological procedure that at its most basic level involves strong chest compressions and forcing air into the lungs. Once emergency teams arrive it also involves the more advanced interventions of delivering high-voltage electric shocks across the chest and the injection of drugs. After CPR attempts most people tend to require treatment in an intensive care unit, for many this will include artificial ventilation, for some it will include renal dialysis or haemo-filtration and circulatory support with drugs and/or mechanical pumps. Even when successful in restoring breathing and circulation, CPR attempts carry significant risks, including rib and/or sternal fractures and hepatic and/or splenic rupture. CPR attempts also carry a risk of subsequent neurological damage, particularly if there was any delay between the cessation of cardiac and pulmonary function and the initiation of CPR (British Medical Association, Resuscitation Council (UK) and Royal College of Nursing 2014).

Initially, when it was introduced in the 1960s, CPR was an emergency treatment reserved for people who experienced a sudden cardiac arrest due to a heart rhythm disturbance (Vandrevala *et al*. 2006). In the original publication about survival rates in those who had experienced an acute myocardial infraction, CPR appeared to be a highly successful intervention with 70% of patients surviving to discharge (Kouwenhoven *et al*. 1960). However, none of its pioneers advocated for it to become universally applied (Safar 1958, Kouwenhoven *et al*. 1960, Zoll *et al*. 1956) and further publications from the same hospital saw the successive survival rates fall to 24% in 1961 (Jude *et al*. 1961) and then 13% in 1983 (Bedell *et al*. 1983). Reduced survival rates have been attributed to CPR evolving from an emergency procedure for those who had been the *“victim of acute insult”* (Kouwenhoven 1960:1064) as a result of an acute cardiac event, to the current position where CPR is carried out on virtually any patient in whom cardiac and respiratory function has failed - unless a prior decision not to attempt CPR has been documented (Lannon and O'Keeffe 2010).

Studies exploring the consequences of CPR for various patient groups are considered practically and ethically problematic to conduct. However, a 2011 meta-analysis of pre-arrest predictors of failure to survive after in-hospital CPR of papers published since 1985 reported that, there are knowable factors prior to cardiopulmonary arrest that have been shown to predict failure to survive to discharge (Ebell and Afonso 2011). These pre-arrest predictors include: cancer or metastatic cancer (Ebell and Preston 1993), renal failure (Eball and Preston 1993, Roberts *et al.* 1990, Rosenberg *et al.* 1993), dependent status (Ballew *et al.* 1994, Urberg and Ways 1987) and sepsis on the day prior to CPR (Ballew *et al.* 1994, Ballew *et al.* 1994, Rozenbaum and Shenkman 1988, Saklayen *et al.* 1995, Taffet *et al.* 1998). Ebell and Afonso (2011) reported metastatic malignancy, advanced age (over 75), impaired renal function and dependent functional status as (predominantly) as reliable pre-arrest predictors of failure to survive CPR, was consistent with the findings of previous meta-analyses (Ebell 1992, Ebell *et al.* 1998, O'Keeffe and Ebell 1994) .

The demographic and functional status of most care home residents with advancing dementia puts that group at a low probability of successful CPR outcomes (Ibrahim *et al.* 2016). Looking specifically at the *in-hospital* success rate of CPR for older patients with dementia, Ebel *et al.* (1998) reported that CPR is three times less likely to be successful for patients with dementia than for cognitively intact patients. Indeed, these authors report, CPR in that group has as poor a success rate as CPR in metastatic cancer.

Older studies exploring success rates in *out of hospital* units such as care homes have described the survival rates in those settings as being poor or *"consistently abysmal"* (Lannon and O'Keeffe 2010:20) (Finucane *et al.* 1991, Finucane and Harper 1999, Kane and Burns 1997, Lannon and O'Keeffe 2010). Poor outcome in this group has been reported again in a 2013 systematic review of pre-arrest predictors of survival from out-of-hospital cardiac arrest in the elderly (van de Glind *et al.* 2013). After reviewing the 23 papers selected for inclusion, these authors state that the survival to discharge rate in those over 70 was between 3.0 – 5.6%, with success being linked to the following criteria:

- the *cardiac arrest* being witnessed;
- having a person proficient in CPR nearby;
- the patient having a shockable cardiac rhythm;
- the speedy arrival of an ambulance;
- and the restoration of spontaneous circulation before hospital admission (Sasson *et al.* 2010).

The 2013 review also found that although there were few studies exploring NCH residents' chances of survival, the available studies suggest that NCH residents had poorer outcomes than the non-NCH population (van de Glind 2013). For example, one study reported on 117 CPR attempts made on NCH residents, where only two survived to discharge. Of those who did not survive 102 were pronounced dead in the emergency room, two died within 24 hours, and 11 died after an average of five days (Applebaum *et al.* 1990). Studies like these confirm what SSCWs at the research site already knew – that people became ill and died in the RCH; that no resident had ever survived a CPR attempt; and that failed CPR attempts were difficult for everyone involved.

Since 2001 the guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing has included a statement on the initial presumption that CPR should be attempted in the absence of an explicit advance decision. The most recent edition of the guidance (2014: 5) states:

> *Where no explicit decision about CPR has been considered and recorded in advance there should be an initial presumption in favour of CPR. However, in some circumstances where there is no recorded explicit decision (for example for a person in the advanced stages of a terminal illness where death is imminent and unavoidable and CPR would not be successful) a carefully considered decision not to start inappropriate CPR should be supported.*

This development had occurred because cardiac and respiratory failure increasingly came to be viewed as an emergency situation which requires emergency treatment with no time for debating the pros and cons of the intervention. Unfortunately, people who are dying with advanced disease also become caught up in these emergency procedures because the terminal event of advanced disease ***is*** cardiac and respiratory failure. However, to discuss the final event of advanced diseases such as dementia as a *'cardiopulmonary arrest'* or a *"sudden collapse"* is to fail to recognise that death is the natural and inevitable conclusion to life with advanced disease – even when that death comes suddenly. Furthermore although the statement in the professional guidance seems to allow *"experienced healthcare professionals"* to make an on the spot decision about CPR it must be recognised that those who make such a decision place themselves in a difficult situation in relation to their employers, their professional body and the law. And others who have made such a decision have not been *"supported by their colleagues"*, rather they have faced disciplinary action and even lost their registration to practice due to charges of professional misconduct. However, as SSCWs in this study had not undergone the required educational and mentorship preparation to be classified as *"healthcare professionals"* they were not be authorised to go against presumption *"that staff would attempt to resuscitate the patient"* in the absence of an *"explicit decision"* about CPR before death. This meant they were obliged to commence CPR in the absence of a DNACPR form.

Increased usage of advance care planning and DNA[CP]R forms were considered as a positive outcome in Hockley's research report, which they may have been. However, it is important to situate these findings clearly in the context within which they were produced. They were produced as part of a high facilitation research project exploring the impact of implementing palliative care tools in NCHs. The project took place over an extended timeframe and was led and facilitated by a skilled and experienced palliative care clinical nurse specialist with links into the wider health and social care system. Under these circumstances, an increased use of these documents during the period of the project may well have been a positive outcome in terms of reducing suffering – and also in terms of reducing costs as CPR is not a cost neutral intervention. Gage *et al. (*2002) reported that the average cost of an in-hospital CPR attempt was £1165.48 rising to £8278.65 per person who survived to discharge[14]. This has obvious implications for NHS budgets. Therefore, some suggest that it is essential to consider the financial

---

[14] This study, the most recent that gave figures in UK pounds, is over 15 years old, so the current cost is likely to be higher.

implications of what is considered as a marginally effective medical intervention (Hilberman 1997) - especially when that intervention may prolong inevitable death, increase family distress and extend patient/residents' suffering (Brindley *et al*. 2001, Brindley and Beed 2013).

The work of planning ahead for *"serious illness"* (informed by the advance care planning document: *My Thinking Ahead and Making Plans* – Appendix 50) produced *"difficult"* conversations with family members. Therefore, this work was not entirely positive when taken from the standpoint of the SSCWs in this study – as highlighted in Chapter Three. Additionally, these conversations were not entirely positive for family members because they were being asked to make *"really hard decisions"* about the DNACPR form which, according to the authorised knowledge in the national policy on DNACPR (Scottish Government 2010), belonged with the *"senior clinician"* (i.e. the resident's GP). The GP was not in attendance at care review meetings and so did not routinely lead on conversations with families to plan ahead for RCH residents. This left family members responsible for deciding on a topic they often did not understand, *"mum has a lot of life to live"*/*"do everything for her"*, and/or could not *"bear to think about"*.

According to the authorised literature, *poorly managed discussions* about death and dying are thought to produce undue or prolonged distress among patients and their families (Social Care Institute for Excellence 2013). After reviewing 40 studies exploring surrogates' experiences, Wendler and Rid (2011) concluded that being asked to make treatment decisions on behalf of another can produce significant and long-lasting negative emotional states and distress - which it did in at least a third of the surrogates asked. Distress was most likely when the consequence of the decision could result in the death of a loved one. The most common reasons for distress cited by surrogates included: not being sure of what the person needing end-of-life care would have wanted; poor communication by staff; insufficient time to make difficult decisions; and a sense of carrying sole responsibility for decisions that leave them feeling uncertain or guilty about their choices (Wendler and Rid 2011). However, Rena Miller (cited in Campbell and Gregor 2002: 107-110) offers a different kind of analysis of the difficulties experienced by families of those who are dying – difficulties which are produced by the socially organised and institutionally oriented actions of professionals employed to *help* and *support*.

Using the distinctive IE formulation of the social organisation of knowledge Miller explored her personal experience of caring for her terminally ill husband in relation to her experience of finding herself increasingly at odds with the assessments and interventions of the palliative care team assigned to her husband's case. After her husband died, she inquired into the textually mediated work up of that experience in the records of the palliative care interventions of the palliative care team – which she accessed through the Freedom of Information processes. Her analysis was, that while well intentioned, the text mediated work processes deconstructed and then isolated particular aspects of her experience as problems that were amenable to authorised interventions, and did so in a way that was organised outside her wishes and needs. For example, on one occasion she was described as being *"teary"* and *"showing stress"* under the problem category *"Family Coping"* in an organisational record called an open flow sheet. She argues that the subsequent intervention organised - *"seeing the hospice volunteer counsellor"* - was not oriented to her as a person who was crying because she had just taken delivery of an unwanted hospital bed, and was facing the reality of no longer sleeping in the same bed as her husband, which was both a current loss and the foreshadowing of an imminent and irreversible future loss. Rather, the intervention was oriented to the textual work up of her experience as a category of problem – in this case *"teary"* and *"shows stress"* – to then be responded to appropriately –*"seeing the hospice volunteer counsellor"* – by a worker - according to the authorised processes of palliative care measures. She writes:

> *There's something belittling about seeing this graphically reduced to separate manageable bits in the open flow sheet, something smug and self-serving about the tidy solutions provided for these constructed problems.* (Campbel and Gregor 2002: 109).

She concludes that the organisational features of professional work resulted in her objectification (*"reduced to separate manageable bits"*) and misunderstanding (categorised as *"stress"* rather than devastating loss). Her point was not that it is unusual for professional activity to be organised in this way, but that it did not work in her or her families' interests. The work of those attempting to help **produced** rather than alleviated suffering, to the extent that she asked them to stop visiting. This demonstrates that institutional interests and family interests can be at odds with each other making it difficult to isolate the cause of family distress without engaging in what Dorothy Smith (1987) has called the subversion of institutionalisation through knowledge that has been constructed from a *non-ruling place*.

Having knowledge about the experience of planning care for a family member, constructed from a non-ruling place, is important because that experience involves difficult and high stakes conversations that touch on death, dying and anticipatory grief making this kind of work more than a paper exercise (Russell 2014). This *more than* aspect of the work of advance care planning is something that could be observed in the real world of SSCWs carrying out their everyday work of organising and planning care for residents at care review meetings in the research site with knowledge and skill and care (Vignettes 4 and 5). However, *"difficult"* discussions about *"serious illness"* and the DNACPR form at the RCH began in relations of ruling and were directed and carried out through paperwork: in a textual mode. In other words, these conversations were oriented to texts (national standards and policies), based on texts (care plans) and generative of texts (the DNACPR form, case file audit documents) in a way that produced problems for the SSCWs and the family members. Therefore, success in caring for sick and dying older adults – and their families - must be acknowledged as more than having kept those older adults in the care home till death - with advance care planning documents and DNACPR form in their notes.

4.3.1.2.2 Barriers and conclusions in Hockley's study

Other barriers reported in Hockley's research were: lack of knowledge among staff about palliative symptom control; lack of knowledge about commonly used palliative care drugs; lack of understanding about how to recognise or manage the dying process; lack of multi-disciplinary team support to care homes; and a resistance to change among some care home staff (Watson *et al.* 2006). Ten years later, the findings from Hockley's research in NCHs have some resonance with my own work in both NCHs and

RCHs. I have also experienced fear and reluctance among many care home staff to talk about death and dying (e.g. for reasons I will explore later in this section, the RCH staff in Vignette 1 did not use the word *dying* to describe events with Resident A with doctors). I have also experienced a lack of knowledge about how to manage the most commonly experienced symptoms of the person who is dying (e.g. pain and agitation as experienced by Resident A), lack use of palliative care drugs (for example in Vignette 1 the NHS 24 doctor administered a (potentially painful) 2ml dose of Diclofenac intramuscularly for pain rather than a (potentially less painful) smaller volume of subcutaneous Morphine) and a lack of multi-disciplinary working and NHS healthcare support to care homes caring for dying residents (e.g. in Vignette 1 and 2 there were no routine visits from doctors or nurses to assess or manage the pain and distress of Resident A or Resident B meaning staff had to make frequent telephone calls to ask for help and support). However, I draw a different conclusion about the reason for this. Rather than being solely due to lack of knowledge and/or willingness on the part of care home staff and the NHS staff charged with supporting them, I suggest that problems exist around managing the care of sick and dying older adults in care homes which need support from community doctors and nurses when there is no automatic or routine support available to care home staff and residents from those groups. I also suggest that palliative care tools have been constructed around the needs of people on a cancer dying trajectory and the activities of medical and nursing staff in relatively self-contained health-care settings, typically hospices. As a result, these tools do not fit the needs of residents with non-cancer diagnoses in care homes with predominantly non-medical and non-nursing staff who are not easily or inevitably linked into the systems of the wider healthcare systems. Another example of palliative care tools not fitting the needs of the RCH staff is that the LCP contained authorised knowledge about the tasks and processes which were considered *best practice* by those considered to be experts in the care of the dying (e.g. palliative care researchers and palliative care specialists etc.) and those who organised, managed and audited that care (e.g. governing bodies such as the Scottish Government, healthcare managers such as Community Health Partnerships, and professional groups such as doctors and nurses etc.). This knowledge informed practice even when the LCP document was not in use – which it was not in the research site or any other RCH in the research area because the LCP was considered a *healthcare* document and therefore not deemed appropriate for use in settings without doctors and/or nurses on-site. In vignette 1 staff had expert knowledge about the resident (that he may be dying). The also knew that they needed help to *"settle"* him. As a result they reached out for support with his symptoms. However, they never mentioned their suspicion that he may be *"dying"* to any of the doctors who attended (and who did not know the resident because they were locum doctors and NHS 24 doctors). Despite being assessed by a number of doctors, the resident did not *"settle"* and so staff knew they needed a different kind of help than they were receiving. When I arrived at the home for the SPAR project meeting they were distressed and did not know what to do next. As a result they sought my advice. My knowledge about how to care for a dying person was organised by the textual practices in the LCP. Therefore, I knew that it was important for a doctor **to make/confirm a medical diagnosis of dying** (after ruling out potentially reversible causes for Resident A's symptoms such as infection or dehydration etc.). This was important so a clear plan of action could be developed by the doctor, communicated to the RCH staff and family and followed up by daily communication with GPs and visits from district nurses. I suggested to the SSCW that she use specific language *"resident A may be dying"*. She did not want to use this language because she knew it would produce tension by appearing to *"tell the doctor what was wrong"* – a response I found confusing and frustrating at the time. On analysis, this is the point at which dominant knowledge organised subsequent actions without reference to what was actually happening at the scene. The dominant knowledge was that there is an official or correct method of caring for a person who is dying (structured by the LCP), and that this must be managed by doctors and nurses (who were not routinely present in the RCH). The first step of the official method was to determine that a person was dying - to *diagnose dying*. To *diagnose* dying, is to perform an act restricted to medical staff (or in some instances nursing staff). The need for a medical diagnosis was problematic in Vignette 1 because no doctor was present at the site and it was difficult to speak to a doctor by telephone. The organisation of adequate care for Resident A hinged on the RCH staffs' expert knowledge of the resident and the freedom to speak plainly about that knowledge (which was: that she suspected that he dying; that he was in pain and distress; that she did not know how to *"settle"* him; and that she and the resident and the family needed some kind of ongoing help and support). Not being permitted to speak plainly meant RCH staff had to wait for medical staff (who did not have expert knowledge about Resident A) to make a diagnosis: or tell them *"what was wrong"*. It was not until the SSCW voiced her suspicion that the resident *"may be dying"* (based on my advice but against her usual practice) that a doctor confirmed what the SSCW had suspected, and formulated a treatment plan. This plan included the use of a syringe pump to administer medication, which was a further point of tension in this case because RCH staff are only authorised to administer oral medication – which this resident could no longer swallow. Additionally, the care home only carried oral medication specifically prescribed for individual residents and it did not have *specialist* equipment such as *palliative care drugs* and/or syringe pumps on-site. Therefore, to administer subcutaneous medication via a syringe pump, RCH staff had to arrange for, and/or wait for:

- a prescription for medication to be written by the doctor;
- the prescription to be taken to the pharmacy by someone from the care home;
- the prescribed medication to be sourced and dispensed by a pharmacist and then delivered to the care home;
- a district nurse (authorised to administer medication via a syringe pump) to be contacted;
- a syringe pump (and associated equipment such as syringes and giving sets etc.) to be sourced and collected from a community storage facility by the district nurse; and
- the syringe pump to be set up and administered to the resident by the district nurse.

This was a time consuming process. Resident A died before the medication in the syringe pump could be sourced, loaded, primed and administered. As a result, a man with needs greater than the staff in the care setting could support without the direct input of doctors and nurses - who were neither routinely involved in his care, nor present at the site - died in pain and distress.

4.3.2.1 Funding research into the experience of death and dying

A final point of note to consider in relation to the use of cancer based palliative care tools is related to the allocation of research funding into the experience of death and dying. In the UK less than 0.25% of the available statutory or charity cancer research funding is devoted to palliative or end-of-life care (Sleeman *et al.* 2012). Cancer based research is the area of practice where most of the - limited - evidence about palliative care and care of the dying originates. Limited funding along with significant ethical constraints around research with this particularly vulnerable client group means that evidence about the biology and the experience of dying is scant. In the wake of the withdrawal of the LCP, calls are being made for dedicated research funding into the biology and experience of dying to be made available.

Dying is an experience that 100% of the population will face and succumb to at some point. This means that the findings of research into the biology and experience of dying is something that all individuals and all societies have a vested interest in furthering their knowledge about. Therefore, more than the current 0.25% of the available *cancer research funding* should be dedicated to exploring this universal experience. Non-cancer based research bodies and organisations should also acknowledge the importance of these topics, and allocate adequate resources to explore the issue of death and dying from different standpoints. This would result in a wider range of evidence to draw from and base decisions on.

I will now draw the threads discussed in part one and part two of this chapter together by describing and then mapping the key relations of ruling that linked my professional work, influenced by the institutional discourse of palliative care, with the promotion of palliative care tools such as SPAR which promoted the use of the DNACPR form at the research site, and beyond. I will also map some of the key relations of ruling that put pressure on the WHO to change the definition of palliative care which led the Scottish Government to mandate the use of palliative care tools in all care settings as a result.

4.3.2 The demise of a mandated palliative care tool: the LCP

Since this study began in 2010, the LCP has been withdrawn from use by the Scottish and UK governments on the grounds of inappropriate usage leading to poor experiences for those who are dying (Department of Health 2013). A recent article in the British Medical Journal stated that lack of education and understanding about the complexity of the dying process led to some staff misinterpreting the LCP as a protocol to be followed to the letter rather a guide to support clinical judgement (Sleeman and Collis 2013). These writers follow the common practice of blaming individual practitioners or wards or hospitals or care homes for what is conceptualised as poor care, in this case poor care in association with the use of the LCP. However, as I have highlighted throughout this chapter, caring for people with advanced progressive disease, including care of that person as they are dying, is a complex activity. This makes all the nuances necessary to care for a dying person well difficult to capture or reflect in any kind of process oriented paperwork - where a person is divided into textual abstractions and classifications to guide and organise particular aspects of care based work.

Shortly after the withdrawal of the LCP, Claude Regnard, consultant in palliative care at St Oswald's Hospice, freely acknowledged that there had been room for improvement in the process of using the LCP in acute settings. His suggestions for improvement included: LCP audits should have focused more on evidence of care delivery rather than documentation; training in the use of the LCP should have been compulsory; and a robust accreditation process should have been in place to validate and authorise settings to use the LCP (Regnard 2014). That the complex activities contained within the LCP were ever imposed on staff groups and care settings without sufficient training or support is alarming and demonstrates the danger of making textually mediated processes mandatory without a clear understanding of whose interests are being promoted and whose interests are hidden from view.

IE analyses institutional work processes to illuminate how things happen as they do – recognising that they are often organised as they are with good intentions, but with bad outcomes. In the case of the mandated use of the LCP ruling bodies, such as managers, worked to ensure that quantifiable (numerically determined) care settings implemented and used the LCP to rule the care of those who were dying. Ruling bodies, such as the national government then relied on that numerical data as evidence that *quality* care was being provided for those who were dying. However, those who became accountable for using the LCP - without a robust system of training or professional support - had no official means of documenting their experiences with the LCP. This means that, although those accountable for using the LCP participated in producing the outcomes leading to its withdrawal, their interests (and needs) were hidden from view. This group then came under significant criticism from the independent review body for the poor outcomes that occurred. The report leading to the withdrawal of the LCP stated that:

> *Many of the problems in the care of the dying highlighted in this report are due to poor understanding among clinicians of existing guidance in care for the dying, and an unwillingness to discuss with patients, their relatives and carers the prospect of death and the clinical uncertainties that accompany it. The Government must therefore ensure that its arms-length bodies collaborate with the clinical professional bodies and other key players in the system, and inject considerable funding into the system, to ensure that guidance on care for the dying is properly understood and acted upon, and tick-box exercises are confined to the waste paper basket for ever" (Department Of Health 2013:11).*

The wording in this report demonstrates that blame for *problems in the care of the dying* was placed on *poor understanding* and *unwillingness* on the part of clinicians, it also cites *lack of compassion* (Department Of Health 2013:48) as a reason for poor care at the end of life, all which may well have been factors. However, as the review did not explore institutional factors, such as attempts to demonstrate that quality care is being provided simply through the presence of particular texts in patients care files, I suggest that its conclusions are incomplete. This is because such explanations do not take account of how the textually mediated world of care work actually works. While there is no suggestion of anything deliberately untoward or malicious in the enthusiasm for implementing palliative care tools, such as the LCP, what is typically hidden in the writing and talking about these text based tools is the way in which these tools and frameworks powerfully substitute local knowledge with particular forms of extra-local knowledge. In the process they transform general care settings (such as hospital wards and care homes) into settings that perform observable tasks that can be *categorised and coded* as palliative care work by managers, auditors and regulators. The process of categorising and coding palliative care work then standardises particular actions and behaviours in a way that increases an everyday focus on specific activities highlighted for attention in the text. It also makes those aspects of care easier to measure, compare and/or demonstrate *quality*, where quality is measured against some quantifiable standard, such as the presence or absence of a form. However, it is not always clear whose definition of quality or quality improvement is valued in such cases. Palliative care tools are typically implemented to solve a particular problem as that problem is seen from a particular perspective. For example, implementing and using palliative care tools in hospital wards and care homes may indeed restructure the knowledge of general staff groups about the activities associated with palliative care practice and solve a management problem of being able to evidence that those activities are taking place for the purpose of audit or inspection. However, it is important to acknowledge that these texts are experienced differently by differently located groups, such as Palliative Care Consultants, Nurses, GPs, Care Home Managers, Care Home Regulators, or SSCWs in RCHs. It is also important to acknowledge that the implementation and use of palliative care tools is not purely for the benefit of those they claim to serve - generalist staff and those with palliative care needs and/or their families. This is because their use also serves the ruling purposes of managers, auditors and government bodies who have different priorities and accountabilities than people with palliative care needs and/or those with direct responsibilities for providing care.

4.3.3 My reflective notes: recognising and mapping the relations of ruling in my professional work with care home staff

There were a number of voices calling for an improvement in the level of palliative care available to care home residents when I took up my new educational outreach role in 2009. Hockley's work on the use of palliative care tools to improve palliative care in care homes was instrumental in forming, and informing, my thinking. Hockley's written and conference presentation based work also influenced both my professional management team, and an external funding body, to first create and then set the direction of the fixed term post offering education to care homes (Hockley *et al.* 2005, Hockley 2006, Watson *et al.* 2006). *Making Good Care Better* (Scottish Executive, Scottish Partnership for Palliative Care 2006) was the primary document used to inform the job description, and set the direction, for the initial period of my employment in that post.

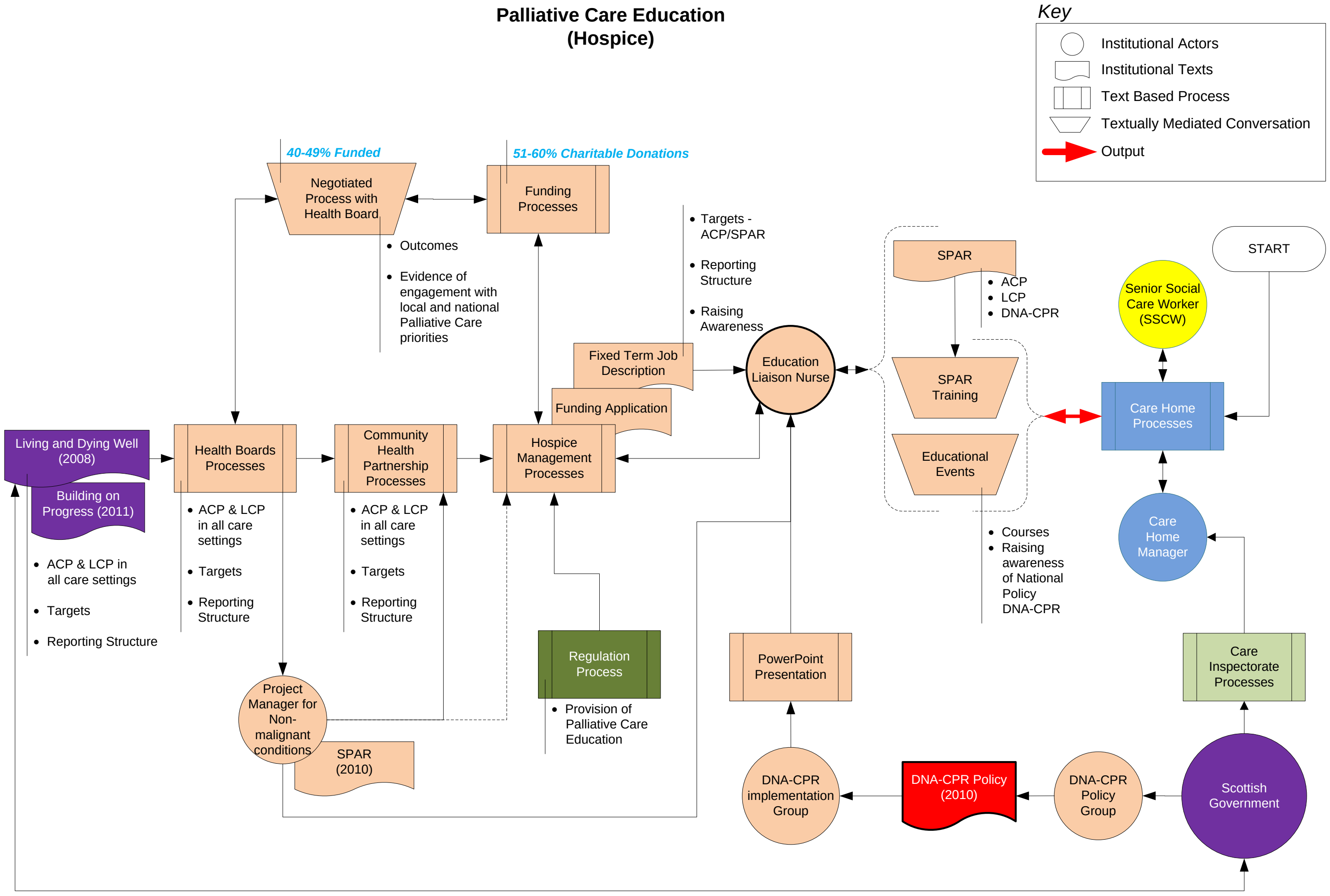
Also in 2009, shortly after the publication of *Living and Dying Well* (Scottish Government 2008), the management team at the hospice came under increasing pressure from the Community Health Partnership (CHP) to make specific commitments about supporting the implementation of palliative tools in care homes. Until the 1st April 2016 when they were replaced by a new organising body, Scotland had 34 CHPs which were sub-divisions of 14 regional National Health Service (NHS) Boards. CHPs were powerful bodies with responsibility for supporting the delivery of national health targets and national outcome agreements.

The hospice had a responsibility to engage with the targets and agreements set by the CHP in response to the national action plan. It also had a need to maintain cordial relationships with the CHP because it is a charitable organisation which relies on financial support to deliver its services. Financial support is raised partly through charitable donations and active fundraising and partly in negotiation with the NHS Board. The level of financial support offered by the NHS Board is influenced by the level of engagement the hospice is recognised as having with national priorities such as those set by the CHP and with the grading received by the regulatory body. Delivering palliative care education to staff from the wider health and social care system is one standard that the hospice is measured on by the regulatory body Health Improvement Scotland. This linked my post with the work of generating income for the hospice through meeting standards and helping the CHP demonstrate to the national government that palliative care tools were being implemented into all care settings – including care homes. Care home based project work to implement palliative care tools and deliver education sessions on national palliative care priorities became a key responsibility of the fixed term post I held. This work included implementing SPAR (Appendices 1-4), which encouraged care home staff to participate in the work of advance care planning, including making and documenting advance decisions on CPR using the DNACPR form. As highlighted previously SPAR was developed by staff who had a direct responsibility for evidencing palliative care tools were being implemented across the Health Board area (Section 1.5).

After 2010, when the national DNACPR policy was launched, my work also included raising awareness of the DNACPR *Integrated Adult Policy* (Scottish Government 2010) and the DNACPR form during education sessions with care home staff. Initially I used a presentation developed by a palliative care physician with a special interest in this work to guide those sessions. Engaging in this awareness raising work was how I became aware of staffs' experiences of failed CPR attempts, and how staff in the RCH under study first became aware of the DNACPR form as the official means of preventing such attempts taking place in the future.

The way in which my professional educational outreach work, described above, entered and directed the work of SSCWs is detailed in Map 4 below.

MAP 4: Opening the door to wider influences through engaging in palliative care education

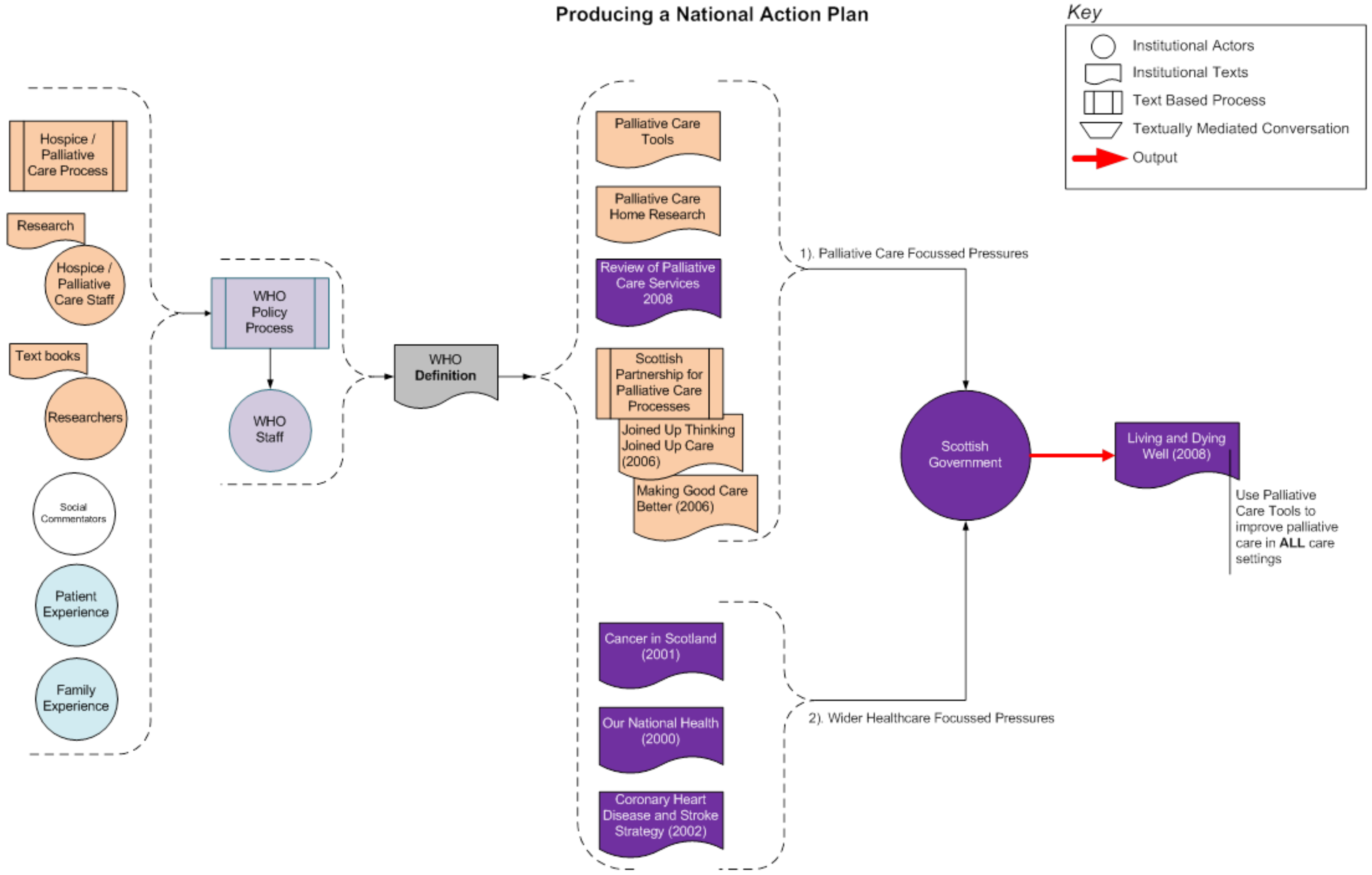


What Map 4 highlights is:

1. How the ruling work of local and national governmental bodies charged with delivering on the nationally driven targets in *Living and Dying Well* (Scottish Executive 2008) entered the research site through the work of palliative care educators – like myself.
2. How I was socially organised to attend to the promotion of advance care planning in care homes through the use of SPAR and awareness raising sessions on the DNACPR form and then reporting on progress with that work to my management team.
3. How my management team reported to local and national reporting bodies charged with delivering on specific national targets set by *Living and Dying Well* (Scottish Executive 2008).
4. How my work was linked to the process of NHS funding allocated to the hospice – which was negotiated on the basis of value added to the wider healthcare system.
5. How my work was linked to the regulatory requirement placed on the hospice to deliver education to generalist staff and settings.

All of the above hinged on the revised WHO (2002) definition of palliative care. This chapter has outlined how that revised definition was influenced by concerns about patients' experiences of care at the end-of-life - as those experiences were reported in research and discussed in newspapers (Section 4.2.1, 4.4.2). It was also influenced by forms of authorised knowledge generated by hospice and palliative care workers working with terminally ill cancer patients - as that knowledge was contained in peer-reviewed journal articles about palliative care (Section 4.3.1). These factors resulted in the production of other policy documents calling for wider availability of palliative care (Section 4.3.1), putting pressure on the Scottish Government to audit *palliative care* in Scotland, leading to the publication of the national action plan as detailed in Map 5 below.

MAP 5: Re-defining and making palliative care work mandatory through the use of standardised palliative care tools



The WHO and the Scottish Government could be described as responding to new thinking about how to answer the problems created by human suffering and need in expanding the definition and practice of palliative care. Nevertheless, this chapter demonstrates that enforced use of standardised textually-mediated tools based on authorised (but limited) knowledge in order to meet nationally mandated targets as the primary means of improving the care of dying people has also resulted in some patients receiving poor care – this time in relation to those tools (Department of Health 2013). In my view, this should serve as a cautionary tale about the dangers of powerful ruling bodies imposing abstract, but authoritative, knowledge embedded in textually mediated practices on staff and settings in ways that take no account of how people actually experience living and dying and take no account of what else is actually happening in –and beyond - the care setting.

4.4 Chapter summary and discussion

This chapter has traced the evolution of the term palliative care from the opening of the first modern hospice, to the re-definition of palliative care by the WHO in 2002, and the current discussions about what it involves and who should deliver, and pay, for it. The chapter highlighted that, while there has been a move away from the central topics of death and dying in more recent discussions of the term palliative care, recognising and talking about the universal experience of death and dying is important work if effective care is to be planned and suffering is to be minimised. Recognising and discussing death and dying are not the exclusive domain of authorised experts, nevertheless authorised knowledge about care of those coming to the end of life has mainly been gathered from the experience of clinicians working with people dying with/from cancer, and from research generated from cancer charity research funding (Sleeman *et al.* 2012). It is unsurprising therefore that the current authorised knowledge base and institutional discourse about death and dying is cancer focussed – but, it must now also be recognised as narrow and limited.

This chapter has also highlighted that changing the definition of palliative care, from a cancer related model of care to something much broader, has been more than a linguistic exercise. In my view, understanding the development of the institutional discourse around this term is more than an esoteric, speculative or academic debate about semantics. This is because subtle changes in the WHO's definition has produced pressure on the Scottish Government to widen access to palliative care to a much larger group for a much longer timeframe. It has also led to: the mandated use of *palliative care tools* - based on the work of specialists caring for cancer patients; and the re-categorisation of caring for sick and dying people using the authorised knowledge in those tools as *"routine"* care - and now the responsibility of all care workers, caring for all people who die with/from all life-limiting conditions in all settings. In other words, authorised knowledge about the *correct* way to care for people who are dying is contained in palliative care tools. Use of these tools has been positively linked with keeping care home residents out of (expensive) NHS hospitals - with a DNACPR form in their personal file - as they die.

As outlined in Chapter Three, in relation to caring for residents with dementia, SSCWs were now caring for a much frailer client group as a result of the following: residents being more frail on admission due to changes in what made residents *"suitable for us";* the care home being under financial pressures to "*keep beds filled*"; the care home being under policy pressures to provide residents with a *"home for life"* leading to a move away from relocating residents to a NCH as their health declined; and the inevitability that frail older adults with dementia will deteriorate and die. This meant that RCH staff were now expected to manage all aspects of residents' needs until those residents died, when previously people with deteriorating health would have been transferred out of the RCH - to be cared for in a care setting with nurses (and doctors). When describing the illness and death of residents with dementia SSCWs regularly spoke of needing help and support from NHS doctors (and nurses). As demonstrated in Vignettes 1, 2, 3 and 6, the medical and nursing help and support available to RCH staff and residents did not match the level of help and support that RCH staff (and residents) needed – either from community or hospital doctors and nurses. Furthermore, RCH staff were not authorised to use the words *"dying"* (Vignette 1) and *"died"* (Vignette 3) when requesting that help and support. This subordinated SSCWs expert knowledge about what was actually happening in the care home to the dominant knowledge that only qualified healthcare professionals should *diagnose* dying and *verify* death - and that the *correct way* for care home residents to die, was to die in the care home rather than the hospital. Therefore, despite the rhetoric surrounding the term palliative care outlined in part one of this chapter, SSCWs did not describe their work of caring for sick and dying residents as: improving *"quality of life"; or "alleviating suffering"*; or being *"routine"*. Instead they often described this aspect of their work as being *"abandoned"* to manage resident's needs without sufficient support, and as being *"pushed"* into having *"difficult"* conversations with family members about death, dying and the DNACPR form.

Even when they knew the DNACPR form was something family members couldn't *"bear"* to think or talk about, and CPR was something that no resident had ever survived in the past.

As I reviewed the authorised literature on the conceptual practice of palliative care, I began to understand that it was not simply a concept or a linguistic device in the RCH. Rather the term palliative care was a widely shared way of knowing and describing situations and happenings – including describing hospital admissions as *inappropriate* for care home residents. Furthermore, the institutional discourse of palliative care – including the institutional requirement to ask family members about death, dying and the DNACPR form - not only dominated how activities associated with it were understood in the RCH, it also subsumed the actual care setting in which the SSCWs worked, the resident/family group that they supported, and the varying levels of healthcare support they could access.

The following chapter will now explore why: despite being the group in possession of blank DNACPR forms; and being the group authorised to activate the form by applying their signature; and being the group designated by the national DNACPR policy (Scottish Government 2010) as the *"senior clinician"* in charge of RCH residents' care, *"none of the doctors…ever raised it"* as a topic for discussion with the RCH staff. It will also glimpse into why there was no routine nursing support for the RCH residents' and staff.

Chapter Five: *"Difficult visits…to difficult patients….at the **expense** of your other paperwork…and meetings"* and *"they are a **social** care setting and – and we only cover nursing care homes":* factors influencing the social organisation of medical and nursing work in the RCH.

5.1 Introduction

McMurdo and Witham (2007) suggested one reason care home residents have received sub-optimal care is the level to which care home residents are dependent on *inexperienced* care home staff to manage their care. They suggest it is problematic that care home residents need to rely on care home staff to firstly determine if a presenting problem needs to be assessed, diagnosed and/or managed by a healthcare professional and then to act on their behalf by making and following up on appointments or referrals (McMurdo and Witham 2007). More recently Handley *et al.* (2014) reported that there was cause for concern about the welfare of RCH residents because: RCH staff found it difficult to distinguish between residents who were near death and those who were not; that visits from healthcare professionals were only in response to specific requests for support with health needs or tasks; and that there was no clear responsibility for supporting RCH staff with regular discussion about resident's current or future health needs. However, the vignettes in this study demonstrate that the RCH staff knew when they needed help to manage residents' care, and they were *"quite regular"* in making those requests for support. What produced increased suffering for sick and dying older people, and their families, was not lack of knowledge among care home staff but: a) the frailer population now being cared for in the RCH

(Chapter Three); and b) the insufficient level of help from the NHS doctors (and nurses) they relied on for medical (and nursing support).

To follow the data into the thread of inquiry that explores medical support to the RCH further, this chapter includes interview data from the only GP recruited to this study. Other GPs were approached, but declined to participate on the grounds of being *"too busy"*. Being *"too busy"* was a common analysis of happenings with GPs. For example: because GPs were *"too busy"* SSCWs knew they had to work around GPs availability when they wanted to seek medical support for residents' who were sick and dying; they also knew GPs were *"too busy"* to respond to every request for support in person and so offered advice and instruction via telephone consultations; they knew GPs were *"too busy"* to attend meetings where residents' health and future healthcare planning was discussed and that GPs input to the six-monthly review process was to review the residents' prescription chart. The RCH managers knew GPs were *"too busy to speak to families"* about the DNACPR form – as a result the manager and SSCWs knew that *"we* [RCH staff] *get the ball rolling"* with DNACPR decision-making. *Busyness* was the analysis offered by the care home manager for GPs lack of support with RCH staff's requests - where some GPs were described as being *"great"* and others were described as being *"rubbish"*. This chapter provides a different analysis of happenings with GPs, one that is based on the complex and fragmented way that GPs are remunerated for their work including: the way in which GPs are pulled into income generating *"paperwork"* and *"meetings"* as a means of producing capital for the GP practice; and the tension between undertaking *"difficult visits"* with *"difficult"* and time-consuming patients/residents, and the resultant *“expense”* to the GP practice of not being available to work on/at the income generating *“paperwork”* and *“meetings”*.

RCH staff also knew that nurses did not routinely visit or assess residents, but only attended when residents were identified as having *“nursing needs”* (e.g. to set and manage a syringe pump (Vignette 2), or to assess and manage a wound etc.). My own view was critical that there was no regular nursing support to the RCH, and the support that was available seemed task rather than person centred. For example, RCH staff were struggling to *“settle”* the man in Vignette 1 – who was not on the regular case load of any nurse. So, I suggested contacting the district nursing service to ask for mouth-care supplies and a nursing assessment. Rather than assessing the situation and offering ongoing nursing support to the staff caring for a man dying in pain and distress, the nurse responding to the SSCWs request *“delivered mouth-care supplies and left”*. However, the RCH staff at the research site did not mention nursing services to the care home as a significant feature during any of my conversations with them, and when I asked about the district nursing support staff said *“the nurses are great”*. As a result I did not explore the social organisation of regular district nursing services. Nevertheless, during the term of this research a new nursing service was established in the geographic area – The (NHS) Care Home Liaison Team. RCHs were excluded from this *“care home”* service and so RCH staff were unaware of this nursing team. My view was that this exclusion was significant and so and this chapter glimpses into the social organisation of this service based on my own knowledge and historically situated changes in how needs are categorised.

5.2 Increased demand on community healthcare services: *"workload"* and older people in need of care being *"dumped on a GPs budget"*

As I have demonstrated, SSCWs found it challenging to access co-ordinated support from NHS doctors (and nurses). For example, responses to requests for help tended to be focussed on tackling the problem at hand, such as giving an injection for pain and delivering mouth-care supplies, rather than assessing the situation being experienced by the person in need of medical (and nursing) care, or assessing the needs of the staff (Vignette 1). Lack of reliable support from GPs led the (recently promoted) deputy care home manager to describe some GPs as *"great"* and others as *"rubbish"* because they did not offer the level of support with DNACPR decision making that she had expected as a SSCWs:

> *…when the [DNACPR] forms first came out and we asked about them some GPs said just said "No, it's too early for that" and others said "OK, I'll sign it the next time I'm in." …and I said… "No, we don't have them. It's you that's got them". They didn't have a clue.*

The authorised knowledge suggests that unpredictable support from doctors and nurses was not unique to the research site. Handley *et al.* (2014: 23) report:

> *As many as 27 different healthcare services can visit to provide care and treatment for RCH residents It is a pattern of service provision that is often uncoordinated, with working relationships individually negotiated and context specific, This means that providing healthcare and particularly end-of-life care is a negotiated process.*

Almost a decade ago, in 2007, Jacqueline Morris, Chair of the British Geriatrics Society Policy Committee, wrote:

> ‘*Both health and palliative care are often poorly organised in [care homes] and are associated with out of hours’ crises and resultant high anxiety and unpredictability for staff and residents. The lack of clarity around clinical leadership for care homes may result in GPs only visiting when called’* (Morris 2007: thebmj:online).

This situation was little better in 2011 when healthcare support was described by the British Geriatric Society as being *“highly variable”* and *“limited”* (British Geriatric Society 2011:48) – as was the case in Vignettes 1,2 and 6. As highlighted, the blame for medical services being *“variable” and “limited”* is often laid at the feet of individual GPs – *“some…are rubbish”*. This chapter will provide a different analysis.

According to the GP interviewed for this study:

> *In the initial stages…when older adults with long term care needs were released from hospital…it was a great saving from the hospital budget but* ***it was dumped on the General Practitioners budget****, which meant it was additional workload for GPs with no extra money to allow us to take on extra staff to go with the extra volume of work.*

The *“extra volume of work…dumped on the General Practitioners budget”* has been produced by an increase in care home beds over the past twenty five years coupled with an increase in the numbers of older people needing long-term care. This means there have been increasing numbers of highly dependent older adults, who would previously have been under the care of on-site NHS staff in long-term NHS facilities, now living in care homes in the community (Section 1.4). The transfer of responsibility for this patient group - from hospital to community – took place without any significant re-organisation of NHS community based services to cope with it (Groom *et al.* 2000) resulting in significant gaps in NHS medical healthcare provision to care homes (Kavanagh and Knapp 1998; British Geriatric Society 2011). Gaps can be traced back to the late 1990s. In 1998 Kavanagh and Knapp (1998) highlighted that downsizing of NHS medical provision for older adults during that year increased demand on GPs by 160 whole time GP equivalents per annum. Groom *et al (2000)* went on to state that as things stood in 2000, GPs were insufficiently resourced to meet the increased demand produced by the growing care home population. When an increased work-load falls to the same number of GPs, demand will begin to outweigh capacity.

According to the GP participant *"work-load"* was not the only consideration – remuneration was also a factor for GPs with the care of older adults being *"dumped on the GPs budget":*

> *I know that GPs are always going on about money…but* ***money becomes important…if you're self-employed****…It's not that the money…necessarily goes into your pocket. It's that you might employ an additional nurse to do some of the work for you…if there was funding attached, you might take on a locum for half a day to allow you to go out and do a care home for half a day…You could use the money that way…*

Concerns about *"money"* and the *"additional workload for GPs"* in relation to care home support is longstanding within the medical community, as can be seen by a 1996 recommendation from the General Medical Services Committee which called for the removal of care home residents from GP's core responsibilities (General Medical Services Committee 1996). Currently, there is no explicit statement from the government that stipulates the obligations and responsibilities on the NHS about the provision of healthcare services for care home residents (British Geriatrics Society 2011). All of which means that it is unclear how care home staff can reliably access the medical (and nursing) support they need to manage sick and dying residents – or plan their care.

The issue of *"funding"* was something the GP participant frequently mentioned during research based conversations, so the following section inquires further into the way that GPs are paid.

5.3: *"It becomes quite pressured"*

The GP participant reported that *"dealing with the intricacies"* of a sick person's care could become quite *"pressured"* and that while *"it has to be dealt with…sometimes you don't have the time to sort it all out"*. Rather than accepting this participant's own analysis of the *"pressure"* coming from not having *"the time to sort it all out"* I looked to her account of work for clues of the possible (dis)connecting of people's practices. She reported:

> *It really is a very difficult job in all fairness…the actual face-to-face consultations take up a lot of time…you can have four or five hours of face-to-face consultations with people who are fit enough to come in to the surgery, and that's the bit the patient sees, the bit the general public sees. What they don't see is all the other bits that there are, the paperwork, the administrative stuff that has to be done…because* ***each consultation can generate a work-load*** *like a prescription or a hospital referral or follow up or something…most consultations generate a workload that has to be dealt with at some point during your working day…*
>
> *Then if you are dealing with an elderly person in a care home with multiple pathology, you go in on a busy Monday morning and you're faced with somebody with Parkinson's Disease that's falling over…its extremely difficult to deal with, it has to be dealt with, but it's extremely difficult to unravel all the intricacies of that person's care and deal with the other 15 calls that you have to deal with that day…**it***

> ***can become quite pressured, and sometimes you don't have the time to sort it all out.***
>
> *Then there are house calls. It might be that you have somebody dying at home that needs a daily visit…you need to find time to fit in the tasks you need to do…plus the on call doctors sometimes can be so busy that they have to prioritise the day's work…so, they might say, "Well, these are the visits that must be done today, but these other six that have come in, I will do later in the week because they need to be seen, but not urgently needing to be seen today." So you need to go back and see them…one of the things over my lifetime as a general practitioner is that the number of house calls has drastically reduced in number…because we didn't have an option in the past…we had to visit everyone that requested a visit, whereas* ***now we can triage*** *and suggest other options for the patient's care. But that means the ones we do see are the difficult patients…nowadays a call to a care home or a patient's own home can take half an hour to forty minutes…realistically, difficult visits like that you can only do two in an hour…and then there is the travelling time…but,* ***that would be at the expense of all your other paperwork…***
>
> *Then* ***there are meetings that have to be had*** *– meetings with the practice team…with the district nurses and health visitors…we have regular meetings about the care of patients."*
>
> *There's just never enough time in the day.*

It is clear from this account that there really were many demands on this GPs time – demands that could make her *"too busy"* to respond to the *"quite regular"* requests for medical support with older adults from the multiple care homes covered by her GP practice – requests that she now has an *"option"* to *"triage"* as a result of changed policy. However, there is more happening in this account than her own analysis of there *"just never being enough time in the day"*. This is because some of the *"paper work"* and *"meetings"* that produced *"work-load"* for this GP was linked to the Quality and Outcomes Framework (QOF) (Scottish Government Health and Social Care Directorates 2014) (Appendix 35). The QOF was a system which measured healthcare work against a set of indicators. Payments were then made to GP practices on the basis of achievement against those indicators (an exploration of this system and three categories of remuneration in this system will be outlined in the following sections of this chapter.)

> *…how GPs are paid really is quite complex…for QOF…at the end of March, you have to submit your numbers that you achieved and you will get a number of points…and* ***points mean prizes****…the points equate to a sum of money…"*

Therefore, not being available for work on *"paperwork"* and *"meetings"* linked with this system of remuneration - because she was on long *"difficult visits"* to *"difficult patients*" – could produce an actual *"expense"* for this GP – and others employed at her practice who were dependant on her labour as a means of generating capital, because in the QOF point system, *"points mean prizes"*.

5.3.1 Following *what counts* toward GP remuneration: *"Points make prizes"*

How GPs are funded is a complex process, as indicted by the GP research participant, with most GPs being self-employed rather than salaried. The largest source of funding for GP practices comes from a *Global Sum Payment* which contributes toward the contracted doctors' costs in delivering what are categorised as *essential services* and includes all aspects of staffing costs. In 2014-2015 the *Global Sum Payment* accounted for £754.2 million paid by NHS Scotland to GP practices (ISD Scotland 2015). *QOF* is the second largest payment made to GP practices – it was one of the (many) factors organising how the GP interviewed for this study could carry out her work with care home residents and *“difficult visits….were* ***at the expense*** *of…other paper-work…and meetings”*. To further explore the link between the QOF payment system and GP activity in the RCH under study a documentary analysis of the QOF Guidance (Scottish Government Health and Social Care Directorates 2014) (Appendix 35) and was carried out.

The *QOF* is based on authorised knowledge about *evidence-based healthcare* which is then used to organise work in GP practices. *QOF* is one of **12** potential sources of income for GP practices. The number of points available in the *QOF* is 659. In 2014-2015 the average achievement among GP practices was 645.4 points or 97.9% - demonstrating a high focus on achieving points within GP practices. The average income per practice generated from *QOF* related work was £95,000 in 2014-2015. This is compared with £130,600 of income generated in the previous year when more points were available under this system (ISD Scotland, NHS National Services Scotland 2015). Income generated from *QOF* based work accounts for up to 15% (approx.) of GP practice income (BMA 2016) and accounted for £96.1 million paid to 958 GP practices in Scotland in 2014-2015. This was a reduction of £32.1 million (25%) from 2013-2014. The reduction resulted from nationally mandated changes in the allocation of points and payments between 2013 and 2014 (ISD Scotland 2015).

To qualify for points and payment -*“points make prizes”* - GP practices must demonstrate achievement of specific percentages of attainment among specific patient populations in line with specific measurable indicators. There are indicators *(*linked to *“paper-work…and meetings”)* for 17 *clinical* domains, five *public health* domains, five *quality and safety* domains and one *medicines management* domain.

For example, in relation to the *QOF* points allocated to the *public health* activity of smoking cessation work (a high value activity), 25 points are available when 50-90% of patients with any single, or any combination of the following conditions have had their smoking status recorded in case records in the previous 15 months: Chronic Heart Disease, Peripheral Arterial Disease, stroke or Transient Ischaemic Attack, Hypertension, [Diabetes, Chronic Obstructive Pulmonary Disease, Chronic Kidney Disease, Asthma, Schizophrenia, Bipolar Affective Disorder or other Psychoses. The allocation of funding for points is not a straightforward process, but broadly speaking one point is worth £133.47. In simple terms this means that recording the smoking status of the above group could generate (a maximum) payment of £3336.75 per practice per year. When this is combined with the threshold achievement of 50-90% in offering current smokers (with the same specific diagnoses') an offer of treatment and support to stop smoking (within the preceding 15 months) (25 points) and offering literature (2 points) to and smoking cessation support and/or treatment to all smokers over 15 years of age (12 points) *smoking cessation* work (64 points in total) could yield a maximum potential annual payment of £8542.08 to GP practices. This payment will be contrasted with payment for what counted as *palliative care work*, *advance care planning work* and *dementia work* in Section 5.3.4.2: Table 2 below.

Medicines Management is another category in the QOF system. This allocates 10 points (maximum payment of £1334.70) to those GP practices who can demonstrate evidence of a medication review having been carried out in the preceding 15 months for those prescribed four or more repeat prescriptions. The QOF Guidance for 2014-2015 (p: 165) states that:

> *The common aim of the indicators within the medicines management domain is to consolidate and* ***continually improve the quality and cost-effectiveness of prescribing*** *in general practice.*

This medicines management work in the QOF system links with the SSCWs report that GPs contribution to the care review process was limited to reviewing the resident's prescription chart, it also linked with the GP participants' report that:

> *…there are the patients on repeat prescription…they request their repeat medication…and the prescriptions have to be checked by general practitioners every day…* ***there are some that need reviewed****, so, you have to very carefully weed them out…. And that can take two hours of your day…we don't do it every day, because we take it in turns to do it…that task got so onerous that the practice managers and partners allocated two people a day…*

The link between the *cost* of prescribing and the *remuneration* for review work in the QOF system provides an analysis for why medication charts were reviewed by GPs for the six monthly review – required by the RCH to meet the *National Care Standards* (Standard 6: Scottish Executive 2001) - but the actual residents were not.

Turning to GP support for care homes, the only mention of care home residents in the QOF system is under one category of patient to consider for a case note review of *incidents* related to the *unintentional harm* caused by medical care. This was a form of *"paperwork"* for GPs (worth 6 points and a maximum payment of £800.82) that involved a twice yearly review of five sets of case notes - selected from a maximum sample of 25 sets drawn from pre-determined *risk groups* – with care home residents being one of the pre-determined *risk groups*. This demonstrates that care home work was not a high priority in the QOF points system.

It is clear that remuneration for work as a GP is a complex process. The fragmented categorisation of people's experience of ill health in the QOF system - with payment being awarded for fragmented activities in association with that categorisation - offers one analyses why GPs were *"always going on about money"*. Rather than being paid for using their medical expertise in the treatment of people experiencing ill health their knowledge was subordinated to the categories of the QOF system, generated by authorised knowledge about *evidence based care*. These ruling relations in the QOF system then co-ordinated textual practices associated with the level of remuneration that could be claimed as a result of *"paperwork…and…meetings"*.

This section has built my analysis of how the QOF remuneration system for medical work organised GPs to make choices on the basis of what they would be paid for. The remaining sections in part one of this chapter continue by exploring that system further. They trace how palliative care, advance care planning and DNACPR decision making for RCH residents was ruled out.

5.3.2 What *counts* as palliative care work?

I reviewed the 2014 – 2015 *QOF* guidance (Appendix 35) and discovered the indicator only allocates points (and thus payment) for the following activity in relation to *palliative care work*:

> *The contractor has regular (at least 3 monthly) multidisciplinary case review meetings where all patients on the palliative care register are discussed*

NHS Boards contract GP services as distinct work items using the QOF system– such as holding *“meetings”* to discuss the care of patients on the *palliative care register*. It then scrutinises the payment processes for those work items.

- *The NHS Board may request that the contractor provides evidence that the meetings took place which could be in the form of minutes of the meetings. Contractors may also be required to provide written evidence describing the system for initiating and recording meetings (QOF Guidance 2014-2015:162).*

The *palliative care register* is intended to highlight all community based patients with *palliative care needs* to GPs and district nurses. To explore this further I reviewed the criteria for inclusion on the *palliative care register* in the QOF guidance. This states:

1. *Their death in the next 12 months can be reasonably predicted (rather than trying to predict, clinicians often find it easier to ask 'the 'surprise question' - 'Would I be surprised if this patient were still alive in 12 months?').*
2. *They have advanced or irreversible disease and clinical indicators of progressive deterioration and thereby a need for palliative care e.g. they have one core and one disease specific indicator in accordance with the GSF Prognostic Indicators Guidance.*
3. *They are entitled to a DS 1500 form* (the DS 1500 form is designed to speed up the payment of financial benefits and can be issued when a patient is considered to be approaching the terminal stage of their illness. A patient is considered as terminally ill if they are suffering from a progressive disease and are not expected to live longer than six

months. It is typically issued to people with a cancer diagnosis.) *(QOF Guidance 2014-2015:121)*

The QOF guidance states the aims of multidisciplinary case review *"meetings"* for people entered onto the *palliative care register* are to:

- *ensure all aspects of the patients care have been considered and documented in the patients records;*
- *improve communication within the team and with other organisations (e.g. care home, hospital, community nurse specialist) and particularly improve handover of information to out-of-hours services;*
- *co-ordinate each patient's management plan ensuring the most appropriate member of the team takes any action, avoiding duplication;*
- *ensure patients are sensitively enabled to express their preferences and priorities for care, including preferred place of care;*
- *ensure that the information and support needs of carers are discussed, anticipated and addressed where ever reasonably possible (QOF guidance 2014-2015:122).*

There is also a recommendation that a checklist (SCR1) (Appendix 52) and a template (SCR2) (Appendix 53) be used to guide discussion of care at care review *"meetings"*.

SCR1 (Appendix 52) includes the following categories for consideration:

- *name of patient and name of carer;*
- *diagnosis and code (projected life expectancy);*
- *key GP; key District Nurse;*
- *problems/concerns;*
- *anticipated needs;*
- *information given/carer issues;*
- *DS 1500 form (typically issued to cancer patients);*

- *clinical nurse specialist/ Macmillan nurse/hospice nurse (the case load of this group of specialist nurses is typically cancer patients);*
- *other specialist;*
- *out of hours handover form;*
- *preferred place of care/death;*
- *actual place of death;*
- *bereavement care;*
- *and any other relevant notes.*

SCR2 (Appendix 53) includes: information about:

- *DS1500 form,*
- *clinical nurse specialist input,*
- *ACP discussion including advance statement of preferences and decisions to refuse treatment,*
- *CPR status and if the person has a legally appointed proxy decision-maker,*
- *priorities and advice for the out-of-hours service on what to try before considering hospital admission.*

This process is based on the Gold Standards Framework which, as highlighted in Chapter Three, is based on the authorised knowledge about how to care for cancer patients – which has now become the *correct* way to care for everyone whose prognosis was not recovery, but death.

Unlike other indicators in the QOF guidance, no achievement threshold percentage was set for *palliative care work*. Also, the points and payment allocated to/for this work were low in comparison to the points allocated to other work streams - which appear less time consuming and less complex. For example, a maximum of three points are available for compiling a *palliative care register* and holding regular *"meetings"* to discuss and action the care of those on the register, resulting in a maximum annual payment to the practice of £400.41, while *smoking cessation* related work could yield a maximum potential annual payment of £8542.08 to GP practices. This makes a significant statement about the value placed on GPs *palliative care work*.

5.3.3 A disjuncture between what counts as palliative care work and what happens in RCHs

There was a disjuncture between what counted as *palliative care work* with sick and dying people in the QOF system and what happened in the RCH with sick and dying people. For example, staff in Vignettes 1-3 felt *"abandoned"* to manage illness and death with no co-ordinated plan of care or regular support from doctors. After reviewing the social organisation of medical support to sick and dying people using *palliative care* category in the QOF points system I suggest this system of categorisation is of limited benefit to RCH residents'. This is because it hinges on the institutional discourse of the conceptual practice of palliative care that is based on the experience of those caring for cancer patients. Therefore, it uses the *surprise question* and the *prognostic indicator guidance* as a means of determining life-expectancy, and it uses the issue of the DS1500 as an additional trigger for inclusion on the *palliative care register*. Older people in care homes have multiple diseases which mean that they may die in the next year, the next month or the next day and authorised knowledge suggests that doctors struggle to predict when those with non-cancer diagnose might die (Zheng *et al.* 2013) – making the *surprise question* and *prognostic indicators* of limited usefulness for that population. Furthermore, RCH residents would not be issued with the DS1500 form because this form is used to fast-track benefit claims for people with: a) a medically diagnosed life expectancy of 6 months; and b) eligibility for financial support to supplement illness related loss of income and illness related *personal care* costs. Care home residents in the RCH were older adults retired from work and so not eligible to claim for loss of earnings, and *personal care* is free for those over 65 in Scotland.

RCH staff had little/no influence over who was on this register. What I knew from the evaluation of the SPAR project (Section 1.5) was that GPs typically refused to enter care home residents' on this register, because it was *"not for care home residents but for very sick people with cancer"*. What RCH staff knew was that the only time a GP had initiated a conversation with a family about the DNACPR form was when that resident also had a diagnosis of cancer. Authorised knowledge suggests that connecting the *appropriate/correct/authorised* use of the *palliative care register* only with the care of people who have cancer was not unique to the GPs in the area under study. A 2013 publication exploring primary care services in Scotland (Zheng *et al*. 2013) highlighted that only 20% of patients with chronic heart, lung, liver or kidney conditions (organ failure) or dementia, either requested or were identified by primary care services for palliative care (and included in the palliative care register) before dying. In contrast, 75% of cancer patients were identified for palliative care before dying. This study also reported that even those patients who were identified for palliative care received it too late to fully benefit – on average only 8 weeks before dying. GPs reported that identifying patients for palliative care was fairly straightforward for those with a cancer diagnosis, whose illness and dying trajectory typically had a clear terminal phase. The study also reported that GPs found it difficult to raise the topics of death and dying with patients. They found it particularly difficult in patients with a non-cancer diagnosis. The findings from Zheng *et al. (*2013) highlight at least two relevant issues, firstly that 80% of those with non-cancer diagnoses were not entered onto the palliative care register and secondly, even doctors find raising the topics of death and dying challenging – particularly when patients do not have a cancer diagnosis with a clear terminal phase.

What the current study adds is an analysis of why care home residents were not typically entered on the GP practice palliative care register - which is that the authorised knowledge about how to care for people who are dying in the QOF based criteria was developed from the experience of those caring for cancer patients. Therefore the institutional discourse of the conceptual practice of palliative care included the *surprise question*, the *prognostic indicator* guidance and whether or not a *DS1500* form had been completed. These ruling relations co-ordinated textual practices that systematically excluded sick and dying RCH residents with non-cancer diagnoses' from entry onto the *palliative care register* and from discussion at the *palliative care "meetings"* where DNACPR forms and other aspects of care were a feature. This leaves decisions and discussions of the DNACPR form and other aspects of care for sick and dying RCH residents vulnerable to being overlooked by GPs.

5.3.4 What *counts* as Advance Care Planning Work in the QOF system?

I have described the work SSCWs carried out during care review meetings under the *"serious illness"* category of the care plan. I have also described how this work was organised by what they had heard from palliative care education facilitators at Advance Care Planning project meetings (*"recent trainings")* where the *My Thinking Ahead and Making Plans* document

(Appendix 50) was promoted (this project work will be explored further in Chapter Six). SSCWs knew that doctors did not attend this meeting.

When I reviewed the QOF Guidance 2014-2015 on advance care planning work, I discovered that this was high value work to the GP practice - worth 45 points and a maximum annual payment of £6006.15. However, there were very specific parameters within which this work was to be conducted. It was expected that advance care planning work would mostly be targeted at people who scored highly on the SPARRA (Scottish Patient at Risk of Admission and/or Readmission) risk prediction tool as being at risk of admission to hospital as an emergency in-patient within the next year (ISD Scotland 2016). SPARRA scores are calculated for approximately 4.2 million patients. This information can be accessed by GP practices and other key professionals. Those with a SPARRA score of 50% are thought to have a 50% risk of admission to hospital in the following year. SPARRA scores are calculated from the following patient-level dataset: hospital inpatient admissions; community dispensed prescriptions; emergency department attendances; new outpatient attendances and psychiatric inpatient admissions (ISD 2016). The purpose of this data is to shift the focus of healthcare (and healthcare professionals) from what is described as *reactive hospital-based treatment* to more *preventative and anticipatory treatment* in the community. GPs are directed to this data to identify and prioritise *anticipatory care* for those patients deemed to have the most complex (and in all likelihood the most expensive) healthcare needs. How they are instructed to do this is, to firstly construct a list of 5% of registered patients on the SPARRA data who are at greatest risk of emergency admission to hospital (5 QOF points). Secondly, they should identify 30% of patients from that list who are most at risk of admission and so most likely to benefit from advance care planning work, which includes carrying out a compulsory poly-pharmacy review (30 points). Finally, the identified 30% (of the original 5%) should be discussed at quarterly practice *"meetings"*. The focus of advance care planning *"meetings"* should be the active management of the 30%, to review their medications, improve their care and also reduce *unscheduled* care – i.e. unplanned hospital admissions.

The QOF guidance states that:

> *an advance care planning should, as a minimum, include the following information:*
>
> - *patient name, date of birth, sex and contact details;*
> - *name and contact details of patient's carer/responsible adult (if applicable);*
> - *lead professional for the individual patient - often called key worker;*
> - *date of assessment and suitable review date(s);*
> - *relevant patient medical conditions;*
> - *medication and poly-pharmacy review;*
> - *allergies (if applicable);*
> - *emergency plans (if appropriate);*
> - *information on other health care professional involved in the patients care e.g. psychiatric nurse (if applicable);*
> - *key messages e.g. patient specific goals (e.g. rescue medication);*
> - *incapacity information, action to be taken in the event of deterioration, entry access code to patient's home, information on key holder for patient's home, patient's first language etc.;*

> - *patient consent, if given, that this information can be shared with other healthcare professional involved in the patients care (i.e. Out Of Hours, community staff etc.) and/or discussed with the multi-disciplinary team (QOF Guidance 2014/14:159).*

The guidance also states:

> *In addition to the above, the following information should also be included in the active management plan if appropriate:*
>
> - *Cardiopulmonary resuscitation - yes/no - indication as to whether or not this has been discussed and if so, giving any details; patient's preferred place of death e.g. home/hospital (QOF Guidance 2014-2015:159).*

This is the only mention of CPR in the QOF guidance. It is mentioned in relation to advance care planning work for a very specific group and for a very specific reason. Furthermore, it is expected that GP's advance care planning work would mostly be conducted with patients identified from the SPARRA data. If patients identified for advance care planning work are not from this data set, GPs are instructed within QOF guidance that they must be able to give a clinical justification for that patient's inclusion in their advance care planning work.

All of the above shows how advance care planning work in GP practices is closely linked with the work of medication review and identifying people at significant risk of hospital admission or readmission. The aim is to improve care while also developing active management plans to reduce the number of emergency admissions to hospital, reducing the length of hospital admissions, and reviewing (and reducing) the number of medications taken by this group. The cost of emergency admissions to hospital has already been discussed in Section 4.3.1.2. This led me to link the accountable advance care planning work of GPs - who are financially incentivised to target people at risk of admission and/or readmission for advance care planning work - with drives by the Scottish Government to reduce the cost of NHS in-patient hospital care and pharmacy budgets.

5.3.4.1 Reducing costs to the NHS

There have been drives to reduce NHS costs particularly among the over 65 age group who are reported as living longer with greater health and care needs than current models of health and social care can sustainably support (Audit Scotland 2014). Audit Scotland (2014) reported on combined NHS and council spending on care services of £4.5 billion for over 65s during 2011-2012. Of that figure emergency hospital admissions accounted for £1.4 billion (30%), and GP prescribing accounted for £379 million (8%).The potential of savings to the state provides an analysis of the significant difference in point allocation between the strand of work that is recognised as advance care planning in the QOF guidance (and worth over £6000) and the strand of work that is recognised as palliative care (and worth just over £400).

In order for a care home resident with dementia to be identified as a priority for advance care planning work in line with the QOF guidance, s/he would typically need to score above 50% in the SPARRA data, calculated on specific categories around hospital and pharmaceutical usage during the previous 12 month period (ISD Scotland 2016). Then s/he would need to be included on the list of 5% of patients identified by the GP practice as being at risk of admission or unscheduled care. Then s/he would need to be included on the list of 30% selected to have active case reviews at quarterly multi-disciplinary *"meetings"* where advanced decisions about CPR and the DNACPR form are a feature. This offers an empirical analysis of why *"none of the* *doctors ever raised [the DNACPR form] with us [RCH staff]"* and why doctors did not attend meetings where residents future health care (advance care planning) was discussed. The ruling relations in the QOF organised and remunerated GPs to carry out advance care planning work based on the SPARRA data on which RCH residents would only appear if they had been admitted to hospital in the previous 12 months – while RCHs are settings organised around keeping people out of hospital (further explored in Chapter Six). These ruling relations co-ordinated the textual practices that systematically excluded from GPs advance care planning work of *active case review* - where the DNACPR form and other aspects of care were a feature.

5.3.4.2 Exploring QOF work under the Dementia category

After identifying the disjuncture described above, I wondered if care home residents with dementia may be identified for advance care planning work support by GP practices through the QOF work stream indicators for dementia. I discovered that 15 points are available for a threshold achievement of 35-70% of patients diagnosed with dementia whose care has been reviewed in a face-to-face review in the preceding 15 months. This threshold remains the same no matter how many patients with dementia are on the GPs register, whether they can visit the practice during routine surgery time, or whether they need to be seen at home or in a care home - which takes considerably more time and must be carried out at the *"expense of… other paperwork… and meetings"*. Additionally, once the percentage of face-to-face reviews has reached 70% there is no additional funding for reviews the remaining 30% during that year - potentially making prioritising this remaining 30% an unattractive and/or untenable financial proposition.

More detailed analysis of the QOF Guidance on dementia revealed that the face-to-face review (and the reporting to NHS Boards of that review) should focus on four key issues:

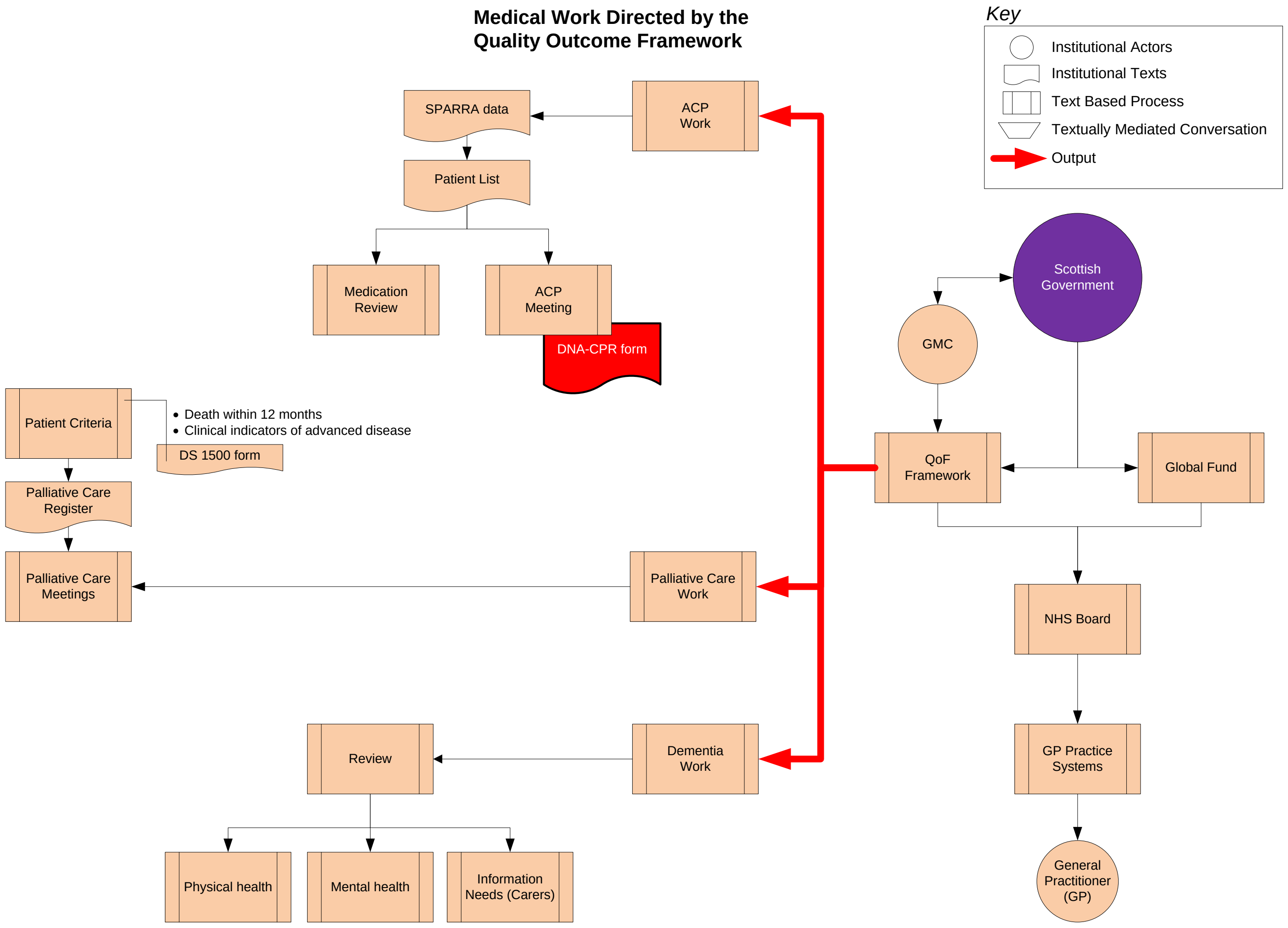
1. physical and mental health review (the guidance states this is to detect common physical symptoms such as joint pain or infection and common mental health issues such as depression);
2. carers needs for information;
3. the impact of caring on the carer;
4. communication and co-ordination arrangements with secondary care (if applicable).

These factors take no account of how older people with dementia actually lived and died in the RCH as their health inevitably deteriorated; nor do they account for the actuality that without a DNACPR form residents (and their families) are denied a peaceful and/or comfortable dying experience; nor do they account for the perception among family members that CPR would be a life-saving intervention for their loved ones – *“mum has a lot of life to live”* and *“do everything for her”* – when statistically it had very little chance of success, and no previous resident had ever survived a CPR attempt.

Linking what has been explored throughout this section with the account offered by the research participant who had worked as a GP, it becomes clear why medical support with decisions about the DNACPR form were unreliable in the RCH – making *“house-calls”* and *“difficult visits”* to *“difficult patients”* in RCHs was a time-consuming activity that had to be carried out at the *“expense of your other* [QOF based] *paperwork…and* [QOF based] *meetings”* which took GPs away from activities that could generate an average £95,000 of capital for the GP practice per year.

The way in which the QOF system socially organised GPs work is illustrated in Map 6 below.

MAP 6: The social organisation of medical care using the QOF system



To conclude this section on funding medical work using the QOF point system the three work-streams explored in this chapter are now compared with the points and payment available to smoking cessation work, quality and safety in relation to a case note review for unintended harm and medicines management.

QOF work-stream	Points available	Maximum payment
Palliative Care	3	£400.41
Quality and Safety	6	£800.82
Medicines Management	10	£1334.70
Dementia	15	£2000.05
ACP	45	£6006.15
Smoking	64	£8542.08

Table 2: Allocation of QOF points and maximum payments

This section demonstrates that while GPs were financially incentivised and socially organised to pay more attention to reducing NHS healthcare costs through activities associated with *advance care planning* and *smoking cessation* related work than to activities associated with *palliative care* or *dementia care* work. It also demonstrates that the aspects of the *QOF* system analysed in this study systematically excluded work with most RCH residents from GP remuneration. When discussing this research with a GP colleague in the final weeks of my study, and in relation to the DNACPR forms she commented that:

> *Organisationally and operationally* ***it makes no difference to us*** *as GPs if care home residents have or do not have DNACPR forms – although* ***it is obviously better for them*** *if they have one.*

The documentary analysis of the QOF points system data in this thesis explicates how DNACPR forms were not the only aspect of medical care that *"organisationally it makes no difference to us as GPs"* if it happened for RCH residents or not. Unfortunately for RCH residents, family members and staff, this was the case even when *"obviously it would be better for them* [the residents]*"* if they were not systematically excluded from GP remuneration and if they were not systematically excluded from sufficient medical support.

Note: In December of 2015, as this study was in its final stages, The Scottish Government issued a statement of intent to abolish the QOF points system in Scotland from the 1st April 2016 (Scottish Government 2015). This decision was reached in agreement with the British Medical Association (BMA) Scotland. Scotland is the first of the historic nations within the UK to abolish the QOF system. It is being abolished because there is a recognition that organising healthcare work using the QOF is both burdensome and restrictive within GP practices. What will replace the QOF system is currently unclear and will not be announced until late 2017.

5.4 Nursing services: *"They are social care settings – and we only cover nursing homes"*

SSCWs in the RCH did not have much to say about nursing input to their service, as highlighted in the introduction. However, I knew that NCHs in the area received regular (3 times per week) visits from a small team of NHS nurses with a specific remit to support care home staff and residents'. This team had direct links into the wider NHS system: *The Care Home Liaison Nursing Team*. Members of this team told me that they had (authorised) knowledge of symptom assessment and management, the SPAR tool, the DNACPR form, and the process for setting up and managing syringe pumps. They also told me that they had knowledge about how to open the door to other NHS services –among other things. However, they did not make visits to RCHs. I found this strange, and when I asked why not the team members stated that, *"they* [RCHs] *are social care settings – and we* [Care Home Liaison Team] *only cover nursing homes"*. This explanation was very frustrating to me because while the RCH staff in this study carried out their work with skill and dedication, they regularly struggled to manage the care of sick and dying residents without support. In my professional view, in light of the increasing vulnerability of the residents in the RCH under study – and in light of the research on the care home population in general (Bowman *et al*. 2004, Froggatt *et al*. 2009, Laing and Buisson 2009, Royal College of Nursing 2010), nursing should have an increasingly valuable and important role to play in the care of RCH residents. It was also my view that the RCH staff (and residents) could have benefited from the regular nursing support that *The Care Home Liaison Team* could have provided. Nevertheless RCH residents were excluded from this nursing team's service on the grounds of being *"social"* care settings. I knew that other district nursing services to the RCH were task specific and time-limited. This meant that despite the inevitability that residents would deteriorate and die during their residency in the RCH there was no regular nursing input to their care. The following section will demonstrate that classifying some needs and settings as *social* has meant that nursing care is becoming less rather than more available to those who could benefit from the support of professional nursing.

5.4.1 Historically situated removal of nursing services from the care of older adults

In 2010, the Royal College of Nursing (RNC) published guidance on staffing in care settings. This guidance made a positive association between the number of RNs on shift and patient outcomes, patient safety and patient care. Despite positive associations between the number of RNs on shift and positive patient outcomes, even in acute hospitals, older people's wards typically have less RNs per patient than other specialities. For example, children's wards tend to have one RN per 4.2 patients, general adult medical and surgical wards have one RN per 6.7 patients but, wards for older adults have one RN between 9.1 to 10.3 patients (Royal College of Nursing 2011, 2012). Inequitable as the ratio of patients per RN in hospital wards for older adults may be, the number of patients per RN is even higher in NCHs. In NCHs the ratio is around 18 patients per RN during the day rising to 26 overnight, with some care homes reporting 35 patients per RN (Royal College of Nursing 2010). These figures represent a reduction in the number of RNs from 34% to 25% of the NCH staff mix between 2007 and 2009 when the most recent figures were collated (Royal College of Nursing 2009, 2010). More recently, a 2015 report for the RCN Foundation, states that while little is known about the role of the RN in care homes because they are an under-researched group, the evidence that is available suggests that: the role of the RN in care homes is broad and multi-faceted; that turnover is high (31%); that the number of RNs working in care homes in the UK has been estimated but never enumerated and there is no clear guidance about safe staffing levels in NCHs generally (Spilsbury *et al*. 2015). Lack of research means that in 2016 when this research was completed, the patient per RN ratio or the average staff mix in for NCHs is unclear in Scotland.

However, despite the increasing dependency and decreasing health of RCH residents, for RCH the patient per RN ration remains the same: 0%.

As highlighted earlier in this thesis, after the *National Care Standards for Care Homes for Older People* (Scottish Executive 2001) was published, the statutory distinction between NCH and RCH was abolished in Scotland and these distinct care settings were reclassified under the single generic title of “care home”. Nevertheless while the statutory distinction has been abolished, some *care homes* in the geographic area are considered to be *healthcare* facilities and so have on-site nurses (NCHs) and regular input from the NHS Care Home Liaison Team - who have knowledge about nursing care and knowledge about how to access the support of other healthcare professionals, while some *care homes* in the geographic area are considered to be *social care* facilities and so have no on-site nurses (RCHs) and are excluded from the support of that NHS nursing team. In my view, this exclusion produces a serious inequity of access to NHS nursing services and it could possibly be legally challenged by a resident or family member on the basis of discrimination.

The value of professional nursing’s contribution to patient care is not always visible, nor is it easy to measure (Royal College of Nursing 2003). As a result, during the late 1980s and 1990s nursing came under increasing scrutiny from policy makers and service providers (Bagust and Slack 1991, Bagust *et al.* 1992, Buchan and Ball 1991, Buchan *et al.* 1997, Carr-Hill *et al.* 1992, Savage 1998). One consequence of this was the 1990 *NHS and Community Care Act* (Department of Health 1990) which re-designated much of what had previously been classified as *nursing care* to become *personal* or *social* care instead (Royal College of Nursing 2003). Patients in the community who were deemed to have *social needs* rather than *nursing needs* would no longer be cared for by professional nurses - working as part of a healthcare team, and funded from the health care budget. Instead they would be cared for by social carers and care assistants - under the supervision of social workers or social care mangers, and funded from the social work budget (Royal College of Nursing 2003). This meant that people deemed to have *social needs* were no longer under the direct care of nurses.

An important consideration to bear in mind here is that while *social care* is a less expensive option than *nursing care*, classifying support needs with activities such as eating, drinking, hygiene and continence as *social needs*, does not account for the way sick and dying people actually experience their lives – as one continuous, interlinked and ever changing experience which is not neatly segregated into *social*, or *health*, or *palliative care* needs. Nor does it recognise the way in which skilful performance of these activities is foundational to the healing and therapeutic process (Nursing and Midwifery Council 2009). Nevertheless, even as the process of re-classification from *nursing* care to *social* care was underway during the 1990's, one economist warned that:

> *Nursing care* ***as a product*** *is highly simplified by non-nurse buyers not possessing a clear idea of what professional nurses can/should do and how it differs from less skilled cheaper labour…Managers may accept unfounded assumptions and myths about nursing costs, care-giver mix and nursing productivity*" (Patterson 1992:203)

Thinking about nursing in relation to care home residents in particular, in 2002 Heath wrote in the British Medical Journal that the demarcation between nursing and social care in care homes had led to a move away from recognising that some/much of care home resident's pain and suffering was directly produced by disease and illness. Heath stated that classifying residents' needs as social -rather than health needs:

> *puts a barrier between people who suffer the greatest and most complicated burden of illness and the specialist healthcare professionals that they need (Heath 2002:1534).*

Cost related classification of needs and settings as *social needs* and *social settings* has *"put a barrier"* between sick and dying RCH residents at the research site. Staff knew they needed support to manage residents with failing health, and the Care Home Liaison Team, in my view, could offer RCH staff some of the support that they needed. However, the ruling relations that classified the RCH as a *social care setting* co-ordinated textual practices that systematically excluded RCH residents from the Care Home Liaison Team's care by classifying people living in the RCH has having *social care needs* without ever seeing them to make an assessment of those needs based on the actuality of their lived experience.

5.5 Chapter summary

This chapter has traced how the social organisation of medical work has been achieved through the *QOF* system (among other income generating streams). It has also shown how RCH residents were systematically excluded from GP remuneration – and attention – under this system. This provides an analysis for why there was no in person GP support for SSCWs with discussions about *"serious illness"* and the DNACPR form. It also provides an analysis of why the only instance the SSCWs could recall when a GP lead the process of DNACPR decision making was for a resident with cancer – thereby included on the *palliative care register* and discussed at the *palliative care meeting* where DNACPR forms and other aspects of care are a feature. It also provides an alternative analysis for why GPs were unavailable for *"difficult"* and time-consuming *"house-calls"* to the RCH. Rather than being unavailable simply because *"there is never enough time in the day"* as the GP participant believed, or because *"some GPs are rubbish"* as the RCH deputy manager believed, lack of availability could be linked to the actuality that GPs work was orientated to the QOF points system where *"points make prizes"* and *"difficult visits"* had to be made *"at the expense"* of that income generating work.

This chapter has also demonstrated how classifying RCHs as *social care settings* has systematically excluded RCH residents from access to the NHS Care Home Liaison Team.

This exclusion of RCH residents from medical and nursing support is concerning in light of the actual needs of the sick and dying people being cared for in the RCH. As highlighted, the actual needs of that group had changed as a result of what made a person "*suitable for us",* the need to *"keep beds filled"* and the *"home for life"* policy – which meant people who were frailer were now being admitted into the RCH to meet the needs of the RCH as a business, and people with greater needs than the RCH staff could manage without support were prevented from being moved to a nursing care home (or hospital) as their condition inevitably deteriorated and they died. This chapter also demonstrates the way in which inequalities were produced between RCH residents and other *community dwelling* older adults who were living in NCHs and their own homes.

The following chapter will explore how DNACPR conversations had become an important topic for assessment and discussion at care review meetings with proxy-decision-makers as a result of: a) *"recent trainings"*; and b) *"the Care Inspectorate"* inspection processes.

Chapter Six: *"Trying to prevent hospital admissions by re-structuring care"* and *"our expectations are the same":* factors influencing conversations about *"serious illness"* in the RCH

6.1 Introduction

This chapter recounts the discovery and description of the ruling relations that appeared in the ruling work co-ordinating SSCWs participation in getting signed DNACPR forms into residents' personal files. This chapter also recounts the discovery and description of the ruling relations in the audit and inspection processes that reinforced RCH managers' and SSCWs' compliance with the ruling practice – getting DNACPR forms signed and in residents' personal files.

SSCWs at the research site knew that what was discussed in the *"serious illness"* section of the care review meeting was to be focussed on *"anything that required a person to go to hospital"*. They knew the content of this discussion had been informed by *"recent trainings"* by staff leading an Advance Care Planning Project where they learned about the *My Thinking Ahead and Making Plans* document, the DNACPR form and that it was *best practice* if residents had a DNACPR form in their care file and were not admitted to hospital when they were dying – even when those actions were not actually *best* for individual residents and/or their family members.

To follow these threads of my analysis further, part one of this chapter includes data gathered from a *palliative care facilitator* (PCF) who co-led a time-limited Advance Care Planning Project (ACP Project). This project, which promoted the use of the *My Thinking Ahead and Making Plans* document, was funded by a Government initiative, managed by senior members of the Community Health Partnership (CHP), and its education sessions were attended by SSCWs from the research site.

SSCWs also knew that the presence or absence of a DNACPR form would be audited by their manager. The care home manager knew that *“things are changing with the Care Inspectorate and everything”*. One of the *“things”* that was changing was that the presence or absence of the DNACPR form was now an aspect of the inspection process. This linked the DNACPR form with the quality grade the RCH would be awarded post-inspection. To explore these relations of ruling further, part two of this chapter includes data gathered from a Care Inspectorate Health Advisor (CIHA).

The threads followed in this chapter lead to the link between national policy drives to reduce NHS spending on people over 75 and the recruitment of the RCH staff to carry out advance care planning work orientated toward *“anything that required a person to go to hospital”*. The chapter explores how one feature of that advance care planning work – to clarify resuscitation status through the presence of a DNACPR form - made requests for DNACPR forms into a *“bit of a battleground”* between GPs - who were not remunerated for this work (Chapter Five), and SSCWs - who needed *“the form”* to prevent a traumatic dying experience, and also to be deemed competent by their manager. This chapter will also demonstrate how conversations about *“serious illness”* and the DNACPR form were linked to the scrutiny process of the Care Inspectorate, where the pre-inspection self-assessment form and annual return forms were designed to *“give them* [care home managers] *a steer”* toward what was considered *quality care* by that ruling body. Those textual practices were directly linked to the quality grade that could be achieved, which was important to the RCH manager because the grade awarded had the potential to impact the RCH's reputation and ability to maintain a high occupancy rate.

6.2 Part One: Palliative Care Education: Helping staff *"know what was meant"* and become more *"co-ordinated"* in advance care planning work - to keep care home residents out of hospital.

Part one of this chapter contains data gathered from a GP who had taken a part-time job as a palliative care facilitator (PCF). This led to involvement in a year- long project to promote *advance care planning* in care homes. Her post was funded by a cancer charity - for one day per week - and a by a Government initiative to reduce emergency bed days among those over 75 - for one day a week.

The research participant reported that:

> *I was initially appointed to help develop community palliative care. That was mainly with GPs and district nurses, but the funding was to enable us to look at the wider community…and non-cancer palliative care…a lot of this care is delivered in the nursing and care home sector. And so…it was decided that this was an area we could look into…**to help develop the workforce within the care homes**…we did a little bit of…evaluation of what we felt was needed…the concern was that **they were not co-ordinated enough**…So, we wondered if we could focus the care homes to develop systems of care…The Scottish Government…through the work undertaken through Living and Dying Well had provided some guidance. And certainly the Health Board looked to that as the kind of road map of how palliative care services should be developed. So anticipatory care planning was…both a national priority and a local priority….we decided to make anticipatory care planning our major project and to involve as many of the care homes as we could…**to help the staff know what was***

> ***meant*** *by anticipatory care planning and how it should be identified…Anticipatory care planning was deemed to be a high priority…not just for the care home sector, but for all areas within the community…a training pack was produced…so that was our starting point…we had materials that we could use…that were readily available to us. When we decided to take on this project we applied for further funding. I was only appointed for one day a week, and obviously there was far more work than could realistically be achieved in one day a week. This coincided with money being made available through the Change Fund. That was quite a significant amount of money…and it was allocated on a CHP by CHP area. So we had a pot of money that was to be used to try and* ***re-structure and re-shape care for the older population****. Again it was with a focus anticipatory and preventative care…****trying to prevent hospital admissions by re-structuring care*** *so that it could be delivered in the patients home, or at least in a home like setting, which is where care homes and residential care homes come in… Some of the Change Fund money…funded my position…to get the money we applied for funding. And to do that we had to produce a project plan of what we hoped to achieve… It went to several bodies. It went to the CHP executive meeting, it went to the GP forum and it went to the older adults JPIG (Joint Implementation and Planning Group). So* ***all those bodies were overseeing it****…*

The account of work from the PCF participant demonstrates that there was a link between her work as a *palliative care facilitator* and the work of the *Health Board* to a) follow the directives in Living and Dying Well (2008) as "*the kind of road map of how palliative care services should be developed*" making the work of promoting advance care planning a *"a national and a local priority"* and to b) develop *"systems that would reduce hospital admissions"*. The *"system"* that was *"developed"* to push forward on both agendas was to recruit care home staff to undertake advance care planning work as a means of focussing care home staff attention on keeping residents out of the NHS hospital.

6.2.1 Advance Care Planning: a compulsory *"voluntary"* conversation

Advance care planning has increasingly been advocated in national healthcare policy documents including: *Living and Dying Well* (Scottish Executive 2008), *Improving Complex Care* (Scottish Government 2009) *Living and Dying Well: Building on Progress* (Scottish Government 2011), T*he Healthcare Quality Strategy for NHS Scotland* (Scottish Government 2010), *Reshaping Care for Older People* (Scottish Government 2010), and *Scotland's National Dementia Strategy* (Scottish Government 2011) among others. The work of the PCF was linked to helping care home staff *"know what was meant"* and become more *"co-ordinated"* in advance care planning work, particularly as that work could be orientated toward keeping care home residents out of hospital. The project team promoted use of the *My Thinking Ahead and Making Plans* document. The PCF reported that her project:

> ***was seen as a pump priming exercise****…each health board was given a certain amount of money…to develop systems that would reduce hospital admissions and in that way* ***reduce costs to the health service as a whole****.*

Use of this document, as the authorised and *correct* way of caring for people who would inevitably die, brought RCH staff into what Dorothy Smith categorises as a text-reader conversation. According to Smith:

> *Reading a text is a special kind of conversation in which the reader plays both parts. She or he "activates" the text – though probably never quite as its maker intended – and at the same time, she or he is responding to it or taking it up in some way. Its activation by a reader*

> *inserts the text's message into the local setting and the sequence of action into which it is read"* (Smith 2006: 105).

The *My Thinking Ahead and Making Plans* document was to be activated as SSCWs routinely discussed *"anything that required a person to go to hospital"* with family members at the six-monthly review meeting – this included the DNACPR form.

The work of advance care planning was also important in the RCH because it was advocated in *The Standards of Care for Dementia in Scotland* - published by the Scottish Government in 2011. The research site was a home which specialised in dementia care. In conversation, the RCH research participants often referred to *The Standards of Care for Dementia* (Scottish Government 2011) as a key text that influenced how care was organised, delivered and measured in their setting – as such, it was one of the texts they were *"working in line with"* and measured against - through internal and external audit based work.

The authorised view on advance care planning in *The Standards of Care for Dementia* (Scottish Government 2011) states that:

> *As a person with dementia I have the right to end-of-life care that respects my wishes* (Scottish Government 2011:40).

When this right is honoured, the Standards claim that the person with dementia will have access to the:

> *full range of palliative care services*; *care that respects previously expressed wishes*; and *protection from inhumane or degrading treatment* (Scottish Government 2011:40).

Advance care planning – sometimes referred to as *anticipatory* care planning – is the authorised means of gathering those *"expressed wishes"*. Advance care planning is described as a *voluntary process* of discussion(s) taking place between an individual and their care provider(s) and/or family, in order to discuss *and document* wishes about what people would and would not like to happen in terms of their future care (Henry and Seymour 2012).

The PCF participant reported that:

> *…talking to people about their wishes…as helpful as that is…does need to be documented in some way…so everyone is clear*

The authorised view is that *reluctance to discuss dying* in care homes – for whatever reason - has led to poor anticipatory planning of what is considered a foreseeable event (Hockley 2006, Moriarty *et al*. 2012), resulting in *inappropriate* hospital admissions in the last days/hours of life. Hospital admissions have been judged *inappropriate* for nursing care home residents if: the resident had wanted to die in the care home; the resident had been admitted to hospital without a GP assessment visit and their condition was potentially manageable within the care home; the resident did not want to go into hospital but the family/GP insisted and the admission was not for an acute event; a resident was admitted for a condition that was not reversible—but the reason given for admission was for treatment; and a frail resident was dying with advanced dementia (Kinley *et al*. 2013). Inappropriate hospital admissions are considered problematic due to the human cost of increased suffering as a result of burdensome, uncomfortable and potentially futile interventions as people are actively dying (Hockley 2006, Watson *et al*. 2010). However, as discussed previously (Section 4.3.1.2), hospital admissions are also considered problematic because they carry a significant financial cost. A

2015 study exploring the difference between geographic areas with care homes and those without suggested that geographic areas with more care homes also had 40-50% more emergency hospital admissions in the over 75 age group than the general population over 75. Many of those admitted to hospital were close to the end of life, with 42% of emergency admissions being among those in the last six months of life (Smith *et al.* 2015). Some argue that if the likelihood of death was more openly recognised and discussed in care homes then residents could remain in familiar surroundings and receive interventions with a *comfort orientated palliative intent* rather than being transferred to hospital for expensive and potentially futile and uncomfortable curative treatment as they approach the end-of-life (Harrison-Denning *et al.* 2012, Hertogh 2006, Watson *et al.* 2010). The discourse of palliative care has promoted the view that the best way to die is to die at home rather than in hospital However, resisting hospital admission is only a positive step if residents are adequately supported. The man in Vignette 1 was *dying with advanced dementia* which was not *reversible* and for which there was no *treatment* - so according to the criteria suggested by Kinley *et al.* (2013), admission to hospital would be classified as *inappropriate f*or this man. However, staff at the RCH knew they could not manage his care without a different kind of support than they were receiving from NHS community doctors and nurses. Therefore, while admitting him to hospital (for assessment and management of his symptoms of pain and distress) could have been considered an inappropriate *institutional* act, it would have been an entirely appropriate *human* act.

The authorised knowledge goes on to suggest that there are practical challenges surrounding the work of planning ahead for people with dementia for at least two reasons. Firstly, people with dementia face increasing communication difficulties as their disease progresses leaving those with advanced disease incapable of expressing their wishes in an end-of-life situation - even if they wanted to (Johnson *et al*. 2009, Triplett *et al*. 2008). This leaves staff supporting people with dementia reliant on any documentation that was collected while, and if, the patient was able to voice their preferences. If clear documentation is unavailable, staff are reliant on information gathered from those who knows the person with dementia well – usually a family member. This precipitates difficult conversations with family members and proxy-decision makers and recent research suggests that the outcome of these conversations does not inevitably accurately represent the wishes of the person with dementia (Harrison-Denning 2014). Staff are also reliant on their own knowledge about the patient's wishes and their own observations and judgments about the person's comfort and freedom from pain and distress (Gjerberg *et al*. 2011, Lawrence *et al*. 2011). Lack of clarity about people's wishes makes it difficult to support individuals to live and to die in accordance with what has been important and valuable to them (Froggatt and Parker 2010, National Council for Palliative Care 2006). A second challenge around advance care planning for people with dementia is the long and unpredictable journey to death (Section 4.2.3). Uncertainty makes it difficult to be clear about when the person with dementia is actually nearing the end-of-life (Rait *et al*. 2010, Xie *et al*. 2008).

Harrison-Denning (2014) states that until very recently most of the evidence on advance care planning came from the USA, where advance care planning conversations are a *requirement* of the health insurance system rather than a *voluntary* process of discussion - as is claimed to be the case in the UK. In a literature review of advance care planning and people with dementia, Harrison-Denning *et al*. 2011 identified the following key themes in the authorised literature: a point exists (often before diagnosis) at which cognition deteriorates so critically in a person with dementia that advance care planning can no longer be discussed with that person; factors are present in family carers and professionals that influence the advance care planning process, such as conflicting motivations between what the person with dementia may have wanted and their current best interests; and the preferences of family carers for life sustaining treatments and *reluctance to forgo such treatment* on behalf of the person with dementia. She concluded that: a) despite national drives to promote advance care planning in the UK, the evidence base for advance care planning was still limited for people with dementia and; b) that family members needed a high level of emotional support to engage in advance care planning.

Nevertheless, in line with *Living and Dying Well* (Scottish Government 2008) which influenced her cancer based funding and the Change Fund requirements, the PCF research participant worked to progress and promote advance care planning in care homes in the geographic area under investigation. Part of this work involved organising a two day course for care home staff. She reported that:

> *We used the NES Education for Scotland training pack…the first day included…the principles and practice of advanced anticipatory care planning…the timing and triggers…and DNACPR -* ***which proved to be quite a contentious issue****…The second day of training was focussed more on communication skills training…because it's actually having the communication skills…is…really crucial…..always during that training, one of the main things that we focussed on…is that* ***it was very much a voluntary process, and that it was not for everybody****. What we were frightened of was that staff…would think this was just a tick box exercise, something they had to do at all costs and, you know, perhaps inappropriately push people to discuss difficult aspects of their care…Some people would want to cover the whole document A few would be happy to discuss their immediate care, but would not like to think…about the possibly difficult times toward the end-of-life. They weren't ready to discuss that yet. We also stressed that it was an ongoing process…one that had to be revisited…and our recommendation to staff was that it should be looked at…and a discussion offered once a year…or sooner depending on…any changes in the conditions or cues they've picked up either from the residents, or the resident's advocate…*

Despite the rhetoric about advance care planning embedded in this account, the actual work of planning for illness and death (either sudden or expected) was not a *voluntary* process at the research site. The textual practices organising work at the RCH meant that a routine review of care was organised every six months and the category of *"serious illness"* was always discussed at that meeting – even when SSCWs knew it was *"important* ***not*** *to be saying stuff"* to people at times and even though the PCF knew that conversations about future care *"were not for everybody"*. The PCFs knowledge that people should not be *"pushed"* into discussing *"difficult times towards the end of life"* when they were not ready to discuss such matters, and the SSCWs knowledge about what was *"important"* to say and not say when talking to family members about the death of their relative - was subordinated to the discourse and ruling knowledge of palliative care and the ruling practices of the managers in (and beyond) the RCH. In relation to the aspect of advance care planning that focused on the DNACPR form, this meant that relatives were asked about the form at every care review meeting until the family member consented to the form (Vignette 6), or the decision was taken out of their hands (Vignette 2), or the resident died without a form *"in place"* (Vignette 3) and so became subject to CPR attempts that had little or no chance of restoring spontaneous breathing and circulation. The ruling relations co-ordinated textual practices that made advance care planning for sickness and death a *compulsory* rather than a *voluntary* process in the RCH. As a result, these discussions did not arise from the everyday lives and needs of older people resident in the RCH, their families and/or the people who provided daily care for those groups, rather they began in the ruling practices that organised: regular review meetings; the authorised knowledge about what should be discussed at those meetings; and the relations of ruling that surrounded the DNACPR form itself.

6.2.2 A glimpse into the link between the DNACPR form and the criminal justice system

One of the *"difficult visits"* described by the research participant working as a GP required that she broach the topic of resuscitation with a patient who was in the terminal phase of his illness. She reported that:

> *I would have looked at the person's notes quite carefully and I would have to see the person and have a discussion with the person if they have capacity and want to have a discussion with me…there's a lot of important things that have to be done with DNACPR…it's not*

> *something you just look at the notes and think that's an end to that…I think it's a much bigger process than that…its quite a long conversation sometimes, it's not a quick two minute run to the home and run out again. It's important, you know.*

One of the reasons it was *"important"* to discuss DNACPR and leave a form in the patient's home was to prevent the following chain of events – as cited on an online module on DNACPR recently completed by the GP (NHS Scotland 2013). I constructed the following account from the real life situation presented in that module.

> *There was no DNACPR form in the house of a person who was dying from cancer. The person collapsed unexpectedly, the family called the emergency services (999 call). The person was dead when the ambulance crew arrived. Although the person was known to be in the final weeks of life, the authorised view was that because death occurred as the result of a sudden collapse it was categorised as "unexpected". This meant the ambulance crew were obliged to contact and inform the police of the death. Then the police had to report the death to the procurator fiscal as an "unexplained" death. This meant the patient's body became material evidence to an investigation, which meant it was removed and held in the police mortuary while the "incident" was investigated. Additionally the bereaved family members were questioned as witnesses to, and potential suspects of, a crime.*

To prevent a similar set of circumstances, this GP completed a DNACPR form and left it in a prominent place in the patient's home. This would indicate, to all official parties, that death was not medically unexpected even if it occurred suddenly for this patient. To leave a red DNACPR form in a prominent place in a patient's home, the patient and family needed to know about the form and understand what it was for – making it *"a long conversation"* –

because as above, patients and families did not always understand the need for the form, or the implications if it was absent.

This account provides a glimpse into another set of legal practices that made a DNACPR form necessary for those who are expected to die as a result of life-limiting illnesses – and from advanced age. This is because, in the event of a sudden, if not entirely unexpected death, the absence of a DNACPR form may link all who were involved with the person at the time of death to the work of the Police Service as witnesses to and suspects of a potential crime – adding a further layer of complexity into the mix.

6.2.3 *Advance Care Planning: "a pump priming exercise"*

The PCF participant's professional goal was orientated toward improving experiences of people who were sick and dying in care homes. There was no central NHS funding to progress this goal and so she had to find and apply for funding to be remunerated for this work. One stream of funding was awarded by a Government initiative called the *"Change Fund"*. The Change Fund financed work which could demonstrate a means of reducing:

> *…rates of emergency bed days used by those aged 75+ by a minimum of 20% by 2021 and at least 10% by 2014/15* (COSLA, The Scottish Government and NHS Scotland 2010:18).

One means of achieving these targets was to encourage:

> *…care providers in CHPs to support the use and sharing of Anticipatory Care Plans (ACPs): a summary or shared record of preferred actions, interventions and responses that care providers should make following a clinical deterioration or crisis in the person's care or support*(COSLA, The Scottish Government and NHS Scotland 2010:20).

As a result of being awarded this funding, this research participant's work was oriented to *"focus on anticipatory care"* as the means of *"co-ordinating"* care home staff to know what they should discuss with patients (and families). I have now come to see this work – of which I have been a part in my professional role - as an insidious *"colonization of minds and hearts of the caregivers with goals and values of"* (Campbell 2006: 93) a political agenda to keep the care home residents in the care home and out of the hospital as they deteriorated and died as one means of "*re-structur[ing] and re-shap[ing] care for the older population"*- and so reducing NHS costs. The SSCWs took up that ruling action intentionally but unknowingly as they carried out their textually-mediated work of discussing *"serious illness"* with family members - influenced by the *My Thinking Ahead and Making Plans* document.

The work of the Community Health Partnership (and other bodies) was to *"oversee"* the progression of the project and to ensure the project team maintained the focus on promoting the use of the *My Thinking Ahead and Making Plans* document as a means of reducing *"hospital admissions"* and NHS *"costs"*. The research participant stated:

> *We had tasks and milestones…I had them on an Excel spreadsheet…I had to input the details that we had on a monthly basis and then that was collated on a three monthly basis.*

To *"oversee"* this *"re-shaping"* work the Community Health Partnership had the promotion and uptake of advance care planning in care homes as a corporate priority in their 2013-2016 development plan (Appendix 49). Regular tracking of the development of the advance care planning project was a requirement of the funding from the Change Fund so progress was tracked through regular reporting on the number of care homes using the *My Thinking*

Ahead and Making Plans document as a result of that project work. Progress was reported to three bodies: The GP Forum; The Older Adults' Joint Implementation and Planning Group and the Community Health Partnership Executive Team. These groups were interested in recording how many care homes had started using the recommended/authorised advance care planning documentation and processes (Appendix 49).

There is a disjuncture between the focus on care homes for this advance care planning project work and the authorised knowledge in the *National DNACPR Integrated Adult Policy* (Scottish Government 2010) which states that decisions on CPR should be made by the *"senior clinician"* involved in the patient's care. Clinical involvement in advance care planning discussions is also recommended by the British Geriatrics Society (BGS) who suggest that such discussions should be initiated by an appropriately trained professional who has developed rapport with the person whose care is being discussed (Royal College of Physicians, National Council for Palliative Care, British Society of Rehabilitation Medicine, British Geriatrics Society, Alzheimer's Society, Royal College of Nursing, Royal College of Psychiatrists, Help the Aged, Royal College of General Practitioners 2009). In this guidance, appropriately trained means a person who has adequate knowledge about the disease, the treatment, and the person whose care is being discussed so that they can sensitively and skilfully offer appropriate information and advice. If the professional who has rapport with the person does not have this knowledge base, the guidance is to refer to a person who does, or to engage in a joint discussion with a professional who has the required (specialist) knowledge. Nevertheless the PCF participant was instructed by the ruling body overseeing her work to focus her attention on care homes rather than

GPs or community nurses as she had done in the past. This was a source of frustration for her, she reported:

> *That was the disadvantage of the focus on care homes…I had always done a round of GP visits before…for seven or eight years in total, but the last two years of my career, because the focus was care homes and the funding was different…**that lapsed**… I felt that was a pity…it would have been nice to have kept that going…to keep palliative care at the top of GPs agenda.*

Rather than using her medical knowledge about working as a GP with a longstanding special interest in the care of sick and dying people *"to keep palliative care at the top of the GPs agenda"*, the PCF participant was obliged to enter numerical data into a spreadsheet for the benefit of bodies *"overseeing"* the ACP Project. This data was used to track, measure and evaluate progress on her work advancing the authorised knowledge about advance care planning with care home staff which drew the RCH staff – who are not NHS employees - into the work of solving the Government fiscal problem of high NHS expenditure by keeping residents in the care home rather than sending them to hospital as they are dying.

Community Health Partnerships delivery plans on advance care planning were also directly related to their responsibility to report to a national group on progress with Action Point 4 in *Living and Dying Well* (Scottish Executive 2008:15), which states:

> *CHPs, palliative care networks, older peoples services and the Long Term Conditions teams in each NHS Board area should collaborate to ensure that timely, holistic and effective care planning is available for those with palliative and end of life care needs and is carried out in a manner which is person centred and responsive to the needs of the*

> *diversity of the population at appropriate stages of the patient journey.*

Action Point 4 was related to statement 29 in *Living and Dying Well* (Scottish Executive 2008:13) which states:

> *Future planning for end of life care should be included as part of this process* (the process referred to here was from statement 28: providing appropriate information and allowing adequate time for discussion to ensure patients and carers can explore care and support options with health and social care teams and arrive at informed and realistic decisions about future care), *and should include opportunities for discussions about the patient's wishes should he/she become physically or mentally incapacitated in the future as well as about cessation of active treatment, preferred place of care, support for care at home if desired, implementation of an integrated care pathway and the patient's wishes regarding resuscitation…Advanced care planning with patients and carers will be an important…as will the adoption by NHS Boards across Scotland of consistent Do Not Attempt Resuscitation (DNAR) policies, such as that developed by NHS Lothian.*

These statements in *Living and Dying Well* (Scottish Executive 2008) were progressed with the publication of the *National DNACPR Integrated Adult Policy* (Scottish Government 2010), an action which was also a recommendation of the National Audit Committee (Audit Scotland 2008). All of these documents were influential in determining the shape and scope of the ACP Project team's work and the reporting that was required as a result of that work. However, writing this work up as numbers on a spreadsheet took no account of what actually happened during the project.

The PCF research participant continued:

> *obviously you have to put things in a project plan that are time dependent, there are many things that can throw that off and that was one of the frustrations…even when you thought you had put forward a realistic time frame, it became quite apparent we were not achieving the milestones…a lot of that was due to difficulties in* ***getting [care home] staff released*** *for the training we had planned… and, although we had money for my post* ***we didn't have money to do very much else****, so we were very* ***dependent on getting free venues****, for example…but to get the free venue you had to go out-with timeframe…,and then we would discover that the care home staff that had signed up didn't send all of their staff. So, there were* ***many catch up days*** *we had to put on. So there were lots of confounding things like that…I think ideally we would have liked to have done it on a care home by care home basis, but that just wasn't realistic with the finance we had available to us and with* ***the staff we could persuade to work with us*** *to deliver the training.*

Numerical data on how many care homes had adopted the use of the *My Thinking Ahead My Making Plans* document took no account of the ability of the care home management to release staff for training or pay for backfill costs. Nor did it take any account of the difficulty the project team experienced in organising *"free"* venues or finding *"staff we could persuade to work with us to deliver the training"* – and do so at no additional cost to the project. The staff who were recruited to *"deliver the training"* were all non-NHS palliative care educators working for charitable organisations – such as myself. Finally, numerical data took no account of the difficulty of organising *"catch up days"* for staff who could not attend the original training, or the fact that this participant typically worked 50 hours a week at her *"part-time"* project but was only remunerated for 16 because *"we only had funding for two days"*, or that she sometimes paid for other people to *"deliver the* *training"* from her personal funds in an attempt to keep the project on track. Therefore, while the research participants' reports were useful to the Community Health Partnership management bodies *"overseeing"* the project work – to demonstrate progress with the actions in their corporate plan to the executive committee; and to demonstrate progress with the work of promoting advance care planning to the Change Fund funding body – and to demonstrate progress to the groups reporting on progress with the actions in *Living and Dying Well* (2008) to the Scottish Government - the actual work of running the project was nowhere to be found in the official account of that work - simply recorded and reported to ruling bodies as numerical data in a spreadsheet.

6.2.4 Advance Care Planning and the DNACPR form - *"a bit of a battleground"*

As highlighted, the PCF participant's work was to promote the use of the My *Thinking Ahead and Making Plans* document. Crucially there was no concurrent focus on supporting or remunerating GPs to support care home staff with the advance care planning work being promoted. Rather a (non NHS) PCF was charged with encouraging (non NHS) care home staff – both NCH and RCH staff – to take up the work of advance care planning (and so get involved in the work of reducing NHS spending).

The RCH management adopted the use of the suggested advance care planning documents, which then increased the institutional focus on getting DNACPR forms into residents care files. An increased institutional focus on DNACPR decision making was not shared by the residents' GPs (Chapter Five) – many of whom were described as not having *"a clue"* about what the RCH home needed in relation to the DNACPR form. This left RCH staff with the task of attempting to negotiate medical support with advance care planning work for RCH residents on a doctor by doctor and resident by resident basis – leading the deputy manager to describe the support of most GPs with this work to be *"rubbish"*.

The PCF participant stated:

> *There are lots of other bodies and people…our project would have an impact on…general practitioners…**we knew it would have an impact on their workload**.*
>
> ***DNACPR was a very contentious issue**…within general practice. There were a lot of GPs who were not particularly happy with the new DNACPR guidelines...The policy has some advantages, but as a GP I could see it had some disadvantages…**there is a work-load for GPs**…I think care homes found it quite difficult because GPs were being asked to respond to a request for a patient…care home staff might have had a discussion with an individual about a DNACPR decision…and again it was difficult because **it becomes a medical decision**…but, GPs were not prepared to come out and have that discussion…and that proved difficult for care home staff…who were under their own pressures, in that their overseeing authorities were keen for them to have all those to have documents in place…but the GPs were not prepared to make the decisions so far in advance…so it became **a bit of a battle ground**.*

The research participant knew the project work she was promoting would have an impact on GPs *"workload"*, and she knew that a DNACPR decision for a frail older adult was a *"medical decision…that GPs were not prepared to make…so far in advance"* and she knew that discussing this was *"proving difficult"* for care home staff. Not only was it difficult, it had become a *"bit of a battle ground"* between GPs and care home staff. The research participant's own analysis of why it had become a *"a bit of a battle ground"* was that there was a lack of education about the DNACPR process and lack of willingness to engage with it on the part of her GP colleagues.

She stated:

> *…when the DNACPR paperwork arrived initially, I don't think there was a tremendous amount of education to support it in the initial phases…It was my understanding that many of the GPs felt it was very time consuming thing that was…**landed on them**…without any sense of consultation…there were education meetings held but…the turnout was dreadful…I don't think the importance of it was fully recognised…In the past…the CHP have insisted that you go to training…I'm thinking of child protection...where **there was a three line whip because it was deemed to be important training**… For that training there was* a monitored register of attendance and funding to attend…*but **DNACPR was voluntary**…and **there was no payment**. The DNACPR forms were delivered to general practices and they were told of the various meetings around they area…but it was voluntary…The people who come to meetings and training are the ones who have an interest and the ones you really want to target don't come…*

There is more going on in this account than a lack of interest or a lack of education among GPs. As an education facilitator with responsibility for statutory and mandatory training within my workplace, I know that the DNACPR process is not categorised as a *mandatory or statutory training* topic by care organisations, or those who regulate them – while *"Child Protection"* is. This means that organisations must demonstrate to their regulatory body that Child Protection training has been completed by staff on a 1-3 yearly basis - depending on role. However, as they are not mandatory or statutory topics, neither the DNACPR process nor the DNACPR form would be considered *"important training"* and the Community Health Partnership management – who contract GP services – would not be under legal obligation to demonstrate that they had provided access to DNACPR training/education for their employees. Therefore, they would not need to have a *"three line whip"* approach to this topic. The research participant continued:

> *A CHP decision was made that most of my time was targeted at care homes…We did some GP practice visits…to discuss the most up to date documentation that we had in palliative care…before my visits to GP practices I would ask "Is there anything you want to cover, anything you want to discuss when we come out? It was* ***DNACPR that was always discussed****. There was* ***a lot of unhappiness about it*** *within the GP community.*

The relations of ruling explicated in this section show how the research participant was socially organised by the reporting systems required by the Community Health Partnership and the Government body funding her post to increase the use of advance care planning documents in care homes - with a view to decreasing NHS costs. *"Recent trainings"* provided by this participant increased requests for support from GPs with DNACPR forms from the RCH staff at the research site, which produced an additional *"workload"* GPs were neither remunerated for (as discussed in Chapter Five) nor consulted about. It is unsurprising therefore that there was *"unhappiness about it within the GP community"* and that working with the DNACPR form became a "*bit of a battleground"* between GPs and care home staff.

Vignette 6 records that Karen dislikes the process of initiating conversations about the DNACPR form, but it has become part of her job, so she feels *she has no option* and just needs to get on with it. The authorised knowledge suggests that care home staff have gaps in their knowledge leading to uncertainty about how to communicate sensitively and honestly with family carers about the unpredictability in dying with/from dementia and the *need* to plan ahead (Fahey-McCarthy *et al*. 2009, Livingston *et al*. 2011). Although the SSCWs did not mention gaps in knowledge as a reason for finding conversations about *"serious illness"* and DNACPR forms *"difficult"*, the manager who had recently been promoted from SSCW to deputy manager stated her concern that some staff *"struggled"* with this aspect of their work due to their *"lack of skill"* . Despite her concern the DNACPR form was an aspect of SSCWs' work that was subject to the ruling relation of the care file audit form – and as this chapter will demonstrate it was also subject to the ruling relations of the regulatory body, therefore her concern was sub-ordinated to the relations of ruling that organised *"needing the form"*.

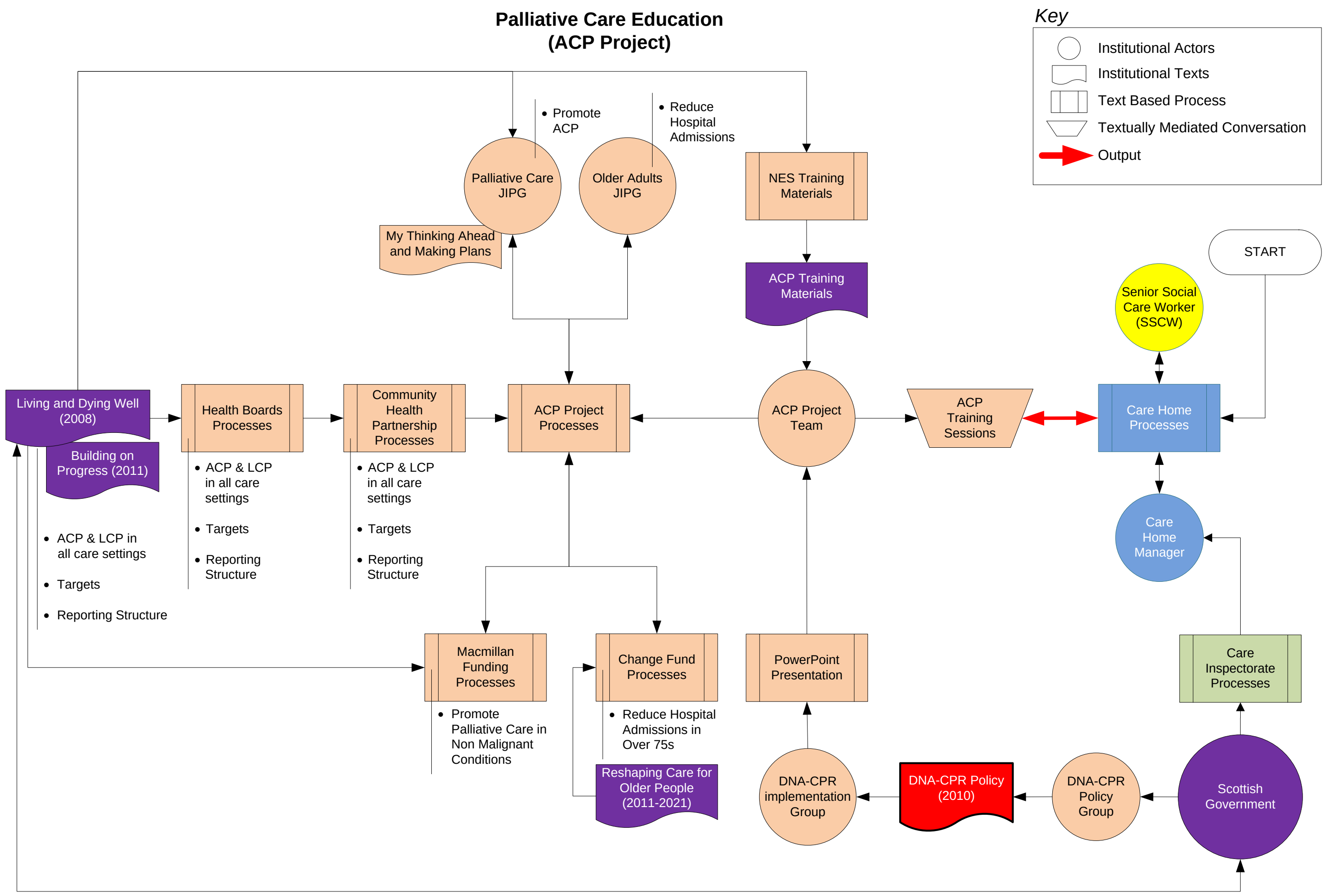
At the same time the research participant reported that during training sessions care home staff were reminded that:

> *DNACPR wasn't a main topic [in the My Thinking Ahead document], but it was an example under one of the headings…it was something that the patient might want to know more about,* ***so there was no obligation to discuss it****…but we had given staff training as to how they might initiate that discussion about DNACPR. Reminding them that it is quite a sensitive issue, and that not everyone wants to talk about, but* ***perhaps even to flag up the need to talk about it*** *with a healthcare professional…****somebody they knew and trusted like their GP*** *for example…before making any decisions.*

This segment of the interview data demonstrates the authorised knowledge on DNACPR decision making that was presented to care home staff during "*the education process*". This was the same authorised knowledge that I presented to care home staff so I knew information on advance care planning had been commissioned by NHS Education for Scotland and generated by a team of hospice based palliative care educators as an education *"toolkit"* with power-point presentations, quizzes and other materials. I also knew that educational materials on the DNACPR policy had been commissioned by the Scottish Government and generated by a hospice consultant as a power point presentation and DVD. These materials were organisational texts that organised a ruling relation and carried the power of the Government within them. I now recognise that the PCF research participant was ideologically captured during these education sessions (as was I, until I undertook this research) and so participated in disseminating the authorised view that: a conversation about DNACPR is a *“sensitive issue”* that *“not everyone wants to talk about”*; that DNACPR is a topic that needs to be *“flagged up”* to care home residents (or their families) for discussion; and that discussion should be with *“somebody they knew and trusted like their GP”*. This authorised knowledge subordinated the research participant’s knowledge of the actuality of the situation, which was: that *“DNACPR became a medical decision”*; that GPs in the area had not attended any education about the newly released DNACPR policy or form; that there was a lot of *“unhappiness”* among GPs about this *“workload”* and lack of remuneration being *“landed on them”* without consultation; that GPs were *“not prepared to discuss DNACPR so far in advance”*; and that the work of discussing DNACPR had become a *“bit of a battleground”* between GPs, care home staff - and the PCF herself. Her knowing of this actuality was translated into organisational texts (*My Thinking Ahead and Making Plans*, DNACPR forms, excel spreadsheets etc.) which articulated her concerns to *“the conceptual order of the institution”* (Campbell 2006: 94) and in the process became the authorised version of what was known about advance care planning in care homes – which was limited how many care homes had agreed to participate in the *“re-structur[ing]”* and cost-reducing project of ruling authorities.

Map 6 details the key actors, texts, text-based processes and textually mediated conversations outlined in part one of this chapter. This map pictorially represents how this work and these texts became the relations of ruling that co-ordinated SSCWs to integrate the authorised knowledge about the correct way to plan care for care home residents who were dying – which was to discuss *“serious illness”* with family members; organise the completion of DNACPR forms; and keep residents out of the NHS hospital.

MAP 7 Drawing SSCWs into the work of managing living and dying within the RCH



6.3 Part Two: Regulating and Inspecting Care Homes – pre-inspection forms *"give them (and us) a steer"*

Part two of this chapter contains data gathered from a Care Inspectorate Health Advisor (CIHA). The Care Inspectorate was set up by the Scottish Government to regulate and inspect care based services, such as care homes for older adults. It is accountable to government ministers. The requirements of the Care Inspectorate were often a source of frustration to SSCWs and the RCH manager(s). This frustration was due in part to the difficulty imposed on the RCH as a result of the quality grades awarded by the Care Inspectorate beginning to slide, bringing the competence of the manager and the care home staff into question by the care home company – and potentially bringing the reputation of the care home into question by its current and future customers. Additionally, I knew from seven years of working with care home staff in my professional role – with both RCH staff and NCH staff - that care home managers, nurses, care staff and senior care staff often gave the requirements of *"The Care Inspectorate"* as an explanation of why work happened as it did in care homes when asked. For example, when I asked the care home manager how care reviews came to be held six-monthly he said *"The Care Inspectorate want it that way"*, when I asked the SSCWs about what education was needed to work in that role said *"The Care Inspectorate (and the Scottish Social Services Council) tell us what we need to have"*. Therefore, to explore how ruling power was exerted through the practices of textual surveillance that held the RCH staff to their ruling requirements I followed the threads of social organisation into the work processes of the Care Inspectorate.

In an attempt to comply with authorised knowledge about how to care for people who were sick and dying - learned at palliative care educational projects/events, and embedded in the pre-inspection (and inspection) documentation of the Care Inspectorate (outlined below) - the RCH manager carried out regular audits of residents care files. As I will demonstrate, this was an audit of those textual processes and practices that could be matched to pre-inspection documents of the Care Inspectorate rather than an audit of residents' actual experiences of living and dying in the care home. The audit checked for the presence and completion of: *DNACPR form; Anticipatory Care Plan; Care plan and Outcome Reviews; Carer Involvement Reviews; and a Summary of Care and Activity Information* (Appendix 51). If any of these documents were missing, the RCH manger would discuss the omission, and the requirements of the Care Inspectorate, with the SSCW at their next supervision/performance review meeting. There were also regular care file audits carried out by other managers from the wider care home company as an additional quality assurance measure. If any of the above documents were missing, the auditing manager would highlight the omission to the on-site manager, who would discuss it with the accountable SSCW. Therefore SSCWs knew the presence or absence of a DNACPR form was something the care home management, the care home company, and the Care Inspectorate inspector, looked for during audits and inspections of residents' care plans.

6.3.1 Inspecting the quality of *palliative care – "a care home is a care home"*

To learn more about the inspection process of the Care Inspectorate I asked the CIHA to describe how it was carried out:

The CIHA participant reported:

> *I know there are resource implications, but for us a care home is a care home.* ***Whether it's residential or nursing it will be inspected in the same way****. The inspection should be the same. I would expect people to have the same care. We need to…because, for example, anticipatory care planning would be just as relevant in a residential care home as a nursing home...****people take ill in a residential care home****…so our expectations are the same.*

This participant knew: the actuality that *"people take ill in residential homes";* that on a human level people should have access to the *"same care"*; and that there are *"resource implications"* in relation to providing the *"same care"* for everyone. This section will explore the way in which the ruling relations of the inspection process – where *"a care home is a care home"* and *"our expectations are the same"* – consistently subordinated the SSCWs knowledge to the dominant professional knowledge and the policy frameworks in which living and dying was organised - as a means of achieving a good quality grading. The point is not that there is anything unusual or malicious in attempting to achieve a high quality grading, but that subordinating their knowledge of residents and family members did not always serve the actual needs of the embodied human beings that SSCWs attempted to support, nor did it always serve their own needs of support from medical (and nursing) colleagues.

The CIHA participant continued:

> *The service provider will be sent a self-assessment form* (Appendix 38). *It's quite a detailed form… a massive document. [The manager] will assess [their service] against the quality themes and quality statements [in the self-assessment document]…****so we have a picture before we go****. And we also have grades …they can tell us how they grade themselves as well.*

> *They also have the annual return, an electronic annual return, an inspector would look at that…there's a lot of information they've got to provide to us…**it gives them a steer** to what we are looking for in the inspection* (Appendix 40).
>
> *The inspection would be an unannounced inspection done by…expert teams, which should be older people's teams. When an inspection happens the inspector would look at the self-assessment and say "Oh, they work closely with the hospice…they've had education…whatever they want to tell us…so **that gives us a kind of steer** for when the inspector gets out.*
>
> *We [as advisors] don't make up [the inspection] documents…but when it was being consulted upon…I tried to say something about life-limiting conditions specifically **so they were reported on**. But, remember there's a number of advisors and we all want to see our speciality promoted. Infection control wants to see that in self-assessment, nutrition wants to see nutrition.*
>
> *[In terms of "palliative care"] the inspector would look at the "quality of care and support", which is 1.3. And what I tried to get in for palliative care specifically is 1.8, which is the statement about people living with life-limiting conditions…**we ask questions about DNACPR, and where they get their palliative care education from**.*

The CIHA participant knows; that the lived experience of older adults living and dying in care homes, both RCHs and NCHs, is broken into multiple measurable units so it can be assessed, inspected, reported and graded by the Care Inspectorate's work processes; that the pre-inspection documents give care home managers *"a steer"* towards what is expected by the Care Inspectorate; that each of the CIHAs has been consulted about how the assessment documents have been constructed; that all of the CIHAs want "*to see our speciality promoted*" in the reporting process; and the way the care home manager completes the required forms gives the Care Inspectorate inspector *"a steer"* about what should be focussed on during the on-site inspection..

In relation to the conceptual practice of palliative care, the RCH manager was required to submit data on work categorised as *advance care planning/palliative care* work through an online annual return form (Appendix 40) and an online self-assessment form (Appendix 38). These forms are standard across care homes in Scotland, those with nursing and those without – *"a care home is a care home…they will be inspected in the same way"*. Inspecting care homes in the same way, using standardised textual practices and forms takes no account of the actual experience of older people living and dying in care homes where those in NCHs had access to on-site nurses and an NHS Care Home Liaison Team (Chapter Five) and those in RCHs did not. The inequitable staff mix and level of NHS support may offer an explanation for why the RCH's quality grade had started to slip. To explore this slippage further, the inspection process could benefit from a more focussed inquiry using the principles of IE to understand how external factors influence and direct the award of quality grading by the Care Inspectorate.

According to the CIHA participant, the self- assessment quality grading around palliative and/or end-of-life care was associated with the following two quality statements and questions:

> ***Quality Statement 1.3 We ensure that service user's health and wellbeing needs are met***
>
> ***Quality Statement 1.8 Living with life limiting conditions is viewed as an integral part of life in this care home.***

Sources of evidence and information that were required from the care home in relation to these statements were:

- *Policy and procedures on care of dying, death and bereavement.*
- *How do you ascertain the service user's and family's wishes for care at the end-of-life?*
- *How are staff supported to feel confident to discuss end-of-life issues with relatives and family?*
- *How do you implement the national care standards on support and care in dying and death?*
- *What has been implemented in your care service in relation to end-of-life care from the best practice guidance document* ***Making Good Care Better: National Practice Statements for General Palliative Care in Adult Care Homes in Scotland by the Scottish Government and the Scottish Partnership for Palliative Care?***

Embedded in these questions is the institutional discourse of biomedicine and palliative care where speaking to people about their medical conditions and how those conditions are expected to progress and conclude in death is considered as the best course of action. Also considered correct is to be told that the options for curative treatment are now limited or exhausted meaning quality of life issues may now be paramount. To achieve quality of life people need to avoid becoming subject to over-treatment or under-treatment on the way to death, this requires intentional focus and planning if disease related and medical intervention related suffering is to be reduced. Also embedded in these questions is what McCoy (2006: 123) refers to as:

> *…the health consumer discourse with its emphasis on the informed and assertive patient who makes treatment decisions based on good*

> *information and a careful assessment of advantages and disadvantages.*

The discourse of palliative care and health consumerism is also evident in the *Making Good Care Better* (Appendix 39) (Scottish Executive, Scottish Partnership for Palliative Care 2006) document which makes frequent reference to the expectation that care home staff will discuss a range of sensitive and complex issues including: current and future palliative care needs; current and future palliative care plans; concerns residents may have about their palliative care needs; feelings of residents around the implications of changes they have experienced as a result of their palliative care needs; quality of life issues the resident may have as a result of their palliative care needs; and resident wishes if the place of care needs to change due to changing/increasing care needs that cannot be managed in the current setting. The practice statements state that discussions about such matters should be included in the resident's care plan.

Most of these topics were discussed with family members in the *"serious illness"* section of the care review meeting. However, they were complex issues for SSCWs to raise, discuss and action without the reliable support of NHS doctors (and nurses) – on whose professional knowledge RCH staff depended as residents inevitably became sick and died. As discussed in Chapter Five, community based medical and nursing care was not solely based on RCH staff or resident need, but influenced by a complex mix of ruling textual practices around remuneration for medical work and historical classifications of care needs and care settings (Chapter Five). Additionally, care in the RCH was socially organised **to keep residents in the RCH** rather than transferring them to a NCH as they inevitably deteriorated and died –

"*home for life*" policy. And it was being socially organised by those beyond the RCH **to keep residents out of the hospital** – e.g. the social organisation ACP Project Work (part one of this chapter) drew SSCW into particular kinds of discussions about *"serious illness"* with family members focussed on *"anything that required a person to go to hospital."* These discussions about *"serious illness"* with family members were inevitably *"difficult"* for SSCWs during care review meetings and at other times in light of the actuality that few people did change their place of care due to changing/increasing care needs – even when that may have been a more supportive course of action (such as in Vignette 1 and Vignette 2).

Making Good Care Better (Appendix 39) (Scottish Executive, Scottish Partnership for Palliative Care 2006) also makes reference to the expectation that care home staff will work jointly with GPs. The expectation is that care home staff will: access GP support; take responsibility for assessing and reporting symptoms that may be interfering with a resident's quality of life to her/his GP; and discussing medication issues with GP. The self-assessment document points to the *Making Good Care Better* (Appendix 39) (Scottish Executive, Scottish Partnership for Palliative Care 2006) document to outline what was recognised (and measured) as good practice around palliative care in care homes. Both documents state that care homes should be held accountable for providing evidence of engagement with GPs around accessing GP services to deliver palliative and end-of-life care. However, there is not an equivalent scrutiny of GPs accountability to care homes around the provision of such services; nor is there any requirement that GP practices demonstrate engagement with care homes attempting to comply with the *Making Good Care Better* (Scottish Executive, Scottish Partnership for

Palliative Care 2006) practice statements or any other standards or policy documents. This means that the RCH staff at the research site were being held accountable to the Care Inspectorate for matters that were beyond their control, such as the scheduling and distribution of medical resources including: the time and attention of the doctor, the sequence and/or shaping of medical consultations, including whether the doctor would come to the RCH or "triage" requests for support and conduct a consultation by phone; and how s/he would use her/his professional knowledge and authority to either sanction and/or with-hold treatments.

In relation to the DNACPR form, the CIHA participant reported that:

> *With DNACPR, what we want to know is: do they [care homes] have a copy of the national policy; do they have access to it; are they going to look at how they're going to implement it [the policy];* ***are they engaging with GPs about DNACPR****; do they know where to look for the DNACPR [form] when the person gets admitted; where are the [forms] kept - they should be at the front of the file…Now inspectors know that when they look at care files, it should be in the front of the care file…*
>
> *We're not discussing the decision…What we look for is that staff are aware of the policy, and they know to try and look for the form, and to see if they are signed and completed…*

A copy of the online annual return form was provided by the CIHA participant. The annual return form required answers to the following questions under the category of *palliative care*:

1. *Do you have a copy of the NHS Scotland "Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Integrated Adult Policy (2010) Yes/No*
2. *Have* ***you*** *implemented the NHS Scotland "Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Integrated Adult Policy (2010) Yes/No*

3. *If yes, when was the above DNACPR policy implemented in your service? DDMMYYYYY*
4. *How has the DNACPR policy been implemented in your service? Please describe any education and training provided and who delivered the education. The dates on which the training and education was provided should also be included.*
5. *When did you last review any local DNACPR policy?*
6. *How many of the residents who died in your care home between 1 January and 31 December had an NHS Scotland DNACPR form?* (Appendix 40)

Crucially this part of the inspection process takes no account of the actual DNACPR discussion – e.g. whether a medical assessment has been undertaken before discussions with patients or proxy-decision makers take place, who initiates the discussion and under what circumstances etc. Nevertheless, the CIHA participant knows that *"they"* – care home staff as a group – are expected to engage with GPs about the form, rather than GPs being expected to engage with care home staff about the form. There is a disjuncture between this expectation and the *Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Integrated Adult Policy* (2010:13) which states:

> *The overall responsibility for making an advance decision about CPR rests with the senior clinician (doctor or nurse) who has clinical responsibility for the patient during that episode of care. This will usually be the medical consultant (in General Hospitals) or the General Practitioner (in the Community based Hospitals, Care Homes or the patient's home). However, it is also reasonable for other grades of experienced medical staff and experienced senior nursing staff to take responsibility for this decision provided that they accept that they have clinical responsibility for the patient during that care episode. It is appropriate that the decision that CPR should not be attempted should be made in consultation with other members of the care team such as medical colleagues including general practitioner and senior nursing staff. For hospital inpatients Junior Doctors with full GMC*

> *licence to practise can sign the DNACPR form but the decision must be fully discussed and agreed with the responsible Senior Clinician who should then sign at the next available opportunity. Junior doctors without full GMC license to practise (i.e. Foundation Year 1) should not make this decision.*

In the RCH under study the staff group *"engaging with GPs"* were SSCWs, who are neither doctors nor nurses - experienced, senior, or otherwise. The work related to this engagement was to: bring up the topic of DNACPR and the DNACPR form with family members; to ask family members to make a decision on whether they wanted the form or not; to manage the family distress and/or anger in relation to being asked about this form; to contact the GP surgery and negotiate time to speak to the GP with the receptionist; to negotiate with the GP to obtain a signed and completed DNACPR form for individual residents; to collect a completed form to put in the resident's file. It was also SSCWs who were socially organised to keep raising the topic of the DNACPR form at six-monthly review meetings if family members would not or could not agree to the form, and it was SSCWs who had to answer to answer to the care home management if the form was not in the resident's notes.

From the questions and statements in the self-assessment form, the annual return form and the palliative care practice statement document *Making Good Care Better* (2006) it becomes clear that to obtain a good quality grade from the Care Inspectorate, the RCH manager must be able to provide the Care Inspectorate inspectors with the textual *"evidence"* they are looking for. For example, according to the CIHA, links with authorised palliative care educators would be viewed favourably by the inspector reviewing the form during the pre-inspection process - *"Oh, they work closely with the hospice…they've had education"*. Working *"closely"* with, and having *"had* *education*" from, hospice based educators – such as myself – demonstrated that care home staff had exposure to the authorised, and therefore supposedly *correct*, way to care for a dying person. The RCH manager was held accountable for ensuring the DNACPR policy had been *implemented*, that education about that policy had been undertaken, and that DNACPR forms had been completed and were in residents' care plans. The link between the auditing process of the Care Inspectorate and the quality ranking awarded to the RCH was crucial to the enforcement of the DNACPR policy. This link also made participation in both the ACP Project and the SPAR Project attractive options for the RCH manager who was keen to demonstrate engagement with the DNACPR policy to the Care Inspectorate in an attempt to maintain the RCHs grading and reputation as a high quality service provider. According to the RCH manager, being counted as successful in this textually mediated *quality* ranking work was becoming harder and harder to achieve.

6.3.2 Authorised knowledge, getting the *right* answers, and the production of inevitable differences and frustration

Having the *right* answers to the questions posed in the pre-inspection process was important to the RCH manager who knew that *wrong* answers would invite further questioning and scrutiny during the on-site inspection. According to the CIHA, looking over the data supplied by care home managers in the required forms was important to the inspector before the actual inspection took place because it influenced what the inspector would pay attention to during the inspection. For example, if there were any concerns about *lack of engagement* with palliative care education, or implementation of the DNACPR policy etc., the inspector could initiate an additional level of scrutiny under the category of *palliative care*. The CIHA explained:

> *There's a lot of demands on inspectors. And we [as advisors] are well aware of that. Because it's not just our health topics, there's other issues that need to be looked at in inspection. Like environment and building and staffing levels…they've got a heap of demands placed on them in the short time that they have to inspect the service. But* ***we've got to keep health in there****. So, we thought, "Would a trigger tool help?"* (Appendix 41) *We consulted on that, then we worked on making up our trigger tools, so when they go out to do the inspection, they would have written guidance in the trigger tools …it helps them know what to look for…like discussions, with GPs, with relatives…about wishes at the end-of-life…because remember* ***the [inspectors] don't have expert knowledge in each of our topics****, so I've got to consider what does the inspector know about anticipatory care planning.*

This means that care homes could become subject to a further level of scrutiny - guided by the *Palliative and End-of-life Care Trigger Tool* (Appendix 41). In Section 7 of the trigger tool inspectors are asked to look for evidence that advance and anticipatory care planning topics are being discussed. Evidence could include reports gathered during the inspection on how service users, relatives and carers were involved in planning a person's care. Section 7 of the tool has links to *The Advance and Anticipatory Care Planning Toolkit* on the NHS Education for Scotland website which links advance care planning with DNACPR decisions. In section 8 of the trigger tool, inspectors are asked to look for evidence that a person's resuscitation status is being considered/discussed and documented. It asks inspectors to ask staff if care home staff know how to access the *Integrated Adult Policy on DNACPR*. It asks inspectors to check the care home's education and training records to see what education and training has been provided about resuscitation decisions. It asks inspectors to find out if there are facilities available for staff to access policies and educational materials on resuscitation and DNACPR. Finally, Section 8 asks inspectors to find out if staff are able to access first aid training. These questions and prompts to the Care Inspectorate inspector are firmly embedded in the authorised knowledge of the conceptual practice of palliative care. For example, the CIHA reported that:

> *[To develop the tool], we [gather] everything that is out there on best practice. That's a troll through the websites – for example, the Scottish Government web-site…the NES web-site, the Scottish Partnership web-site. I'd tap into the…health board web-sites to see what they are recommending…because what you use in Grampian is not necessarily the same as you use in Glasgow or what you use in Lothian. All the health boards are at different stages and what they use as tools, so we tap into what they currently use. And then we use our contacts…and I try to attend all the conferences I can…I go down to England as well…then I sit down and write the trigger tool…"After I write it goes to the health team then it goes through a process for sign-off. It would go to my line manager and then to the communications team who stylise all our documents now. Then it went to the executive team and they would decide if it's beneficial or the right approach…The last one got sent back to me because it didn't have enough human rights and it wasn't outcome-focussed enough…The tools were probably more process focussed before…**that's not in vogue now**…it has to be outcome focussed. In the past it would have been "Do you have this form" "Have you sent people to education"…At the same time **I'm still wanting the inspector to go into the process** bit of it…*

This participant's account demonstrates the taken for granted way in which abstract nature of this authorised knowledge about advance care planning, palliative care, and the DNACPR form make their way into the care home inspection process – through ruling policy documents and authorised education sources etc. It demonstrates how this abstract knowledge makes its way into audit texts and these audit texts stand in for what actually happened in the

RCH. This account also demonstrates how the conceptual practice of advance care planning, palliative care and the DNACPR policy and form are linked and brought together in the consciousness of the care home managers completing the required pre-inspection documentation and answering questions during the on-site inspection. In other words, the work of completing the required forms gives the managers *“a steer”* as to what is expected by the ruling body of the Care Inspectorate.

The inspection documents are the same – no matter what Health Board the Care Inspector works within, no matter the staff group who work in the care home, no matter the support those staff are able to access from NHS doctors and nurses. That *“the expectation”* and the inspection documents of the Care Inspectorate are the same but the care settings are different produced an inevitable frustration in the RCH manager(s) in this study – *“things are changing with the Care Inspectorate…SSCWs need to do it…we need the form…but it’s a concern with some of them”* My analysis of that frustration is that the RCH mangers were being placed in a difficult position by being held accountable for matters beyond their control, in relation to the scheduling and distribution of medical services described above and also to provide evidence to the Care Inspectorate that the *“same service”* was being delivered in the RCH as that being delivered in NCHs in the area. In my view, this is an unreasonable expectation, because while the staff group working in RCHs had not changed other factors had. For example, residents: were more frail on admission to the RCH; were rarely moved to a NCH when their condition deteriorated; families were discouraged from considering admission into an NHS hospital; and RCH staff needed *“quite regular”* support from GPs which could now be *“triaged”* and offered by telephone rather than in-person support. In relation to the DNACPR form, needing *“the form”* to demonstrate quality in the provision of palliative care to the Care Inspectorate inspector was a ruling practice. The auditing process of the Care Inspectorate pressured the care home manager to insist that SSCWs to carry out work that the DNACPR policy recognises as the responsibility of senior doctors and nurses. Furthermore, residents in NCHs had direct access to: professional nurses with professional nursing knowledge working on-site; and the option of regular weekly input and support from the NHS Care Home Liaison Team, with professional nursing knowledge and knowledge about how to get access into the wider NHS system. Residents in the RCH had access to neither because the care home was classified as a social care setting – and District Nursing services had to be negotiated on the basis of recognised *nursing needs*. This means that falling Care Inspectorate grades attributed to the RCH in relation to what is measured as *palliative and or health care* could more reasonably be attributed to a lack of quality healthcare support from the wider healthcare system rather than lack of quality care for sick and dying people on the part of the RCH staff.

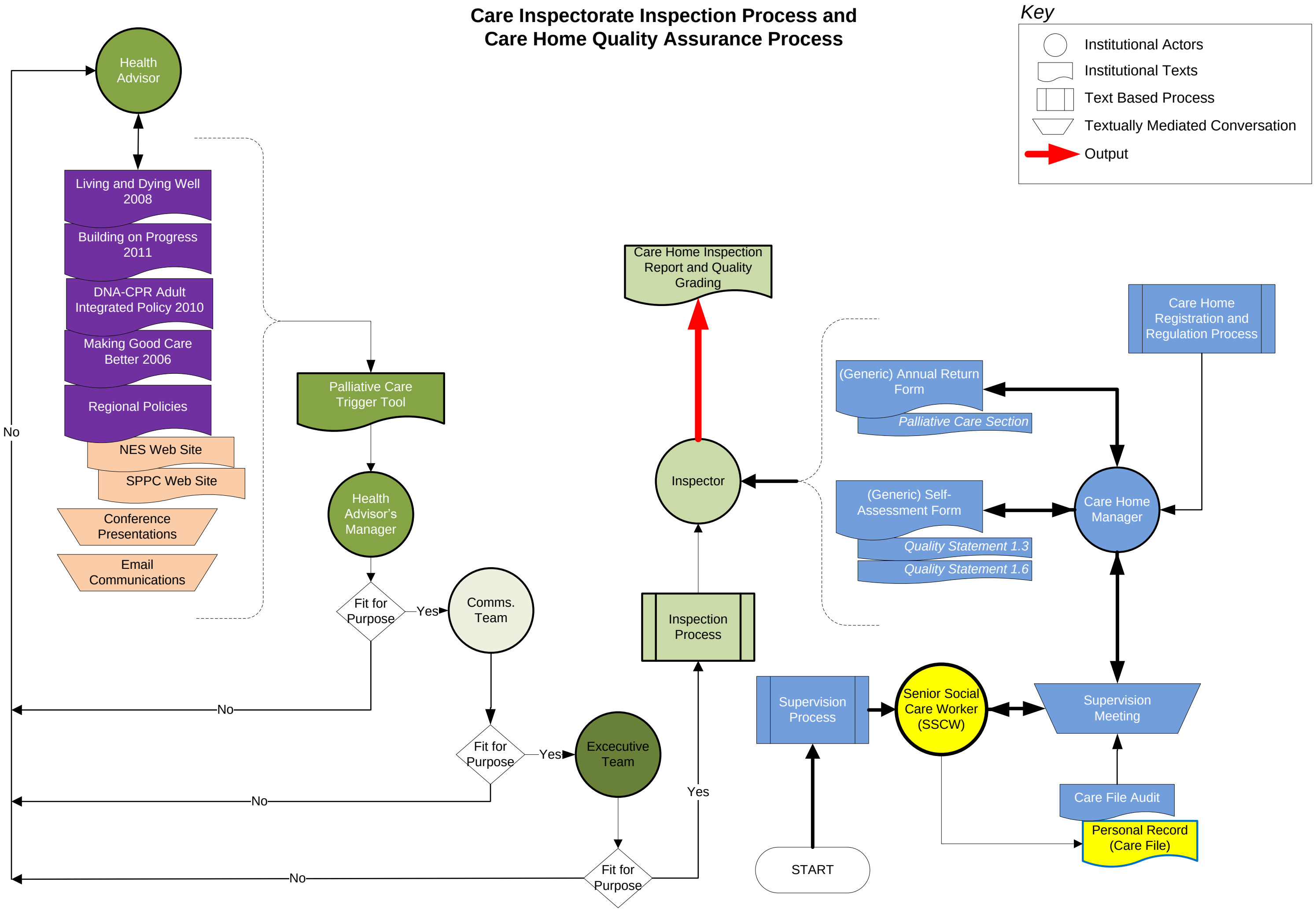
The CIHA account also demonstrates how authorised knowledge about topics related to the conceptual practice of palliative care become linked in the consciousness of the inspectors reviewing that documentation and carrying out the inspection – inspectors who often *“don’t have expert knowledge”* about the care of people who are sick and dying; who have *“heaps of demands”* placed on them by the Care Inspectorate management; and who have *“limited time”* to carry out their inspecting work. This part of the account also highlights a disjuncture between the CIHAs knowledge about the actuality that most inspectors *“don’t have expert knowledge”* about practices associated with what is measured as *palliative care*, and his expectation that inspectors will *“go into the process bit of”* inspecting how people who are sick and dying are cared for in care homes. This expectation is out of alignment with the reality that Care Inspectorate inspections are based on the textual representation of work in the RCH, rather than actuality of work with older adults in need of long term care. The inadequacies of the text-mediated knowledge generated by the Care Inspectorate’s audit processes are different to how the CIHA understands those inadequacies. In other words, inadequacies are not produced by the inspectors’ abilities or how much time they have, rather problems are routinely produced by the kind of abstract knowledge the audit process relies on and produces. Furthermore, although these textual processes restrict and distort what is known about the actuality of living and dying in care homes this kind of abstract - but authoritative - knowledge is what administrative and policy decisions are often based on.

As highlighted, SSCWs knew that talking about the DNACPR form was upsetting and something they dreaded, but had to do. They also knew that some family members were not able or willing to think and talk about the death of someone they have cared for/about – particularly when the outcome of that conversation was the perceived withdrawal of life-sustaining support, *“mum has a lot of life to live”*. Making judgements about the quality of care on the basis of yes/no answers about the presence/absence of specific documents such as the DNACPR form gives no recognition of the disjuncture between the SSCWs need to have *“the form”* - to prevent a traumatic death experience for residents (Vignette 3); to follow the guidance of *experts* in the care of people who are dying (Chapter Six: Part One); and to be deemed competent by their management - *“they need to do it”* (Section 3.2.6.1) -

with the lack of support they could expect from the *“senior clinician”* in charge of the resident’s case - who typically asked SSCWs *“what do the family want”* (Chapter Five).

Map 7 offers a pictorial representation of how authorised knowledge about the conceptual practice of palliative care entered and subsumed working practices at the research site. It highlights how SSCWs’ were socially organised to generate evidence of compliance with policies and regulations to assist the RCH manager(s) to meet the requirements of the quality award generating body - the Care Inspectorate. And did so in a way that took no account of what actually happened when residents were sick and dying in the RCH.

MAP 8: Organising SSCWs to generate evidence of compliance with policies and regulations



At this point it is worth noting that **none** of the SSCWs (or managers) I interviewed for this study has remained in post two years after the research interviews took place. One SSCW was rapidly promoted into management as a result of a period of internal disruption within the care home and has subsequently taken a management role at another care home, the other three have left care home work for older adults' altogether due to work-related stress. The manager, after being in post for almost 20 years, also left after a period of work-related stress related sick leave. This resulted in three interim managers running the service for six month spells each before a new manager was appointed. The deputy manager also left the service to transfer to an educational post within the same organisation because this was considered a less stressful role. This level of disruption was unexpected, as one of the reasons I chose this RCH to be the research site was the long-term stability of the staff group – along with the previously consistently high quality grading attained by this service. That all but one of the staff left RCH work for stress related issues seemed significant. The production of stress among RCH staff is a further issue which could benefit from a study using the principles of IE.

6.4 Chapter Summary

The analysis in this chapter shows that there were many efforts to induce RCH staff to participate in practices related to the work of discussing *"serious illness"* and the DNACPR form that would have the effect of preventing sick and dying residents from being admitted to NHS hospitals. It has highlighted that Government policy and funding drives to promote advance care planning in care homes had recruited (non NHS) palliative care facilitators, (non NHS) palliative care educators and (non NHS) care home staff to engage in work to reduce NHS costs. The involvement of these groups included undertaking work to reduce hospital admissions by keeping residents in the (non NHS) care homes rather than sending them to the NHS hospital to die. That residents should die in the care home rather than the NHS hospital – with a completed DNACPR form - was the desired institutional outcome of this auditing/inspecting process. This was despite the actuality that: dying in the RCH was not always peaceful nor comfortable for residents; dying in the RCH was not always manageable by RCH staff without medical and nursing support and; NHS medical and nursing support to the RCH was often unpredictable and insufficient.

As demonstrated in the Vignettes, SSCWs in this study were dependent on the support of GPs (and community based NHS nurses) to care for sick and dying residents. However, SSCWs had little power over doctors (and nurses) working practices – indeed they were excluded from the support of the NHS Care Home Liaison Team's services on the grounds the RCH was a *"social care setting"*. This dependence placed them, and other RCH staff, in position of tension between:

- the needs of frail older adults who would inevitably die;
- the social organisation of work in the RCH;
- the ruling practices of the Care Inspectorate (and the Scottish Government);
- the social organisation and distribution of NHS resources;
- and the complexity of working with the needs/obligations/relations of ruling of the older person's family members acting as proxy-decision maker.

This chapter also uncovers how Care Inspectorate audits and inspections acted as a form of surveillance of care home compliance with DNACPR policy that took no account of the actuality that the DNACPR Integrated Adult Policy (2010) acknowledged discussions and decisions about DNACPR were the responsibility of experienced/senior doctors and experienced/senior nurses. To obtain a high quality grade from the Care Inspectorate, and to maintain the reputation of the RCH as a service and as a business, the RCH manager was given a *“steer”* toward providing evidence that staff in the RCH had implemented the policy, attended education about the policy, and engaged GPs in discussions about DNACPR forms so they could report how many residents had died with a DNACPR form during the previous year. While GPs were *“quite regular”* in responding to requests for help from the RCH staff (by phone consultation and/or by in-person consultation), they were **not** *“quite regular”* in their involvement with discussions or decisions about the DNACPR form for RCH residents – where SSCWs got “*the ball rolling*”. Rather GPs were regularly pulled into other kinds of (income generating) *“paperwork…and meetings”* (Chapter Five) at their GP surgery.

The following chapter pulls the analytic threads uncovered in this research together to highlight the ruling practices that acted as the ground of SSCWs experience of work with the DNACPR form. It remains in the standpoint of SSCWs to offer some key conclusions and recommendations.

Chapter Seven: Putting it all together: ruling concepts and practices, explanations and conclusions

7.1 Introduction

This research took the standpoint of SSCWs working in RCHs – an important but under-represented group of care workers, about whom little is published in the authorised literature. The SSCWs who participated in this study supervised, organised and participated in meeting the everyday needs of a group older adults with dementia. Meeting those needs included serving breakfast, giving baths, and making *"regular"* calls to the doctor for help when those in their care were sick and dying. It also included ordering birthday cakes, organising the medication cupboard, and caring for family members as the lives of residents drew to an end. This work, known as *"running the shift"* mostly took place in the background. It ensured that broken door handles were fixed, and resident's files were managed and organised, and relief staff were paid. It also ensured that regular conversations with family members about *"serious illness"* and the DNACPR form occurred, despite the authorised position that key aspects of this conversation were the responsibility of the "*senior clinician"* in charge of resident's care – typically the resident's GP.

My research question – *how had SSCWs work become tied into the medical, legal and bureaucratic practices that rule death, dying and DNACPR decision-making in Scotland's RCHs* – focused on uncovering how SSCWs working lives were socially organised in ways that routinely produced puzzling and troubling experiences around lack of medical (and nursing) support. I chose to inquire into the social organisation of SSCWs work with the DNACPR form because it represented an extreme example of the *"abandonment"* that SSCWs felt and described. It also pointed to serious problems and contradictions present in SSCWs working lives – and by extension in the lives the RCH residents.

As a result of taking this standpoint and adopting this focus, my study has mapped the social organisation of care review meetings where SSCWs were *“pushed”* into discussing *“serious illness”* and the DNACPR form with legally appointed family members granted decision-making powers (Chapter Three). It has shown the discourse of palliative care as a powerful and taken for granted enacting feature of social organisation taken up by those in and beyond the RCH to organise care till death in the care home - with a DNACPR form - rather than sending residents to the NHS hospital (Chapter Four). It has uncovered the social organisation of medical and nursing services that limited - or excluded - services to residents in the RCH thereby producing inequalities between RCH residents and other *community dwelling* older adults (Chapter Five). It has traced the social organisation of policy oriented education and surveillance work which induced SSCWs to take up the work of *advance care planning* and the DNACPR policy for institutional rather than person-centred purposes (Chapter Six). And it has linked compliance with the work of *advance care planning* and (aspects of) the DNACPR policy in the RCH with the *quality* grading awarded by the Care Inspectorate – which RCH staff knew had the potential to impact the reputation and income generating potential of the RCH as a service and as a business (Chapter Seven).

This chapter will now summarise how the experiences of SSCWs were organised by people taking up the discourse of palliative care and other ruling concepts and practices. It will offer a different explanation for the problem of *“poor care”* among dying people in care homes than the typical reasons offered – i.e. lack of knowledge, skill and/or compassion among staff. It will challenge the prevailing problems in taken for granted ways of knowing and acting.

The thesis will conclude by: stating the original contribution to knowledge produced by this research; commenting on the significance of this knowledge and the method of inquiry; and highlighting important areas for further research – which I recommend should be carried out from a non-ruling perspective.

7.2 The discourse of palliative care and other ruling concepts and policies as powerful organising features in and beyond the RCH

The SSCWs worked in a setting which employed no nurses or doctors. This meant staff and residents were entirely dependent upon NHS medical and nursing support to manage all aspects of illness and dying in the care home. However, despite the actuality that staff and people living in the RCH needed *"quite regular"* support from medical (and nursing) staff as residents' health deteriorated and they died, the level of support available to staff and residents was insufficient. This left SSCWs feeling *"abandoned"* to manage aspects of residents' living and dying that they recognised as being beyond their knowledge and skill set – which resulted in unrelieved suffering in sickness and death among residents', and their families.

SSCWs were expected to work in such a way as to smooth over and absorb historical and more recent changes taking place in and beyond the RCH. For example there had been changes in what made older adults with dementia *"suitable for us"* allowing frailer people to enter the RCH to *"keep beds filled"*. There had been changes in what was expected of staff at the RCH as a result of the *"home for life"* policy and the work of those *"trying to prevent* *hospital admissions by restructuring care"*. The combination of these and other ruling practices meant that it was rare for people to be transferred to other (potentially more suitable) care settings as their health inevitably declined and they died.

Changes had also occurred in what the Care Inspectorate considered quality care. For example, the inspection process of the Care Inspectorate now required specific information about: DNACPR forms; the implementation of the DNACPR policy; and staff education on this policy – among other aspects of care categorised as *palliative care* and *advance care planning*.

The discourse of palliative care and the DNACPR policy were uncovered as powerful organisers of people's activities in this research. The discourse of palliative care and the DNACPR policy were taken up by SSCWs who worked to obtain a signed DNACPR form in their personal file of residents. It was essential for residents to have a DNACPR form to protect them from the automatic application of CPR when their heart and breathing inevitably stopped. It was also essential to have the DNACPR form so SSCWs could be seen as competent workers by the care home manager – who needed DNACPR forms to comply with the Care Inspectorate surveillance process - *"things are changing with the Care Inspectorate and things…we need the form…they* [SSCWs] *need to do it* [discuss the DNACPR form with family members]. To obtain a DNACPR form SSCWs said they had been *"pushed"* into accepting the responsibility for asking family members to consent to a DNACPR form - as a result of *"recent trainings…and things"*. This conversation between SSCWs and family members constituted a clear disjuncture between the authorised position that it is *"an unnecessary and cruel burden to ask…relevant others* *to decide about CPR when it is not a treatment option"* (Scottish Government 2010: 10) – which for many RCH residents it was not - and the actuality that families thought they were being asked to make a life or death decision for their relative – *"do all you can"* and *"she has a lot of life to live"*. The conversation about the DNACPR form between SSCWs and family members was also clear disjuncture between the actuality of DNACPR decision-making in the RCH and the authorised view in the DNACPR policy which stated that that decisions and discussions about DNACPR are the responsibility of the *"senior clinician"* in charge of that resident's care – in the case of RCH residents, the *"senior clinician"* is the residents' GP. However, while what happened in the RCH was out of step with the DNACPR policy, it cannot be simply described as an error of practice because this research has demonstrated how happenings in the RCH were socially organised experiences concerted with and connected to the conceptually informed knowledge based work taken up by those in and beyond the RCH.

The discourse of palliative care and the DNACPR policy were taken up by care home mangers who sent SSCWs to *"palliative care education"* sessions where the authorised view on the best and most correct way for care home residents to die was re-enforced by palliative care facilitators - through their ACP project work to promote the *My Thinking Ahead and Making Plans* document and the national DNACPR policy. It was taken up by management groups within the Community Health Partnership's as they tracked the number of care homes engaging with the ACP project and its associated documents. It was taken up by representatives from those management groups when they reported their numerical data to the Health Board and the Scottish Government. Working in this way assumes the problem of poor experiences in dying among care home residents is simply or inevitably attributable to lack of education among care home staff. Although limited education may be a contributing factor, this research has demonstrated the way problems are produced is also as a result of particular, unquestioned, taken for granted, knowledge based ruling practices.

Knowledge based ruling practices informed by the discourse of palliative care and the DNACPR policy were taken up by care home managers when they pressured SSCWs to initiate *"difficult"* conversations with family members who had legal decision making powers about how to manage *"serious illness"*, death and dying despite knowing that some SSCWs needed a lot of *"guidance"* with that conversation and that *"it's a concern with some of them"*. It was taken up by care home managers when they audited the presence/absence of DNACPR forms in residents' care files (and discussed the absence with SSCWs in supervision meetings) to demonstrate compliance with the authorised position on *palliative care* and DNACPR policy in the Care Inspectorates audit and surveillance processes. Care home managers participated in this audit and surveillance work in the hope of being awarded a high quality grade from the Care Inspectorate -as one means of guarding the reputation and income generating potential of the RCH, as a care setting and as business.

The discourse of palliative care and the DNACPR policy were taken up by those who designed the Care Inspectorate audit/inspection/surveillance processes and awarded quality grades on the basis of that discourse. It was taken up when Care Inspectorate workers designed and then used the same inspection documents to inspect care in RCHs and NCHs to ensure that the *"same care"* would be delivered in the RCH as would be delivered in a NCH –

i.e. that residents would be cared for **in** the care home **with** a signed DNACPR form, rather than in the NHS hospital. This expectation took no account of the fact that as a RCH the research site had no nurses on staff, that medical support was limited, and that as a *social care* setting the RCH was excluded from the support of the NHS Care Home Liaison Nursing Team - *"they are a social care setting…and we only cover nursing care homes"*.

Everyone interviewed for this study took up the discourse of palliative care in ways that organised RCH residents to remain in the care home - with a signed DNACPR form in their personal file - where they could be *"comfortable"* as they became sick and died rather than being *"inappropriately"* transferred to the NHS hospital. I want to emphasise that it is my personal view and the assumption of the theoretical framework of IE that on the whole people did their work in good faith and with good intentions. Nevertheless, because people are socially organised to work ideologically rather than experientially, well intentioned work informed by the conceptually informed discourse of palliative care and other ruling concepts and policies often took no account of the actuality that NHS medical and nursing support to the RCH was unreliable, that residents were not always *"comfortable"* when they died in the RCH, and that transfer to the NHS hospital may have been the only way for RCH residents to receive the medical and nursing attention they actually needed – making hospital admission **entirely** appropriate.

Unfortunately for RCH residents, staff and family members, the dominant discourse that right way for care home residents to die is for them to die in the care home – with a signed DNACPR form - rather than the hospital was also taken up by hospital staff – as found in the case of the woman in the last weeks of life and experiencing difficult symptoms from Vignette 2. RCH staff could not manage this woman without medical (and nursing) support. As a result she was admitted to hospital in pain and distress – two days later she was sent back to the care home with a letter from a hospital consultant recommending that she not be admitted to hospital again in the future, but cared for in the care home till death. This recommendation took no account of the actuality that RCH staff required medical (and nursing) support to care appropriately for this woman, and the medical support available to them up to that point had been limited to telephone conversations with her GP. This series of events acts as an example of the difficulties that arise when concepts and categories are taken up and enacted as relations of ruling which are present as unquestioned and prevailing ways of knowing about what is best that take no account of the actuality of the situation. This way of working placed this particular dying woman, her family and the staff attempting to care for her in a difficult and vulnerable position.

7.3 The social organisation of long-term care for older adults and limited medical and nursing support to RCHs as alternative explanation for *"poor care"* in dying.

The study traced how historically, in the 1990s, as a result financially driven moves to restructure NHS care, large numbers of people who had been long-term NHS patients were *"released"* from NHS care settings into (predominantly) non-NHS care homes. This meant that the NHS was *"released"* from the financial burden of funding long-term care of those people and costs were transferred to: the Local Authority, the older adults themselves and/or a third party acting on their behalf. As a result, SSCWs worked in a RCH which had been set up to provide care for people no longer eligible for long term NHS care, as such it was both a care setting and a business.

SSCWs work in assessing residents for admission was tied into income generation work for the RCH - to *“keep beds filled”*. As a result of changes in the admission criteria, residents were less able on admission. As a result of the *“home for life”* policy they were no longer transferred to NCHs as their health inevitably declined. SSCWs took up the discourse of palliative care and the DNACPR policy to talk with family members about *“serious illness”* and get a signed DNACPR form into residents’ personal files to plan ahead for inevitable death. SSCWs work to talk about *“serious illness”* and the DNACPR form was tied into the surveillance and quality grading work of the care home manager and the Care Inspectorate. Compliance with what was discussed with family members about *“serious illness”* was related to the SSCW being seen as a competent worker by her/his manager. Competence in this aspect of SSCWs work was important to the care home manager because it was related to her/his ability to attain a high quality grading score from the Care Inspectorate inspector. Attaining a high score was important to the care home manager if s/he was to be seen as a competent worker by the management team of the care home company. This score was linked to the reputation and income generating potential of the RCH as a care setting and also as a business.

After NHS long-term wards for older adults closed and people were *“released”* into the community, medical care for those now resident in care homes was “*dumped on the General Practitioners budget”*. In other words the increased medical *“work-load”* produced by increased numbers of (sick and frail) older adults living in the community was not offset by increasing either the community based medical workforce or the community based medical funding. The study traced how GPs work with increased numbers of community dwelling frail older adults excluded RCH residents from GP remuneration for work categorised as *palliative care* and *advance care planning* under the QOF system. The study linked the way GPs were socially organised to take up the QOF with the wider institutional purpose of economising on NHS acute care by targeting those at risk of hospital admission for medical attention (and remuneration). As most care home residents did not have cancer and as care in the care home was organised to keep RCH residents out of the hospital those residents were unlikely to appear on the lists of patients to be targeted for this focused medical attention. The study linked the actuality that GPs were routinely absent from meetings where the DNACPR form was a feature with the actuality that *"difficult visits…to difficult patients"* always had to be made *"at the expense of…other paperwork…and meetings"*. The *"paperwork…and meetings"* of the QOF system socially organised GPs to attend to the (potentially) cost-saving work (to the NHS) of carrying *advance care planning* and *palliative care "paperwork and meetings"* in ways that excluded most RCH residents from medical attention. The *"paperwork…and meetings"* of the QOF system also socially organised GPs to generate necessary income for the GP practice – *"points make prizes"*. The system of payment for medical work as a GP is complex and fragmented, and so "*money*" and concerns about *"work-load"* and *"difficult visits" and "paper-work…and meetings"* all became *"important"* to the GP interviewed for this study, because these factors all impacted the income generating potential for the GP practice. It was important for GPs to choose work on the basis of remuneration because GPs are *“self-employed”* workers with buildings, and heating bills and other employees to think about *“funding”* – they are not salaried NHS staff.

Turning to nursing support, the value (and cost) of nursing care came under increasing scrutiny in the 1990s. As a result, what had once been recognised as *“nursing care needs”* were reclassified to become *“social care needs”* instead. This reclassification meant people categorised as having *“social care needs”* could be re-assigned to *social* carers rather than professional nurses as a more cost-efficient means of managing their everyday care needs. However, this move gave no recognition to the contribution of nursing: nor did it account for the way people actually experience living, aging, becoming ill and dying as a continuous whole rather than in compartmentalised episodes that can be variously parcelled out to more or less expensive care providers with no regard to what else is happening in the lives of those impacted by that experience. The study traced how the categorisation *“social care”* had become a ruling relation which excluded the RCH residents from the services of the NHS Care Home Liaison Team.

Typically, knowledge, skill and compassion deficiencies (among care home, medical, nursing and government staff among others) are blamed for the problems of poor care in dying among care home residents. As a result of what has been traced in this research, an alternative explanation can be offered. This is because it has uncovered, explored and described how the working lives of those who participated in this study (SSCWs and others) were co-ordinated to care for residents in the care home – with a completed DNACPR form in their personal record - as they became sick and died rather than sending them to the NHS hospital. It has also traced how community medical staff and community nursing staff from the Care Home Liaison Team participated in enacting the socially organised exclusion of most RCH residents from key aspects of medical and nursing support as they followed the QOF system and upheld the categorisation of “*social care*” as a means of identifying and engaging in appropriate work. It has also traced how staff in and beyond the care home took up the ruling concepts and policies - of “*social care*” and the discourse of palliative care and the *“home for life”* policy and the DNACPR policy and the QOF system - as they went about their ordinary every day work. In so doing they intentionally, but unknowingly, worked to create the *“abandonment”* that RCH research participants had described - and do so for institutional purposes, such as reducing the cost of NHS acute care, and maintaining the reputation and income generating potential of the RCH, and organising medical work in relation to the income generating potential for the GP practice.

7.2 Conclusions

Using the principles and practices of IE, I traced and mapped how SSCW local knowing of what was actually happening in the RCH was replaced by ruling knowledge and practices that ruled death, dying and DNACPR decision making in the RCH. I traced how the resident’s personal file and other texts became a technology of ruling as they were taken up by the SSCWs (and others) to organise and enact a conversation about *“serious illness”* and the DNACPR form with family members who had accepted legal decision-making powers over residents’ lives.

Although what was discussed during that conversation was out of step both with the DNACPR policy and the actual needs of SSCWS, family members, and residents for medical support, the conversation itself was not simply an error of practice. This is because the conversation was an event which had been textually planned, organised, and co-ordinated across healthcare institutions, professional groups, the regulatory body acting on behalf of the Scottish Government and the management and care staff of the RCH itself. As a result of the enactment of ruling concepts and practices this research has shown that discussions about *“serious illness”* and the DNACPR form in the RCH were not the sensitive, voluntary, patient-centred conversations between clinicians and decision-makers that the rhetoric about *advance care planning* suggests. Rather they were compulsory conversations between hesitant, often anxious SSCWs and poorly informed, often distressed family members that were driven by institutional purposes rather than individual wishes and needs.

The explication of ruling relations that organised and co-ordinated the experiences of research participants in this study has traced and mapped, materially and empirically, that the social organisation of everyday life in (and beyond) the RCH is complex. It has also shown that what happened in the RCH extended beyond the boundaries of the RCH and the experience of any one person interviewed for this study. This is because what happened in the RCH was discursively organised by linked and co-ordinated ruling practices that existed across care settings, organisations and professional groups.

The contribution made by the analysis in this study is to have shown how ruling concepts, theories and policies informed the work knowledge and discursive practices of everyone participating in this study (including myself). It has shown how RCH workers (and others) were hooked into authorised knowledge about how care home residents should be cared for in death in ways which was so widely taken for granted that policy makers could rely on health and social care staff to take up their precepts. On the one side of the relation were theories and concepts found in policies, professional discourses and training that directed work in and to RCHs. On the other side were the experiences of the SSCWs (and residents, and families). In either case dominant theories and concepts accomplished the organisation of people's experiences. In the RCH, people took up the theories, concepts and polices - and their surveillance – to organise: what was required and what was recorded in the personal file of RCH residents; what was discussed between SSCWs and their managers, and what was discussed between SSCWs and residents' family members. Beyond the RCH, people took up the theories, concepts and policies – and their surveillance - to organise: the education of RCH staff and the inspection of the RCH to monitor compliance with the discourse of palliative care and the DNACPR policy. Everyone who participated in this study (including myself) understood, and took for granted, that care in death for care home residents should be organised in advance, that death should take place in the care home rather than the NHS hospital, and that death should occur without the automatic application of CPR. All of which seems reasonable until it is recognised that this ideological standpoint determined how the world was framed (ideologically and experientially) for those who were living it. And that those who took up this ideological standpoint without reference to what was actually happening in the material world that they actually inhabited (intentionally but unknowingly) took up the very tools of oppression that dominated and overpowered their lives.

It is my hope that the systematic and empirical analysis in this research will act to disrupt the trustworthiness of the taken for granted ruling knowledge and ruling practices that organised those experiences. My research has shown the routine way that authorised knowledge in text-based systems acted **to create** the problems which SSCWs (and RCH residents and their families) suffered from. In other words: SSCWs *"difficult"* experiences with sick and dying residents who had limited access to medical and nursing support, and who were rarely transferred to other (potentially more suitable) care settings as their care needs increased; and SSCWs *"difficult"* conversations with family members about the DNACPR form were **produced** by the textually mediated, planned and co-ordinated processes identified in this study. This highlights that inevitable problems will be encountered when textually mediated practices subordinate what is actually known to authorised versions and conceptual accounts which obscure and hide what happening in the material and everyday world. It also highlights that everyone involved in this study took up ruling concepts as they went about their accountable work with good intentions and in good faith – emphasising that ruling is not something done to us by powerful others who are completely removed from ourselves but something we activate as we go about our everyday lives in concert with the everyday lives of others.

There is now an expectation that RCH staff can, and should, manage the sickness and death of an increasingly frail group of older adults in the RCH – and do so at minimal cost to the NHS. In my view, this is unrealistic, unfair and unjust therefore I recommend that there is an urgent review of:

- the actual needs of older adults living and dying in RCHs;
- the admission criteria and *"home for life"* policy in RCHs;

- the organisation of (and remuneration for) medical and nursing support to RCH staff and residents;
- the admission criteria of the Care Home Liaison Team;
- the regulation and scrutiny of care homes;
- the organisation of educational support to care homes;
- and the expectations placed on SSCWs.

Furthermore, I recommend that all of the above should be reviewed and researched from a non-ruling perspective.

Inquiring into the difficulties faced by SSCWs, and doing so from their own standpoint, has required that I learn to see and put aside (and continue to learn to see and put aside) the authorised knowledge that I had previously relied on to understand how things happened as they did. Having spent over twenty years immersed in the discourse of palliative care I found this *seeing and putting aside* to be extremely difficult and frustrating work. However, what I have been able to learn as a result of looking into the social world from **SSCWs standpoint** at what is actually happening has led me to become more convinced of the significance and importance of IE as a method of inquiry.

At the end of this part of the research journey, my responsibility as an institutional ethnographer (and as a professional nurse), is to meaningfully engage in follow up work that is for the benefit of those who work in Scotland's RCHs. This follow-up work will be important to help people who have chosen to care for older adults in (and beyond) care homes *"to recognise their own participation in the relations that rule them...and to make the conditions of people's everyday lives known and knowable as the basis for action"* (Campbell and Gregor 2002: 128). I consider this future work to make the conditions of SSCWs everyday working lives *known and knowable as the basis for action* to be a serious and valuable contribution to knowledge.

References and Bibliography

Abbey, J., Froggatt, K.A., Parker, D., Abbey, B. (2006) Palliative care in long-term care: a system in change. *International Journal of Older People Nursing.* 1 (1) 56–63.

Adams, T.E., Holman-Jones, S., and Ellis, C. (2014) *Auto-ethnography (Understanding Qualitative Research)*. Oxford: Oxford University Press.

Addington-Hall, J., Fakhoury, W. and McCarthy, M. (1998) Specialist palliative care in non-malignant disease. *Palliative Medicine*. 12 (6) 417-427.

Ahmad, S. and O'Mahony, M.S. (2005) Where older people die: a retrospective population- based study. *QJM: an International Journal of Medicine*. 98 (12) 865–870.

Ammentorp, J., Sabroe, S., Kofoed, P.E. and Mainz, J. (2007) The effect of training in communication skills on medical doctors' and nurses' self-efficacy. A randomised controlled trial. *Patient Education and Counselling*. 66 (3) 270-277.

Aoun, S.M. Kristjanson, L.J., Hudson, P.L., Currow, D.C. and Rosenberg, J.P. (2005) The experience of supporting a dying relative: reflections of caregivers. *Progress in Palliative Care: Science and Art of Caring*. 13 (6) 319-325.

Applebaum, G.E., King, J.E., and Finucane, T.E. (1990) *Journal of American Geriatrics Society*. 38 (3) 197-200.

Ashby, M.A. (2011) The futility of futility: death causation is the 'Elephant in the Room' in discussions about limitation of medical treatment. *Journal of Bioethical Inquiry*. 8 I51-154.

Ashton, S., McClelland, B., Roe, B., Mazhindu, D. and Gandy, R. (2009) An end-of-life care initiative for people with dementia, *European Journal of Palliative Care*. 16 (5) 240–243.

Audit Scotland. (2008) *Review of Palliative Care Services in Scotland*. Edinburgh: Audit Scotland.

Audit Scotland. (2014) *Reshaping Care for Older People*. Available from: http://www.audit-scotland.gov.uk/docs/central/2014/nr_140206_reshaping_care.pdf [accessed June 2016]

Badger, F., Thomas, K., Clifford, C. (2007) Raising standards for elderly people dying in care homes. *European Journal of Palliative Care*. 14 (6) 238-241.

Bagust, A., and Slack, R. (1991) *Ward nursing quality*. York: University of York: York Health Economics Consortium.

Bagust, A., Slack, R., and Oakley, J. (1992) *Ward nursing quality and grade mix*. York: University of York: York Health Economics Consortium.

Bakhitin, M. (1981) *The Dialogic Imagination: Four Essays.* Austin. University of Texas Press.

Ballew, K., Philbrick, J., Caven, D., Schorling, J. (1994) Predictors of survival following in-hospital cardiopulmonary resuscitation: a moving target. *Archives of Internal Medicine*. 154 (21) 2426-2432.

Ballew, K., Philbrick, J., Caven, D., Schorling, J. (1994) Differences in case definitions as a cause of variation in reported in-hospital CPR survival. *Journal of General Internal Medicine*. 9 (5) 283–285.

Beauchamp, T. L. and J. F. Childress. (2009) *Principles of biomedical ethics*. New York: Oxford University Press.

Bedell, S.E., Delbanco, T.L., Cook, E.F., Epstein, F.H. (1983) Survival after cardiopulmonary resuscitation in the hospital. *New England Journal of Medicine*. 309 (10) 569-576.

Bejekal, M. (2002) *Health Survey for England 2000. Care Homes and their residents*. London: The Stationary Office.

Birch, D. & Stokoe, D. (2010) Caring for people with end-stage dementia. *Nursing Older People*. 22 (2) 31-36.

BMA. (2016) *NHS contracts for primary medical services: contractual routes*. Available from: http://www.bma.org.uk/support-at-work/gp-practices/service-provision/prescribing/the-gp-practice/nhs-contracts-for-primary-medical-services [accessed June 2016]

Bourdieu, P., and Wacquant, L., J., D. (1992) *An Invitation to Reflexive Sociology*. Chicago: The University of Chicago Press.

Bower, K. (2009) Ghostwriting: Generating Authoritative Research Texts in Feminist Post-Realist Research. *Crossroads*. 3 (2) 12-19.

Bowman, C.E., Whistler, J., Ellerby, M. (2004) A national census of care home residents. *Age and Ageing* 33 (6) 561–566.

Boyd, C.M., and Fortin, M. (2010) Future of Multimorbidity Research: How Should Understanding of Multimorbidity Inform Health System Design? *Public Health Reviews*. 32 (2) 451-474.

Brayne, C., Gao, L., Dewey, M., Matthews, F.E. and Medical Research Council Cognitive, Function and Ageing Study Investigators. (2006) Dementia before death in ageing societies – the promise of prevention and the reality. *PLOS Medicine*. 3 (10) 397.

Brazil, K., McAiney, C., Caren-O'Brien, M., Kelly, M.L., O'Krafka, P., Sturdy-Smith, C. (2004) Quality end-of-life care in long-term care facilities: service providers' perspective. *Journal of Palliative Care*. 20 (2) 85–92.

Brindley, P.G., Markland, D.M., Mayers, I., Kutsogiannis, D.J. (2001) Predictors of survival following in-hospital adult cardiopulmonary resuscitation. *Canadian Medical Association Journal*. 167 (4) 343–348.

Brindley, P.G., and Beed, M. (2013) Adult cardiopulmonary resuscitation: "who" rather than "how". *British Journal of Anaesthesia*. 112 (5) 777-779.

British Columbia Nurses Union. (2010) *Managing to Nurse: A Cautionary Note about Contradictory Knowledge*. Available from: http://www.workingtv.com/bcnu2010/sos-waysofknowing.html#janet [accessed June 2016]

British Geriatrics Society and Royal College of General Practitioners. (2009) *Frailty, Older People and Care: Can we do better? Improving what we do*. Available from: http://www.bgs-scotland.org.uk/Material/Frailty%20Older%20People%20and%20Care%20Homes%20final%20report.pdf [accessed June 2011]

British Geriatrics Society. (2011) *Quest for Quality Joint Working Party Inquiry into the Quality of Healthcare Support for Older People in Care Homes: A Call for Leadership, Partnership and Quality Improvement*. Available from:

http://www.bgs.org.uk/campaigns/carehomes/quest_quality_care_homes.pdf [accessed Sept 2013]

British Medical Association, Resuscitation Council (UK) and Royal College of Nursing. (2014) *Decisions relating to Cardiopulmonary Resuscitation (3rd edition)*. Available from: https://www.resus.org.uk/dnacpr/decisions-relating-to-cpr/ [accessed June 2016]

Buchan, J. and Ball, J. (1991) *Caring costs: nursing costs and benefits, report 208*. Brighton: Institute of Employment Studies.

Buchan, J., Seccombe, I., and Ball, J. (1997) *Caring costs revisited: a review for the Royal College of Nursing report 321*. Brighton: Institute of Employment Studies.

Cairns, W. (2001) The problem of definitions. *Progress in Palliative Care*. 9 187-189.

Calman, K. and Hine, D. (1995) *A Policy Framework for Commissioning Cancer Services: A Report by the Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales*. Available from: http://www.doh.gov.uk/cancer/pdfs/calman-hine.pdf [accessed Oct 2015]

Campbel, M. and Manicom, A. (1995) *Knowledge, experience and ruling relations: Studies in the social organisation of knowledge*. Toronto: University of Toronto Press.

Campbell, M. (1984) *Information systems and management of hospital nursing: A study in social organisation of knowledge*: PhD Thesis. Toronto: University of Toronto.

Campbell, M. (1988) Management as “ruling”: A class phenomenon in nursing. *Studies in Political Economy*. 27 (3) 29-51.

Campbell, M. and Manicolm, A. (1995) *Knowledge, Experience and Ruling*. Toronto: University of Toronto Press.

Campbell, M. and Gregor, F. (2002) *Mapping Social Relations: A Primer in Doing Institutional Ethnography*. Ontario: Garmond Press.

Campbell, M.L. (2006) Institutional Ethnography and Experience as Data. In: Smith, D. (ed) (2006) *Institutional Ethnography as Practice*. Maryfield: Rowman and Littlefield Publishers.

Cantor, M. D., Braddock, C.H., Derse, A.R., Edwards, D.M., Logue, G.L. Nelson, W., Prudhomme, A.M., Pearlman, R.A., Reagan, J.E., Wlody, G.S., Fox, E. (2003) Do-not-resuscitate orders and medical futility. *Archives of Internal Medicine*. 163 (22) 2689-2684.

Caplan, G.G., Meller, A., Squires, B., Chan, S., and Willett, W. (2006) Advance care planning and hospital in the nursing home. *Age & Ageing*. 35 (6) 581-586.

Care Commission and Mental Welfare Commission of Scotland. (2009) *Remember I'm Still Me: Care Commission and Mental Welfare Commission joint report on the quality of care for people with dementia living in care homes in Scotland.* Dundee: The Care Commission.

Care Commission. (2009) *Better care every step of the way: Report on the quality of palliative and end of life care in care homes for adults and older people*. Dundee: Care Commission.

Care Information Scotland. (2014) *How do I pay for care: paying care home fees*. Available from: http://www.careinfoscotland.co.uk/how-do-i-pay-for-care/paying-care-home-fees.aspx [accessed June 2014]

Carr-Hill, R., Dixon, P., Gibbs, I. (1992) *Skill mix and the effectiveness of nursing care*. York: University of York: Centre of Health Care Economics.

Centre for Policy on Ageing. (2009) *Ageism and age discrimination in primary and community health care in the United Kingdom*. Available from:)http://www.cpa.org.uk/information/reviews/CPA-ageism_and_age_discrimination_in_primary_and_community_health_care-report.pdf [accessed June 2016]

Chaplin, J. and Patterson, E. (2010) *Supportive and Palliative Action Register and Guidance Notes*. Glasgow: Greater Glasgow and Clyde Health Board.

Cigolle, C.T., Langa, K.M. Kabeto, M.U., Tian, Z., and Blaum, C.S. (2007) Geriatric conditions and disability: the Health and Retirement Study. *Annals of Internal Medicine*. 147 (3) 156-164.

Clifford, C., Badger, F., Plumridge, G., Hewison, A., Thomas, K. (2007) *Using the Gold Standards Framework in Care Homes: An Evaluation of the Phase 2 Programme*. Birmingham: University of Birmingham.

Clwyd, A and Hart, T. (2013) *A Review of the NHS Hospitals Complaints System: Putting Patients Back in the Picture*. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/255615/NHS_complaints_accessible.pdf [accessed Nov 2015]

Conroy, S. Luxton, P.T. (2006) Controversy cardiopulmonary resuscitation in continuing care settings: Time for a rethink? *British Medical Journal*. 332 (7539) 479-482.

COSLA, The Scottish Government, NHS Scotland. (2010) Reshaping Care for Older People: A Programme for Change 2011-2021. Available from: http://www.gov.scot/resource/0039/00398295.pdf [accessed June 2016]

Costantini, M., Beccaro, M., Higginson, I.J. (2008) Cancer trajectories at the end-of-life: is there an effect of age and gender? *BMC Cancer* 8- 127. Available from: http://www.biomedcentral.com/1471- 2407/8/127 [accessed Jan 2015]

Cronin-Stubbs, D., Beckett, L.A., Scherr, P.A., Field, T.S., Chown, M.J., Pilgrim, D.M., Bennett, D.A. and Evans, D.A. (1997) Weight loss in people with Alzheimer's disease: a prospective population based analysis. British Medical Journal. 314 (7075) 178-179.

Crosby, C., Evans, K.E. and Prendergast, L.A. (2000) *Factors Affecting Demand for Primary Health Care Services by Residents in Nursing Homes and Residential Care Homes*. Ceredigion: The Edwin Mellen Press.

Davies, E. and Higginson, I.J. (2004) *Better Palliative Care for Older People: Report*. *Geneva:* World Health Organisation.

Davis, F. (1960) Interview guide for problems of the handicapped in everyday social situations. Cited in: Robson, C. (2002) *Real World Research*. 2nd ed. Oxford: Blackwell Publishing.

De Gendt, C., Bilsen, J., Stichele, R.V. and Deliens, L. (2013) Advance care planning and dying in nursing homes in Flanders, Belgium: a nationwide study. *Journal of Pain and Symptom Management*. 45 (2) 223-234

Department of Health. (1990) *NHS and Community Care Act*. London: HMSO.

Department of Health. (2008) *End of Life Care Strategy: promoting high quality care for all adults at the end of life*. London: Department of Health.

Department of Health. (2008) *High Quality Care For All: NHS Next Stage Review final report*. Available from: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825 [accessed Oct 2015]

Department of Health. (2013) More care, less pathway: a review of the Liverpool Care Pathway. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf [accessed July 2014]

DeVault, M., and McCoy, L. (2006) Institutional ethnography: Using interviews to investigate ruling relations. In: D. E. Smith (ed) *Institutional ethnography as practice*. New York: Rowman and Littlefield Publishers.

Diamond, T. (1992) *Making grey gold: Narratives of nursing home care*. Chicago: University of Chicago Press.

Diamond, T. (2006) Where did you get the fur coat, Fern? In: D. E. Smith (ed) (2006) *Institutional ethnography as practice*. New York: Rowman and Littlefield Publishers.

Dixon-Woods, M., Kirk, D., Agarwal, S., Annandale, E., Arthur, T. and Harvey, J. (2005) *Vulnerable groups and access to health care: A critical interpretive review.* London: NCCSDO.

Donohoe, R. T., Haefeli, K, and Moore, F. (2006) Public perceptions and experiences of myocardial infarction, cardiac arrest and CPR in London. *Resuscitation*. 71 (1) 70-70.

Doyal, L., Doyal, L., and Sokol, D. (2009) The resuscitation game continues: What is really going on? *Postgraduate Medical Journal*. 85 (1009) 561-563.

Doyle, D. (2003) Proposal for a new name as well as having the new WHO definition of palliative care. *Palliative Medicine*. 17 (1) 9-10.

Dudman, J. (2007) Context and concepts. In: Help the Aged (2007) *My Home Life: Quality of Life in Care Homes. A review of the literature. Prepared for Help the Aged by The National Care Homes Forum*. London: Help the Aged.

Ebell, M. (1992) Prearrest predictors of survival following in-hospital cardiopulmonary resuscitation: a meta-analysis. *Journal of Family Practice*. 34 (5) 551-558.

Ebell, M., Becker, L., Barry, H., Hagen, M. (1998) Survival after in-hospital cardiopulmonary resuscitation: a meta-analysis. *Journal of General Internal Medicine*. 13 (12) 805–816.

Ebell, M., Preston, P. (1993) The effect of the APACHE II score and selected clinical variables on survival following cardiopulmonary resuscitation. *Family Medicine*. 25 (3) 191-196.

Ebell, M.H., and Afonso, A.M. (2011) Pre-arrest predictors of failure to survive after in-hospital cardiopulmonary resuscitation: a meta-analysis. *Family Practice*. 28 (5) 505-515.

Ehlenbach, W. J., Barnato, A.E., Curtis, J.R., Kreuter, W., Koepsell, T.D., Deyo, R.A., Stapleton, R.D., (2009) Epidemiologic study on in-hospital cardiopulmonary resuscitation in the elderly. *New England Journal of Medicine*. 361 (1) 22-31.

Eliott, J. and Olver, I. (2008) Choosing between life and death: Patient and family perceptions of the decision not to resuscitate the terminally ill cancer patients. *Bioethics*. 22 (3) 179-189.

Ellershaw, J. and Wilkinson, S. (2002) *Care for the Dying; A Pathway to Excellence*. Oxford: Oxford University Press.

Ellershaw, J. and Wilkinson, S. (2010) *Care of the Dying: A Pathway to Excellence*. (2nd ed.) Oxford: Oxford University Press.

Ellingson, L.L. (2009) *Engaging Crystallization in Qualitative Research: An Introduction.* California: Sage Publications.

Ellis, C. (2004) *The Ethnographic I.* California: AltaMira

Ellis-Smith, C. (2014) A protocol for the development of the palliative care outcome scale for dementia (POS-Dem): An intervention for people with dementia living in residential care homes. *Palliative Medicine*. 28 (6) 895-896

Fahey-McCarthy, E., McCarron, M., Connaire, K. and McCallion, P. (2009) Developing an education intervention for staff supporting persons with an intellectual disability and advanced dementia. *Journal of Policy and Practice in Intellectual Disabilities.* 6 (4) 267–275.

Fallowfield, L., Lipkin, M. and Hall, A. (1998) Teaching senior oncologists communication skills: results from phase 1 of a comprehensive longitudinal program in the United Kingdom. *Journal of Clinical Oncology*. 16 (5) 1961-1969.

Feldt, K.S., Warne, M.A., and Ryden, M.B. (1998) Examining pain in aggressive cognitively impaired older adults. *Journal of Gerontologicial Nursing*. 24 (11) 13-22.

Finucane, T.E., and Harper, G.M. (1999) Attempting resuscitation in nursing homes: policy considerations. *Journal of American Geriatric Society*. 47 (10) 1261-1264.

Finucane, T.E., Boyer, J.T., Bulmash, J., Fanale, J.E., Garrell, M., Johnson, L.E., Katz, P.R., Pattee, J.J., Rappaport, S.A., Ryan, J.J. (1991) The incidence of CPR in Nursing Homes. *Journal of the American Geriatrics Society*. 39 (6) 624-626.

Forbes, S., Bern-Klug, M., and Gessert, C. (2000) End-of-life decision-making for nursing home residents with dementia. *Journal of Nursing Scholarship,* 32 (3): 251-259.

Forder, J. and Fernandez, J.L. (2011) Length of stay in care homes, Report commissioned by Bupa Care Services, PSSRU Discussion Paper 2769, Canterbury: PSSRU. In: Age UK. (2015) *Later Life in the United Kingdom*

Factsheet. Available from: http://www.ageuk.org.uk/Documents/EN-GB/Factsheets/Later_Life_UK_factsheet.pdf?dtrk=true [accessed Jan 2015]

Frank, A. W. (1995) *The wounded storyteller*. Chicago: University of Chicago Press.

Froggatt, K. (2001) Life and death in English nursing homes: Sequestration or transition? *Ageing and Society*. 21 (3) 319-332.

Froggatt, K. (2004) *Palliative Care in Care Homes for Older People*. London: National Council of Palliative Care.

Froggatt, K.A., Poole, K. and Hoult, L. (2002) The provision of palliative care in nursing homes and residential care homes: a survey of clinical nurse specialist work. *Palliative Medicine*. 16 (6) 481-487.

Froggatt, K.A, and Payne, S. (2006) A survey of end-of-life care in care homes: issues of definition and practice. Social Care in the Community. 14 (4) 341-348.

Froggatt, K., Davies, D. and Meyer, J. (2009) Research and Development in Care Homes: Setting the Scene. In: Froggatt, K., Davies, D., and Meyer, J. (eds.) (2009) *Understanding Care Homes: A Research and Development Perspective*. London: Jessica Kingsley Publishers.

Froggatt, K., Parker, D. (2010) Care homes and long-term care for people with dementia. In: Hughes, J., Lloyd-Williams, M., Sachs, G. (eds.) (2010) *Supportive Care of the Person with Dementia*. Oxford: Oxford University Press.

Froggatt, K., Hockley, J., Parker, D. and Brazil, K. (2011) A system lifeworld perspective on dying in long term care settings for older people: Contested states in contested places. *Journal of Health and Place*. 17 (1) 263-268.

Gage, H., Kenward, G., Hodgetts, T.J., Castle, N., Ieson, N., Shaikh, L. (2002) Health system costs of in-hospital cardiac arrest. *Resuscitation*. 54 (2) 139-146.

Gage, H., Dickinson, A., Victor, C., Williams, P., Cheynel, J., Davies, S., Iliffe, S., Froggatt, K., Martin, W. and Goodman, C. (2012) Integrated working between residential care homes and primary care: a survey of care homes in England. *BMC Geriatrics*, 12 (71) Available from: http://eprints.lancs.ac.uk/76991/ [accessed June 2016

General Medical Council. (2010) Treatment and care towards the end-of-life: good practice in decision-making. Available from: http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp [accessed May 2015

General Medical Services Committee (GMSC). (1996) *GMSC core services: taking the initiative*. London: British Medical Association.

Georghiou, T. and Bardsley, M. (2014) *Exploring the cost of care at the end of life*. Available from: http://www.nuffieldtrust.org.uk/sites/files/nuffield/publication/end_of_life_care.pdf [accessed June 2016]

Gjerberg, E., Førde, R. and Bjørndal, A. (2011) Staff and family relationships in end-of-life nursing home care. *Nursing Ethics*. 18 (1) 42–53.

Gladman, J.R.F. (2010) *Medical Crises in Older People. Provision of medical care in care homes in the UK*. Available from: http://nottingham.ac.uk/mcop/documents/papers/issue1-mcop-issn2044-4230.pdf [accessed Dec 2011]

Glaser, B., Strauss, A. (1965) *Awareness of Dying*. London: Aldine Transaction.

Gold Standards Framework. (2005) The Gold Standards Framework Scotland. Available from: http://www.gsfs.scot.nhs.uk/ [accessed November 2014]

Gold Standards Framework. (2015) *The Gold Standards Framework: Pepsi Cola aide memoire – palliative care monthly checklist*. Available from: http://www.goldstandardsframework.org.uk/cd-content/uploads/files/Library%2C%20Tools%20%26%20resources/SCR4%20Pepsi%20cola.pdf [accessed Jan 2015]

Gold Standards Framework. (2015) *The Gold Standards Framework: Prognostic Indicator Guidance*. Available from: http://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf [accessed Jan 2015]

Gomes, B. and Higginson, I. (2008) Where people die (1974-2030): past trends, future projections and implications for care. *Palliative Medicine*. 22 (1) 33-41.

Goodall, H. L. (2000) *Writing the new ethnography*. New York: Alta Mira Press.

Goodman, C., Woolley, R. and Knight, D. (2003) District nurses' experiences of providing care in residential care home settings. *Journal of Clinical Nursing*. 12 (1) 67-76.

Goodman, C., Evans, C., Wilcock, J., Froggatt, K., Drennan, V., Sampson, E., Blanchard, M., Bissett, M. and Iliffe, S. (2010) End-of-life care for community dwelling older people with dementia: an integrated review. *International Journal of Geriatric Psychiatry* 25 (4) 329–337.

Goodman, C., Mathie, E., Crang, C., Wright, J., Handley, M., Barclay, S., Froggatt, K., Thompson, D., Cowe, M., Fenner, P., Gage, H., Garlick, R., Iliffe, S., Manthorpe, J., Mendoza, A., Munday, D. and Westwood, D. (2010) *The Experiences and Expectations of Older People Resident in Care Homes, Their Carers and Professionals of End of Life Care and Symptom Relief Needs: A Prospective Study*. A report for the National Institute for Health Research for Patient Benefit Programme PB PG 0906 11387. NHS Hertfordshire.

Goodman, C., Amador, S., Elmore, N., Machen, I., and Mathie, E. (2013) Preferences and priorities for ongoing and end-of-life care: a qualitative study of older people with dementia resident in care homes. *International Journal of Nursing Studies*. 50 (1) 1639-1647.

Goodman, C., Davies, S.L., Dickinson, A., Gage, H., Froggatt, K., Morbey, H., Victor, C., Masey, H., Martin, W. and Iliffe, S. (2013*) A Study to develop integrated working between primary health care services and care homes.: NIHR Service Delivery and Organisation programme. NIHR.* Service Delivery and Organisation Programme.

Gott, M., Barnes, S., Parker, C., Payne, S., Seamark, D., Gariballa, S., Small, N. (2007) Dying trajectories in heart failure. *Palliative Medicine*. 21 (2) 95-99.

Griffith, A.I. (2006) Constructing Single Parent families for Schooling: Discovering an Institutional Discourse. In: Smith, D. (ed) (2006) *Institutional Ethnography as Practice*. Maryfield: Rowman and Littlefield Publishers.

Groom, L., Avery, A.J., Boot, D., O'Neill, C., Thornhill, K., Brown, K. and Jones, R. (2000) The impact of nursing home patients on general practitioners' workload. *British Journal of General Practice*. 50 (455) 473-476.

Hakim, R. B., Teno, J.M., Harrell, F.E., Knaus, W.A., Wenger, N., Phillops, R.S., Layde, P., Califf, R., Connors, A.F. Jr., Lynn, J. (1996) Factors associated with Do-not-resuscitate orders: Patients' preferences, prognoses, and physicians' judgements. *Annals of Internal Medicine*. 125 (4) 284-293.

Hall, S., Kolliakou, A., Petkova, H., Froggatt, K. and Higginson, I.J. (2011) *Interventions for improving palliative care for older people living in nursing care homes : Cochrane Database of Systematic Reviews*. 3, CD007132.

Handley, M., Goodman, C., Froggatt, K., Mathie, E., Gage, H., Manthorpe, J., Barclay, S., Crang, C., and Iliffe, S. (2014) Living and dying: responsibility for end-of-life care in care homes without on-site nursing provision – a prospective study. *Health and Social Care in the Community*. 22 (1) 22-29.

Harraway, D. (1988) Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective. *Feminist Studies*. 14 (3) 575-599.

Harrison Denning, K. Greenish, W. Jones, L., Mandal, U., and Sampson, E.L. (2012) Barriers to providing end-of-life care for people with dementia: a whole system qualitative study. *British Medical Journal Supportive and Palliative Care*. 2 (2) 103-107.

Harrison Denning, K., Jones, L. and Sampson. E.L. (2011) Advance care planning in dementia: A review. International Psychogeriatrics. 23 (10.1535-1551.

Harrison-Denning, K. (2014) *Advance Care Planning in Dementia: Understanding the Preferences of People with Dementia and their Carers.* PhD Thesis: London: University of London.

Hayes, B. (2013) Clinical model for ethical cardiopulmonary resuscitation decision-making. *Internal Medicine Journal*. 43 (1) 77-83.

Hazelwood, M. (2013) Thanks and Close [Closing remarks to annual conference] 31 October 2013 Scottish Partnership for Palliative Care Annual Conference: *Palliative Care in Many Guises.* Edinburgh: Royal College of Physicians of Edinburgh.

Health Improvement Scotland and NHS Scotland (2015) *Scottish Palliative Care Guidelines.* Available from: http://www.palliativecareguidelines.scot.nhs.uk/guidelines/symptom-control.aspx [accessed Jan 2015]

Heath, I. (2002) Long term care for older people: increasing pressure for change. *British Medical Journal.* 324 (7353) 1534-1535.

Helft, P. R., M. Siegler., Lantos, J. (2000) The rise and fall of the futility movement. *New England Journal of Medicine.* 343 (4) 293-296.

Hennings, J., Froggatt, K. and Keady, J. (2010) Approaching the end of life and dying with dementia in care homes: the accounts of family carers. *Reviews in Clinical Gerontology.* 20 (2) 114–127.

Hennings, J., Froggatt, K. and Payne, S. (2013) Spouse caregivers of people with advanced dementia in nursing homes: a longitudinal narrative study. *Palliative Medicine.* 27 (7) 683-669.

Henry, C. and Seymour, J. (2012) *Advance Care Planning: A guide for health and social care staff*. London: Department of Health, End-of-life Care Programme.

Hertogh, C.M. (2006) Advance care planning and the relevance of a palliative approach in dementia. *Age and Ageing*. 35 (6) 553-555.

Hicks, K.L., Rabins, P.V. and Black, B.S. (2010) Predictors of mortality in nursing home residents with advanced dementia. *American Journal of Alzheimer's Disease and Other Dementias*. 25 (5) 439–445.

Hilbermann, M., Kutner, J., Parsons, D, Murphy, D.J. (1997) Marginally effective medical care: ethical analysis of issues in cardiopulmonary resuscitation (CPR). *Journal of Medical Ethics*. 23 (6) 361-367.

Hiller, R. (1988) Palliative Medicine, a new speciality [Editorial]. *British Medical Journal*. 297 (6653) 874–875.

Hockley, J. and Clark, D. (eds.) (2002) *Palliative Care for Older People in Care Homes*. Milton Keynes: Open University Press.

Hockley, J., Dewar B., Watson, J. (2004) *Bridges Initiative Project Phase 3: Developing quality end- of-life care in eight independent nursing homes through the implementation of an integrated care pathway for the last days of life*. Available from: www. stcolumbashospice.org.uk/professional/research/ bridges.shtml [accessed May 2014]

Hockley, J., Dewar, B., Watson, J. (2005) Promoting end-of-life care in nursing homes using an integrated care pathway for the last days of life. *Journal of Research in Nursing*. 10 (2) 135–52.

Hockley, J. (2006) *Developing High Quality End-of Life Care in Nursing Homes: An Action Research Study*. PhD Thesis. Edinburgh: University of Edinburgh.

Hockley, J. Watson, J., and Murray, S.A. (2008*) The Midlothian "Gold Standards Framework in Care Homes" Project*. Available from: http://www.goldstandardsframework.org.uk/cd-content/uploads/files/Midlothian%20GSFCH%20full%20report%202008.pdf [accessed July 2015]

Hockley, J., Watson, J., Oxenham, D. and Murray, S.A. (2010) The integrated implementation of two end-of-life care tools in nursing care homes in the UK: an in-depth evaluation. *Palliative Medicine*. 24 (8) 828-838.

Ibrahim, J.I., MacPhail, A., Winbolt, M. and Grano, P. (2016) Limitation of care orders in patients with a diagnosis of dementia. *Resuscitation*. 98 118-124.

International Longevity Centre (2014) *The Future Care Workforce*. ILC: London.

ISD Scotland. (2015) *NHS Payments to General Practice, Financial Year 2014-2015*. Available from: https://www.isdscotland.org/Health-Topics/General-Practice/Publications/2015-11-03/2015-11-03-ScotlandGPPayments2014-15-Report.pdf [accessed June 2016]

ISD Scotland. (2015) *Quality and Outcomes Framework: Prevalence, achievement, payment and exceptions data for Scotland, 2014-2015*. Available from: https://www.isdscotland.org/Health-Topics/General-Practice/Publications/2015-10-13/2015-10-13-QOF-Summary.pdf [accessed June 2016]

ISD Scotland. (2016) *SPARRA health and Social Care: What is SPARRA?* Available from: http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/SPARRA/ [accessed June 2016]

ISD Scotland. (2016) *SPARRA Risk Calculator: Health and Social Care*. Available from: http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/SPARRA/Calculator/fe-cohort/ [accessed June 2016]

Jacobs, S., Alborz, A., Glendinning, C. and Hann, M. (2001) *Health services for homes: A survey of access to NHS services in nursing and residential homes for older people in England*. University of Manchester: NPCRDC.

Johnson, A., Chang, E., Daly, J., Harrison, K., Noel, M., Hancock, K. and Easterbrook, S. (2009) The communication challenges faced in adopting a palliative care approach in advanced dementia. *International Journal of Nursing Practice*. 5 (5) 467–474.

Johnson, H. M. and Nelson, A. (2008) The acceptability of an information leaflet explaining cardiopulmonary resuscitation policy in the hospice setting: A qualitative study exploring patients' views. *Palliative Medicine*. 22 (5) 647-652.

Joseph Rowntree Foundation. (2008) *Improving care in residential care homes: a literature review*. Available from: http://www.jrf.org.uk/sites/files/jrf/2326.pdf [accessed Jan 2015]

Joseph Rowntree Foundation. (2012) *Older people's housing: choice, quality of life and under-occupation*. Available from: https://www.jrf.org.uk/report/older-peoples-housing-choice-quality-life-and-under-occupation [accessed June 2016]

Jude, J. R., Kouwenhoven, W.B. and Knickerbocker, G.G. (1961) Cardiac arrest: Report of application of external cardiac massage on 118 patients. *JAMA*. 178 (11) 1063-1070.

Kane, R.S. and Burns, E.A. (1997) Cardiopulmonary resuscitation policies in long-term care facilities. *Journal of American Geriatric Society*. 45 (2) 154-157.

Katz J (2003) Managing dying residents. In: Katz, J. and Peace, S. (eds.) (2003) *End-of-life Care in Care Homes: a palliative care approach*. Oxford: Oxford University Press.

Katz, J.S. and Peace, S. (2003) *End of Life Care in Care Homes: A Palliative Care Approach*. Oxford: Oxford University Press.

Kavanagh, S and Knapp, M. (1998) The impact on general practitioners of the changing balance of care for elderly people living in institutions. *British Medical Journal*. 317 (7154) 322-327.

Kayser-Jones, J., Chan, J., Kris, A. (2005) A model long-term care hospice unit: care, community, and compassion. *Geriatric Nursing*. 26 (1) 16–20.

Kendall, M, Carduff, E., Lloyd, A, Kimbell, B., Cavers, D., Buckingham, S, Boyd, K., Grant, L., Worth, A, Pinnock, H, Sheikh, A, Murray, S.A. (2015) Different experiences and goals in different advanced diseases; Comparing serial interviews with patients with cancer, organ failure, or frailty and the family and professional carers. Journal of Pain and Symptom Management. 50 (2) 216-224.

Kinley, J., Hockley, J., Stone, L., Dewey, M., Hansford, P., Steward, R., McCrone, P., Begum, A., and Sykes, N. (2013) The provision of care for residents dying in UK nursing care homes. *Age and Aging*. Available from: http://ageing.oxfordjournals.org/content/early/2013/10/15/ageing.aft158.full.pdf [accessed June 2016].

Kouwenhoven, W. B., J. Jude, Knickerbocker, G.G. (1960) Closed chest cardiac massage. *JAMA*. 173: 1064-1067.

Krakowski, I. (2006) Supportive care for people affected by cancer: concept and management. *Rev Prat*. 56 (18) 1989– 1996.

Krisman-Scott, M.A. (2001) *The room at the end of the hall. Care of the dying, 1945 – 1976*. PhD Thesis. Pennsylvania: University of Pennsylvania.

Lacey, D. (2005) Nursing home social worker skills and end-of-life planning. *Social Work and Health Care,* 40 (4) 19-40.

Laing and Buisson. (2009) Care of Elderly People UK Market Survey 2009. Cited in: Hockley, J., Watson, J., Oxenham, D., Murray, S.A. (2010) The integrated implementation of two end-of-life tools in nursing care homes in the UK: an in-depth evaluation. *Palliative Medicine*. 24 (8) 828-838.

Laing and Buisson. (2014) Care of Older People.UK Market Report 2013-2014. Cited in: Paying For Care. (2016) Care Home Fees. Available from: http://www.payingforcare.org/care-home-fees [accessed June 2016]

Lane, A., McCoy, L. and Ewashen, C. (2010) The textual organisation of placement into long-term care for older adults with mental illness. *Nursing Inquiry*. 17 (1) 3-14.

Lannon, R. and O'Keeffe, S.T. (2010) Cardiopulmonary resuscitation in older people: a review. *Reviews in Clinical Gerontology*. 20 (1) 20-29.

Lawrence, V., Samsi, K., Murray, J., Harari, D. and Banerjee, S. (2011) Dying well with dementia: qualitative examination of end-of-life care. *British Journal of Psychiatry*. 199 (5) 417–422.

Leadbeater, C. and Garbe, J. (2010) *Dying for change*. London: Demos.

Leon, D.A. (2011) Trends in European Life expectancy: a salutary view. *International Journal of Epidemiology*. Available from: http://www.oxfordjournals.org/our_journals/ije/press_releases/freepdf/dyr061.pdf [accessed June 2016]

Livingston, G., Lewis-Holmes, E., Pitfield, C, Manela, M., Chan, D., Constant, E., Jacobs, H., Wills, G., Carson, N., and Morris, J. (2013) Improving the end-of-life for people with dementia living in a care home: an intervention study. *International Psychogeriatrics*. 25 (11) 1849-1858.

Livingston, G., Pitfield, C., Morris, J., Manela, M., Lewis-Holmes, E. and Jacobs, H. (2012) Care at the end of life for people with dementia living in a care home: a qualitative study of staff experience and attitudes. *International Journal of Geriatric Psychiatry*. 27 (6) 643-650.

Lofland, J. and Lofland, L.H. (1995) *Analysing Social Settings: A Guide to Qualitative Observations and Analysis*. 3rd ed. California: Wadsworth.

Luce, J. M. (1995) Physicians do not have a responsibility to provide futile or unreasonable care if a patient or family insists. *Critical Care Medicine*. 23 (4) 760-766.

Lunney, J.R., Lynn, J., Foley, D.J., Lipson, S., Guralnik, J.M. (2003) Patterns of functional decline at the end-of-life. *The Journal of the American Medical Association* 289 (18) 2387–2392.

Macmillan Cancer Support. (2016) Organisation and History. Available from: http://www.macmillan.org.uk/about-us/who-we-are/organisation-history.html#248128 [accessed June 2016]

Maguire, P., Faulkner, A., Booth, K. Elliot, C., Hillier, V. (1996) *Helping cancer patients disclose their concerns. European Journal of Cancer*. 32 (1) 78-81.

Marengoni, A., Angleman, S., Mellis, R., Mangialasche, F. Karp, A., Garman, A., Meinow, B., and Fratiglioni. L. (2011) Aging with multimorbidity: a systematic review of the literature. *Ageing Research Reviews,* 10 (4) 430-439.

Marx, K. (1954) *Capital, Vol 1-4*. Moscow: Progress Publishers.

McCarthy, M., Addington-Hall, J., and Altman, D. (1997) The experience of dying with dementia: A retrospective study. *International Journal of Geriatric Psychiatry*. 12 (3) 404-409.

McCoy, L. (2006) Keeping the Institution in View: Working with Interview Accounts of Everyday Experience. In: Smith, D. (ed) (2006) *Institutional Ethnography as Practice*. Maryfield: Rowman and Littlefield Publishers.

McMurdo, M.E.T. and Witham, M.D. (2007) Health and welfare of older people in care homes. British Medical Journal 334 (7600) 913-914.

Mead, G.H. (1938) The Philosophy of the Act. Chicago: University of Chicago Press.

Mitchell, S.L., Teno, J.M., and Kiely, D.K. (2009) The clinical course of advanced dementia. *New England Journal of Medicine*. 361 (16) 1529-1538.

Moore, D. and Hanratty, B. (2013) Out of sight, out of mind? A review of data available on the health of care home residents in longitudinal and nationally representative cross-sectional studies in the UK and Ireland'. *Age and Ageing* 42 (6) 798–803.

Moriarty, J., Rutter, D., Ross, P.D.S. and Holmes, P. (2012) *SCIE Research briefing 40: End of life care for people with dementia living in care homes.* London: Social Care Institute for Excellence.

Morris, C. and Hill, K. (2007) *S/NVQ Health and Social Care: Assessors Handbook*. Oxford: Heinemann.

Morris, J. (2007) Better targeted care will ensure care home residents human rights and dignity. Available from: http://www.bmj.com/rapid-response/2011/11/01/better-targeted-health-care-will-ensure-care-home-residents-human-rights-a [accessed June 2016]

Murray, S., Kendall, M., Boyd, K. and Sheikh, A. (2005) Illness trajectories and palliative care. *British Medical Journal*. 330 (7498) 1007-1011.

Mykhalovskiy, E. (2001) Troubled hearts, care pathways and hospital restructuring: Exploring Health Services research as active knowledge. *Studies in Culture, Organisations and Societies*. 7 (2) 269-296.

Mykhalovskiy, E. (2003) Evidence-based medicine. Ambivalent reading and the clinical re-contextualisation of science. *Health*. 7 (3) 331-352.

Mykhalovskiy, E., McCoy, L. and Bresalier, M. (2004) Compliance/adherence, HIV and the critique of medical power. *Social Theory and Health*. 2 (4) 315-340.

National Council for Hospice and Specialist Palliative Care Services. (1997) *Changing gear – guidelines for managing the last days of life in adults*. London: NCHSPCS.

National Council for Palliative Care. (2006) *Exploring Palliative Care for People with Dementia*. London: National Council for Palliative Care.

National Institute for Clinical Excellence. (2004) *Improving supportive and palliative care for adults with cancer: The manual*. Available from: https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-773375005 [accessed June 2016]

National Institute for Health and Care Excellence. (2011) *End-of-life care for adults: NICE quality standard QS13*. Available from: http://guidance.nice.org.uk/QS13 [accessed March 2016]

National Institute for Health and Clinical Excellence. (2006) *Dementia: supporting people with dementia and their carers*. London: NICE.

NHS Scotland. (2013) *STAR DNACPR Video Presentation*. Available from: http://www.mystar.org.uk/dnacpr/launch-module.asp [accessed June 2016]

Nicholson, C. (2007) End-of-life care. In Help the Aged (2007) *My Home Life: Quality of life in care homes: a review of the literature*. London: Help the Aged.

Nobel, B. and Winslow, M. (2015) Development of palliative medicine in the United Kingdom and Ireland. In: Bruera, E., Higginson, I., von Guten, C. and Moritia, T. (eds.) (2015*) Textbook of Palliative Medicine and Supportive Care* 2nd ed. Florida: CRC Press.

Nolan, Y. (2008) *Health and Social Care (adults)*. Essex: Heinemann.

Nursing and Midwifery Council. (2009) *Guidance for the care of older people*. Available from: http://www.nmc-uk.org/documents/guidance/guidance-for-the-care-of-older-people.pdf [accessed Jan 2015]

Nursing and Midwifery Council. (NMC) (2008) *The code: Standards of conduct, performance and ethics for nurses and midwives*. London. NMC.

Nursing and Midwifery Council. (NMC) (2015) *The Code: professional standards of practice and behaviour for nurses and midwives*. London: NMC.

Oakley, A. (1981) Interviewing women: a contradiction in terms. In: Roberts, H. (ed) (1981) *Doing Feminist Research*. London: Routledge and Kegan Paul plc.

O'Keeffe, S.T., Ebell, M.H. (1994) Prediction of failure to survive following in-hospital cardiopulmonary resuscitation: comparison of two predictive instruments. *Resuscitation*. 28 (1) 21-25.

Pace, V., Treloar, A. and Scott, S. (2011) *Dementia: From advanced disease to bereavement (Oxford Specialist Handbooks)*. Oxford: Oxford University Press.

Pastrana, T., Junger, S., Ostgathe, C. Elsner, F. and Radruch, L. (2008) A matter of definition – key elements identified in a discourse analysis of definitions of palliative care. *Palliative Medicine*. 22 (3) 222-232.

Patterson, C. (1992) The economic value of nursing. *Nursing Economics*. 10 (3) 193-204.

Payne, S. and Seymour, J. (2008) Overview. In: Payne, S., Seymour, J. and Ingleton, C. (2008) *Palliative Care Nursing: Principles and Evidence for Practice*. Berkshire: Open University Press.

Payne, S., Froggatt, K. (2006) Dying in late old age: the final frontier? *International Journal of Palliative Nursing* 12 (5) 200.

Prince, M., Accosta, A., Ferri, C.P. Guerra, M, Huang, Y., Jacob, K.S., Jotheewaran, A.T. Jiu, Z., Rodriguez, J.J., Slas, A.L. and Williams, J.K. (2011) The association between common physical impairments and dementia in low and middle income countries, and, among people with dementia, their association with cognitive function and disability. A 10/66 Dementia Research Group population-based study. *International Journal of Geriatric Psychiatry,* 26 (5) 511-519.

Rait, G., Walters, K., Bottomley, C., Petersen, I., Iliffe, S. and Nazareth, I. (2010) Survival of people with clinical diagnosis of dementia in primary care: cohort study. *British Medical Journal*. 341 (3584) Available from: http://dx.doi.org/10.1136/bmj.c3584 [accessed Feb 2015]

Rankin, J.M., and Campbell, M.L. (2006) *Managing To Nurse: Inside Canada's Health Care Reform*. University of Toronto Press: Toronto.

Regnard, C. (2014) The demise of the Liverpool Care Pathway: should we ban the highway code because of bad drivers*? Age and Aging*.43 (2) 171-173.

Regnard, C. and Hockley, J. (eds.) (2004) *A Guide to Symptom Relief in Palliative Care*. 5th ed. Oxen: Radcliffe Medical Press.

Reid, L., Snowden, A., and Kydd, A. (2012) An exploration of palliative care provision in Scottish care homes. *British Journal of Nursing* 21 (1) 8-15.

Reynolds, P.D. (1979) *Ethical Dilemmas and Social Science Research*. San Francisco: Jossey-Bass.

Rhodes, C. (2000) Ghost-writing Research: Positioning the Researcher in the Interview Text. Qualitative Inquiry. 6 (4) 511-525.

Richardson, L. (1990*) Writing Strategies: Reaching Diverse Audiences*. California: Sage Publications Inc.

Richmond (2005) Dame Cicely Saunders, founder of the modern hospice movement, dies. *thebmj*. Available from:

http://www.bmj.com/content/suppl/2005/07/18/331.7509.DC1 [accessed June 2016]

Riess, H., Kelley, J.M., Bailey, R.W., Dunn, E.J. and Phillips, M. (2012) Empathy Training for Resident Physicians: A Randomized Controlled Trial of a Neuroscience-Informed Curriculum. *Journal of General Internal Medicine*. 27 (10) 1280-1286.

Roberts, D., Landolfo, K., Light, R., Dobson, K. (1990) Early predictors of mortality for hospitalized patients suffering cardiopulmonary arrest. *Chest*. 97 (2) 413-439.

Robson, C. (2002) *Real World Research*. 2nd ed. Oxford: Blackwell Publishing.

Rosenberg, M., Wang, C., Hoffman-Wilde, S., Hickham, D. (1993) Results of cardiopulmonary resuscitation: failure to predict survival in two community hospitals. *Archives of Internal Medicine* 153 (11) 1370 – 1375.

Royal College of Nursing (2009) *The socioeconomic case for nursing: RCN submission to the Prime Minister's Commission on Nursing and Midwifery*. London: RCN.

Royal College of Nursing. (2003) *Defining Nursing*. London: RCN.

Royal College of Nursing. (2010) *Care homes under pressure: an England report*. London: RCN.

Royal College of Nursing. (2010) *Guidance on safe nurse staffing levels in the UK*. London: RCN.

Royal College of Nursing. (2010) *Principles of nursing practice. Principles and measures consultation*. London: RCN.

Royal College of Nursing. (2011) *Views from the frontline. RCN employment survey 2011*. London: RCN.

Royal Collage of Nursing (2012) *Persistent challenges to providing quality care: an RCN report on the views of frontline nursing staff in care homes in England*. RCN: London.

Royal College of Nursing. (2012) *Safe staffing for older people's wards: summary recommendations and guidance*. London: RCN.

Royal College of Physicians. (2007*) Palliative care services: meeting the needs of patients*. Available from: https://www.rcplondon.ac.uk/sites/default/files/documents/palliative-care-services.pdf [accessed Dec 2011]

Royal College of Physicians. (2007) Palliative Care Services: Meeting the Needs of Patients. Available from: http://bookshop.rcplondon.ac.uk/contents/ec579e02-64fd-4f36-bb5d-5159a276077f.pdf [accessed June 2014]

Royal College of Physicians, National Council for Palliative Care, British Society of Rehabilitation Medicine, British Geriatrics Society, Alzheimer's Society, Royal College of Nursing, Royal College of Psychiatrists, Help the Aged, Royal College of General Practitioners. (2009) *Advance Care Planning. Concise Guidance to Good Practice series, No. 12.* London: Royal College of Physicians.

Rozenbaum, E.A., Shenkman, L. (1988) Predicting outcome of in-hospital cardiopulmonary resuscitation. *Critical Care Medicine*. 16 (6) 583-586.

Rurup, M.L., Onweteaka-Philipsen, B.D., Roeline, H., Passman, W., Ribbe, M.W. and Van Der Wal, G. (2006) Attitudes of physicians, nurses and relatives towards end-of-life decisions concerning nursing home patients with dementia. *Patient Education and Counseling*. 61 (3) 372-380.

Russell, S. (2014) Advance care planning: Whose agenda is it anyway? *Palliative Medicine*. 28 (8) 997-999.

Sachs, G.A., Shega, J.W. and Cox-Hayley, D. (2004) Barriers to excellent end-of-life care for patients with dementia. *Journal of General Internal Medicine*. 19 (10) 1057–1063.

Safar, P. (1958) Ventilatory efficacy of mouth-to-mouth artificial respiration: Airway obstruction during manual and mouth-to-mouth artificial respiration. *JAMA*. 167 (3) 335-341.

Saklayen, M., Liss, H., Markert, R. (1995) In-hospital cardiopulmonary resuscitation: survival in 1 hospital and literature review. *Medicine*. 74 (4) 163-175.

Sampson, E.L. (2010) Palliative care for people with dementia. *British Medical Bulletin*. 96 (1) 159-174.

Sampson, E.L., Burns, A., Richards, M. (2011) Improving end-of-life care for people with dementia. *British Journal of Psychiatry*. 199 (5) 357-359.

Santonocito, C., Ristagno, G., Gullo, A., Weil, M.H. (2013) Do-not-resuscitate order: a view throughout the world. *Journal of Critical Care*. 28 (1) 14-20.

Sasson, C., Rogers, M.M., Dahl, J., Kellermann, A.L. (2010) Predictors of survival from out-of-hospital cardiac arrest: a systematic review and meta-analysis. *Circulation and Cardiovascular Qualitative Outcomes*. 3 (1) 63-81.

Saunders, C. (1993) Foreword to Oxford Textbook of Palliative Medicine. In: Doyle, D., Hanks, G., MacDonald, N. (eds.) *Oxford Textbook of Palliative Medicine* (1st edn.) Oxford University Press: Oxford.

Saunders. C. and Clarke, D. (2006) *Selected Writings 1958 – 2004*. Oxford: Oxford University Press.

Savage, E.B. (1998) *An examination of the changes in the professional role of nursing outside Ireland: a report prepared for the commission on Nursing*. Dublin: The Stationery Office.

Schneiderman, L. J., Jecker, N.S., and Jonsen, A.R. (1990) Medical futility: Its meaning and ethical implications. *Annals of Internal Medicine*. 112 (12) 949-954.

Schneiderman, L.J., Jecker, N.S., and Jonsen, A.R. (1996) Medical futility: Response to critiques. *Annals of Internal Medicine*. 125 (8) 669-674.

Schofield, N., Green, C., Franklin, A., Pitceathy, C., Heaven, C. (2015) *Effective Communication with Patients, Families and Colleagues*. Manchester: The Maguire Communication Skills Training Unit.

Scott, J.F., Pereira, J., and Lawlor, P. (2015) Development of Palliative Care in Canada. In: Bruera, E., Higginson, I., von Guten, C. and Moritia, T. (eds.)

(2015) *Textbook of Palliative Medicine and Supportive Care* 2nd ed. Florida: CPR Press.

Scottish Credit and Qualifications Framework (2014) *The SCQF: Scotland's framework for lifelong learning: A guide for learners, providers and employers*. Available from: http://www.sqa.org.uk/files_ccc/SCQF_leaflet_July_2014.pdf [accessed Oct 2015]

Scottish Executive, Scottish Partnership for Palliative Care. (2006) *Making good care better: national practice statements for general palliative care in adult care homes in Scotland.* Available from: https://www.palliativecarescotland.org.uk/content/publications/Makinggoodcar-bette--CareHome-PracticStatements.pdf [accessed June 2016]

Scottish Executive. (2000) *Our National Health: a plan for action, a plan for change*. Available from: http://www.gov.scot/resource/doc/158732/0043081.pdf [accessed June 2016]

Scottish Executive. (2001) *Cancer in Scotland: Action for Change*. Available from: http://www.gov.scot/Resource/Doc/158657/0043044.pdf [accessed June 2016]

Scottish Executive. (2001) *National care standards: care homes for older people*. Edinburgh: Scottish Executive.

Scottish Executive. (2002) *Coronary Heart Disease and Stroke Strategy for Scotland.* Available from: http://www.gov.scot/Resource/Doc/46997/0013955.pdf [accessed June 2016]

Scottish Executive. (2008) *Living and Dying Well: a national action plan for palliative and end of life care in Scotland.* Edinburgh: The Scottish Government.

Scottish Government Health and Social Care Directorates. (2014) *Quality and Outcomes Framework Guidance for NHS Boards and GP Practices 2014/15.*

Available from: http://www.sehd.scot.nhs.uk/publications/DC20140502QOFguidance.pdf [accessed June 2016]

Scottish Government. (2001) *The Regulation of Care (Scotland) Act*. Available from: http://www.legislation.gov.uk/asp/2001/8/contents [accessed Oct 2015]

Scottish Government. (2007) *National Care Standards: Care Homes for Older People*. Available from: http://www.gov.scot/resource/doc/205928/0054733.pdf [accessed Oct 2015]

Scottish Government. (2009) *Long Term Conditions Collaborative: Improving Complex Care*. Edinburgh: Scottish Government.

Scottish Government. (2010) *Do Not Attempt Cardiopulmonary Resuscitation (DNACPR): Integrated Adult Policy*. Available from: http://www.healthcareimprovementscotland.org/our_work/person-centred_care/dnacpr.aspx [accessed June 2016)]

Scottish Government. (2010) *Reshaping care for older people*. [Online] Available from: http://www.scotland.gov.uk/Resource/Doc/1095/0097691.pdf [accessed Jan 2015]

Scottish Government. (2010) The Healthcare Quality Strategy for NHS Scotland. Available from: http://www.gov.scot/resource/doc/311667/0098354.pdf [accessed June 2016]

Scottish Government. (2011) *Living and Dying Well: Building on Progress*. Edinburgh: Scottish Government.

Scottish Government. (2011) *Promoting Excellence Framework: A framework for all health and social services staff working with people with dementia, their families and carers*. Available from:

http://www.gov.scot/resource/doc/350174/0117211.pdf [accessed June 2016]

Scottish Government. (2011) *Scotland's National Dementia Strategy*. Available from: http://www.scotland.gov.uk/Resource/Doc/350188/0117212.pdf [accessed Jan 2015]

Scottish Government. (2011) Standards of Care for Dementia in Scotland: Action to support the change programme. Scotland's Dementia Strategy. Available from: http://www.gov.scot/resource/doc/350188/0117212.pdf [accessed June 2016]

Scottish Government. (2015) National Indicator: *Emergency Admissions*: *Reduce emergency admissions*. Available from: http://www.gov.scot/About/Performance/scotPerforms/indicator/admissions [accessed June 2016]

Scottish Government. (2015) *Scotland first to abolish bureaucratic system of GP payments*. Available from: http://news.scotland.gov.uk/News/Scotland-first-to-abolish-bureaucratic-system-of-GP-payments-206a.aspx [accessed June 2016]

Scottish Government. (2015) *Strategic Framework for Action on Palliative and End of Life Care 2016-2021: Supporting Evidence Summary*. Available from: http://www.gov.scot/Resource/0049/00491390.pdf [accessed May 2016].

Scottish Partnership for Palliative Care. (2006) *Joined up thinking: Joined up care*. Available from: https://www.palliativecarescotland.org.uk/content/publications/2006-11-Joined-up-thinking-Joined-up-care-Full-Report.pdf [accessed June 2016]

Scottish Partnership for Palliative Care. (2015) Scottish Partnership for Palliative Care: *About us*. Available from: http://www.palliativecarescotland.org.uk/content/about/ [accessed Jan 2015]

Scottish Qualifications Authority. (2013) Guidance on assessment of Scottish Vocational Qualifications (SVQs): Available from: http://www.sqa.org.uk/files_ccc/DB6083_Guidance_on_Assessment_of_SVQs.pdf [accessed Oct 2015]

Scottish Qualifications Authority. (2014) *SQA Awarding Body Code of Practice*. Available from: http://www.sqa.org.uk/sqa/files_ccc/SQA_Awarding_Body_Code_of_Practice.pdf [accessed Oct 2015]

Scottish Social Services Council. (2009) *Qualification Criteria: All workers in care home services for adults*. Available from: http://www.sssc.uk.com/component/option,com_docman/Itemid,486/format,raw/gid,1729/task,doc_view/tmpl,component/ [accessed July 2014]

Scottish Social Services Council. (2009) *Registration: Find out about qualifications*. Available from: http://www.sssc.uk.com/registration/what-qualifications-do-i-need/find-out-about-qualifications?qualified=0&service=adult-services&category=supervisor-of-adult-services&role=supervisor-in-a-care-home-service-for-adults [accessed Oct 2015]

Scottish Social Services Council. (2014) *MySSSC guidance*. Available from: https://my.sssc.uk.com/SequencePortal/Public/Downloads/MySSSC.pdf [accessed Oct 2015]

Scottish Social Services Council. (2014*) Parts of Register and required registration dates*. Available from: http://www.sssc.uk.com/about-the-sssc/multimedia-library/publications/55-registration/parts-of-register-and-reqd-dates [accessed Oct 2015]

Seedhouse, D. (2009) *Ethics: The heart of health care*. 3rd ed. Wiltshire: Wiley-Blackwell.

Seymour, J., Kumar, A. and Froggatt, K. (2011) Do nursing homes for older people have the support they need to provide end-of-life care? A mixed methods enquiry in England. *Palliative Medicine* 25 (2)125–138. Available from: http://www.nottingham.ac.uk/nmp/documents/open-access-publication-eol-in-nursing-homes.pdf [accessed June 2016]

Shaw, K.L., Clifford, C., Thomas, K., Meehan, H. (2010) Improving end-of-life care: a critical review of the Gold Standards Framework in primary care. *Palliative Medicine*. 24 (3) 317-329.

Sidell, M., and Komaromy, C. (2003) Who dies in care homes for older people? In: Katz, J. and Peace, S. (eds.) (2003) *End-of-life Care in Care Homes: a palliative care approach*. Oxford: Oxford University Press.

Sleeman, K.E, Gomes, B., Higginson, I.J. (2012) Research into end-of-life cancer care – investment is needed. *The Lancet*. 379 (9815) 519.

Sleeman, K.E. and Collis, E. (2013) *The* Liverpool Care Pathway: a cautionary tale. *British Medical Journal* 347 (Jul31 1) f4779.

Smith, D. (ed) (2006) *Institutional Ethnography as Practice*. Maryfield: Rowman and Littlefield Publishers.

Smith, D. E. (1990) *The Conceptual Practices of Power: A Feminist Sociology of Knowledge*. Toronto: University of Toronto.

Smith, D.E. (1987) *The everyday world as problematic: A feminist sociology*. Toronto: University of Toronto Press.

Smith, D.E. (2002) Institutional Ethnography. In: May, T. (ed) (2002) *Qualitative Research in Action*. London: Sage.

Smith, D.E. (2005) *Institutional Ethnography: A Sociology for People*. Lanham, Maryland: Altamira Press.

Smith, D.E. (ed) (2006) *Institutional Ethnography as Practice*. Lanham, Maryland: Rowman and Littlefield.

Smith, P., Sherlaw-Jonson, C., Aritin, C., Bardsley, M. (2015) *Focus on: Hospital admissions from care homes*. Available from; http://www.health.org.uk/sites/default/files/QualityWatch_FocusOnHospitalAdmissionsFromCareHomes.pdf [accessed June 2016]

Social Care Institute for Excellence. (2004) *Terminal Care in Care Homes Report 10.*

Available from: www.scie.org.uk/publications/briefings/breifing10 [accessed 23 June 2015]

Social Care Institute for Excellence. (2013) *GP services for older people: a guide for care home managers. Guide 52.* Available from: http://www.scie.org.uk/publications/guides/guide52/[accessed Jan 2015]

Social Services Knowledge Scotland. (2011) Dementia Informed Practice Level Videos. Available from: http://www.ssks.org.uk/topics/dementia-promoting-excellence/dementia-informed-practice-level-videos.aspx [accessed June 2016]

Social Services Knowledge Scotland. (2011) Dementia Skilled – Improving Practice Learning Resource. Available from: http://www.ssks.org.uk/topics/dementia-promoting-excellence/dementia-skilled---improving-practice-learning-resource.aspx [accessed June 2016]

Spilsbury, K., Hanratty, B., McCaughan, D. (2015) *Supporting nursing in care homes: Patient care and Professional Development for Nursing Staff in Care and Nursing Homes. A Report for the RCN Foundation: University of York.* Available from: http://www.rcnfoundation.org.uk/?a=620718&now=1429088648 [accessed May 2016]

Stedeford, A. (1987) Hospice: a safe place to suffer? *Palliative Medicine* 1 (1) 73-74.

Steves, C.J., Schiff, R., and Martin, F.C. (2009) Geriatrics and care homes: perspectives from geriatric medicine departments and primary care trusts. *Clinical Medicine*. 9 (6) 528–533.

Taffet, G., Teasdale, T., Luchi, R. (1998) In-hospital cardiopulmonary resuscitation. *JAMA*. 260 (14) 2069-2072.

Taubman-Ben-Ari, O. and Noy, A. (2010) Self-consciousness and death cognitions from a terror management perspective. *Death Studies*. 34 (10) 871-892.

The Knowledge Network Scotland. (2011) Module 3: Promoting Health and Wellbeing for People with Dementia. Available from: http://www.knowledge.scot.nhs.uk/media/5222798/dementia%20skilled%20final_1_module3.pdf [accessed June 2016]

The Mid Staffordshire NHS Foundation Trust. (2013) Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry: Executive Summary. Available from: http://webarchive.nationalarchives.gov.uk/20150407084003/http://www.midstaffspublicinquiry.com/report [accessed June 2016]

Thomas, K. (2003) *Caring for the Dying at Home*. Abingdon: Radcliffe Medical Press.

Tomlinson, T. and Brody, H. (1990) Futility and the ethics of resuscitation. JAMA. 264 (10) 1276–1280.

Townsend, S.C. and Hardy, J. (2008) End-of-life decision-making in intensive care: The case for an international standard of care? *Internal Medicine Journal*. 38 (5) 303-304.

Triplett, P., Black, B. S., Phillips, H., Richardson, Fahrendorf, S., Schwartz, J., Angelino, A. F., Rabins, P. V. (2008) Content of advance directives for individuals with advanced dementia. *Journal of Aging and Health*. 20 (5) 583-596.

Tschanz, J.T., Corcoran, C., Schooq, I., Khachaturian, A.S., Herrick, J., Hayden, K.M., Welsh-Bohmer, K.A., Calvert, T., Norton, M.C., Zandi, P. and Breitner, J.C. Cache County Study Group (2004) Dementia: The leading predictor of death in a defined elderly population: the Cache County Study. *Neurology,* 62 (7)1156-1162.

Turner, M., Payne, S. and Froggatt, K. (2009) All tooled up: an evaluation of end of life care tools in care homes in North Lancashire. *End of Life Care*. 3 (4) 59.

Turner, S.M. (2006) Mapping Institutions as Work and Texts. In: Smith, D. (ed) (2006) *Institutional Ethnography as Practice*. Maryfield: Rowman and Littlefield Publishers.

Tyrer, F., Williams, M., Feathers, L, Faull, C., and Baker, I. (2009) Factors that influence decisions about cardiopulmonary resuscitation: The views of doctors and medical students. *Postgraduate Medical Journal*. 85 (1009) 564-568.

University of Oregon. (2010) *Institutional Ethnography*. Available from: https://www.youtube.com/watch?v=1RI2KEy9NDw [accessed June 2016]

Urberg, M., Ways, C. (1987) Survival after cardiopulmonary resuscitation for an in-hospital cardiac arrest. *Journal of Family Practice*. 25 (1) 41-44.

Van de Glind, E.M.M., Van Munster, B.C., Van De Wetering, F.T., Van Delden, J.M., Scholten, R.J.P.M. and Hooft, L. (2013) Pre-arrest predictors of survival after resuscitation from out-of-hospital cardiac arrest in the elderly: a systematic review. *BMC Geriatrics*. Geriatrics. 13 68.

Vandervoort, A., Van Den Block, L., Van Der Steen, J.T. Van Der Stichele, R., Bilsen, J. and Deliens, L. (2012) Advance directives and physicians' orders in nursing home residents with dementia in Flanders, Belgium: prevalence and associated outcomes. *International Psychogeriatrics* 24 (7) 1133-1143.

Vandrevala, T., Hampson, S.E., Daly, T., Arber, S. and Thomas, H. (2006) Dilemmas in decision-making about resuscitation - a focus group study of older people. *Social Science and Medicine*. 62 (7) 1579-1593.

Watson, J., Hockley, J. and Dewar, B. (2006) Barriers to implementing an integrated care pathway for the last days of life in nursing homes. *International Journal of Palliative Nursing*. 12 (5) 234-240.

Watson, J., Hockley, J. and Murray, S.A. (2010) Evaluating effectiveness of the GSFCH and LCP in care homes. *End-of-life Care* 4 (3) 42-49.

Wendler, D. and Rid, A. (2011) Systematic Review: The Effects on Surrogates of Making Treatment Decisions for Others. *Annals of Internal Medicine*. 154 (5) 336-346.

Whitney, D., and Trosten-Bloom, A. (2003) *The power of appreciative inquiry: A practical guide to positive change*. California: Berrett-Koehler Publishers, Inc.

World Health Organisation. (1990) *Cancer Pain Relief and Palliative Care. Technical Report Series 804*. Geneva: WHO.

World Health Organisation. (1996) *Cancer pain relief. With a guide to opioid availability* 2nd ed. Geneva. WHO.

World Health Organisation. (2002) *National Cancer Control Programs: Policies and Managerial Guidelines*. 2nd ed. Geneva: World Health Organisation.

World Health Organisation. (2002) *Definition of Palliative Care*. Geneva: World Health Organisation.

World Health Organisation. (2004) *Palliative Care: the solid facts*. Geneva: World Health Organisation.

World Health Organisation. (2011) *Palliative Care for Older People: Better practices*. Geneva: World Health Organisation.

World Health Organisation. (WHO) (2014) *Global Atlas of Palliative Care*. Available from: http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf [accessed June 2016]

World Health Organisation. (WHO) (2014) *Press release: First ever global atlas identifies unmet need for palliative care*. Available from: http://www.who.int/mediacentre/news/releases/2014/palliative-care-20140128/en/ [accessed June 2016]

World Health Organisation. (WHO) (2014) *The top 10 causes of death: Factsheet No 310*. Available from: http://www.who.int/mediacentre/factsheets/fs310/en/ [accessed June 2014]

World Health Organisation. (2016) *Definition of Palliative Care*. Available from: http://www.who.int/cancer/palliative/definition/en/ [accessed Feb 2016]

Xie, J., Brayne, C., Matthews, F.E. and Medical Research Council Cognitive, Function and Ageing Study Collaborators. (2008) Survival times in people with dementia: analysis from population based cohort study with 14 year follow-up. *British Medical Journal*. 336 (7638) 258-262.

Youngner, S. J. (1987) Do-not-resuscitate orders: No longer secret, but still a problem. *Hastings Centre Report* 17 (1) 24-33.

Zheng, L., Finucane, A., Oxenham, D., McLoughlin, P., McCutcheon. H, and Murray, S.A. (2013) How good is UK primary care at identifying patients for generalist and specialist palliative care: a mixed methods study. *European Journal of Palliative Care*. 20 (5). Available from: https://www.researchgate.net/publication/260042262_How_good_is_UK_primary_care_at_identifying_patients_for_generalist_and_specialist_palliative_care_a_mixed_methods_study [accessed June 2016]

Zoll, P.M., Linenthal, A.J., Gibson, W., Paul, M.H., Norman, L.R. (1956) Termination of ventricular fibrillation in man by externally applied electric countershock. *New England Journal of Medicine*. 254 (16) 727-732.

Zorza, V. and Zorza, R. (1978) *Death of a Daughter*. The Guardian Weekly 12 Feb, p118.

Zorza, V. and Zorza, R. (1981) *A Way to Die: Living to the End*. London: Sphere.

Zuliani, G. Galvani, M., Prendini, S., Boari, B., Buerzoni, F., and Gallarani, M. (2011) Discharge diagnosis and co morbidity profile in hospitalized older patients with dementia. *International Journal of Geriatric Psychiatry,* 27 (3) 313-20.

Appendices (in Volume Two)

The Social Organisation of Exclusion, *"Abandonment"* and Compulsory Advance Care Planning Conversations:

How Ruling Concepts and Practices about Death, Dying and the *Do Not Attempt Cardiopulmonary Resuscitation* form entered, organised and ruled the working practices of Senior Social Care Workers in a Residential Care Home in Scotland: An Institutional Ethnography

(Volume Two: Appendices)

By

Lorna Margaret Reid

A thesis submitted in partial fulfilment of the requirements of Edinburgh Napier University, for the award of Doctor of Philosophy

March 2017

Appendix 1: SPAR

1

Identification of Need for Enhanced Support and Palliative Care 2010
Supportive and Palliative Action Register

Patient Name **Care Home** **Date Commenced:**

FAILING RATE Minimal GREEN Monthly review	Date																												
Palliative Performance Scale	Score																												

FAILING RATE Moderate AMBER Weekly review	Date																												
Palliative Performance Scale	Score																												

FAILING RATE Rapid / Major RED Daily review	Date																												
LCP																													
Palliative Performance Scale	Score																												

19.10.10

Euan Paterson and Jacquelyn Chaplin

Assessment of Severity and Speed of Change - Failing Rate	Action
GREEN No major change in physical and/or mental status over last month and care needs remain stable	GREEN Review every month or sooner if significant or sudden change Continue to provide optimum management of long term conditions
AMBER Sign of irreversible impairment – moderate and/or slow decline e.g. ♦ history of recent fall(s) ♦ recent infection ♦ slight weight loss despite nutritional supplements ♦ lack of interest in usual activities e.g. socialising Rate of decline month by month Decline in Palliative Performance Score and Admission to hospital is not appropriate	AMBER Discuss deterioration with family – agree plans for management/care of resident - to potential outcomes ♦ Improves ♦ Maintains current functional status ♦ Continues to deteriorate Review weekly or sooner if sudden deterioration Revise Supportive and Palliative Action Register (SPAR) Consider commencing / updating Anticipatory/Advance Care Plan Discuss with GP completion of ♦ Out of Hours Handover/ ePCS ♦ DNA- CPR ♦ RN VOED form
RED Rapid severe day by day deterioration OR Significant and/or accelerating deterioration where extent of reversible deterioration is uncertain or unlikely e.g. ♦ history of recent fall(s) ♦ repeated infections ♦ reduced food/ fluid intake ♦ weight loss ♦ lack of interest in life e.g. staying in bed Rate of decline week by week Further or significant decline in Palliative Performance Score and Admission to hospital is not appropriate -------------------------------- IF CLINICAL JUDGEMENT INDICATES RESIDENT IS DYING	RED Discuss deterioration with family - prepare for possibility of imminent death/recovery - agree plans for management/ care of resident - potential outcomes ♦ Improves ♦ Maintains current functional status ♦ Continues to deteriorate Review daily or more often according to clinical need Revise Supportive and Palliative Action Register (SPAR) Commence / update Anticipatory/Advance Care Plan Discuss with GP completion of ♦ Out of Hours Handover/ ePCS ♦ DNA- CPR ♦ RN VOED form -------------------------------- COMMENCE LCP – REVIEW REGULARLY

Appendix 2: SPAR Guidance

2

CHANGING NEEDS IN PALLIATIVE CARE
SUPPORTIVE AND PALLIATIVE ACTION REGISTER

INTRODUCTION

Palliative care is care that improves the quality of life for patients and their families facing the problems associated with life-limiting illness. It focuses on the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain, other physical symptoms and any additional problems including psychosocial and spiritual concerns.

Anticipatory/Advance Care Planning

As you will be aware a very important part of all care is to think ahead to what is likely to happen and what might happen. Basically this is about considering probability and possibility and is talked of increasingly as Anticipatory/Advance Care Planning. This is particularly important when people need more support as they begin to fail and start to approach the end of their life. In turn this helps professional carers to prioritise their time as they are more aware of who they need to be concerned about and also who, to a certain extent, needs less of their time.

Why Recognising Change Matters

The key to developing a meaningful Anticipatory/Advance Care Plan is to recognise which of your residents are beginning to fail and thus have increasing care needs. It may be that the recognition that a resident is failing alerts you to that person's increasing needs or it may be the other way around and the recognition that someone's care needs are greater alerts you to the fact that they are beginning to approach the end of their life. The speeds with which these changes occur are frequently very important. Someone who seems to be failing very slowly is likely to continue to do so whereas someone whose care needs increasing daily is likely to continue to deteriorate rapidly. This failing rate and changing need in turn can suggest to some extent how long you might expect the person to live for.

Diagnosing 'Dying' - Approaching the End of Life

As a person fails and begins to approach the end of their life there are a number of care issues that should be considered. Knowing the resident's and their family and loved ones wishes is extremely helpful in making sure that the care at this time is appropriate for the individual.
There is a need to make sure that the other Health Care Professionals involved are aware of the person's changing need e.g. the GP, the Care Home Liaison Nurse and the Out of Hours Services. Professional carers should consider what might happen as well as what is likely to happen and plan accordingly. One important matter to consider is the most appropriate place for the continued care of the resident and in particular whether the resident's care needs can best be met in the Care Home rather than in Hospital. It is also vital that the resident and their family are as aware as is practical of the deterioration and indeed the possible closeness of death.
It is attention to matters such as these that makes up a good Anticipatory/Advance Care Plan.

Levels of Supportive and Palliative Need

We would suggest that you divide your residents into three broad categories:

- **Rate of deterioration nil / minimal – 'Green'** - Those who do not appear to be failing or who are failing very slowly, whose needs do not appear to be changing and who hardly seem any different over a number of months. In this situation it is likely that the resident's life expectancy can probably be estimated in a large number of months if not years. This group's requirement for supportive and palliative care is fairly small.
- **Rate of deterioration moderate – 'Amber'** - Those who are noticeably failing and whose care needs are increasing and who seem to be noticeably deteriorating but in a fairly slow manner, perhaps over a few weeks to a month. It may be that you might expect a resident in

this category to survive for a few months (e.g. 3 -6 months). This group's supportive and palliative care needs should be assessed.

- **Rate of deterioration rapid / major - 'Red'** - Those who are failing quickly, whose care needs are increasing equally quickly and who are deteriorating rapidly. In this situation death might be anticipated in just a few weeks (or even a few days). This group have a high level of need for supportive and palliative care.

The most important point is that there is **evidence of changing need** as a result of **irreversible deterioration.**

HOW TO DO THIS

Overview

There are four aspects that are worth considering

- What disease / condition the resident has
- Their current wellbeing and what they are able to do
- How quickly they are deteriorating
- The 'Surprise question'

Disease / Condition

The first thing to consider is what disease or diseases does the person suffer from.
As all professional carers have seen, some diseases can lead to death very quickly (e.g. widespread cancer), some have a slower but still quite clear deterioration (e.g. chronic lung disease) whilst other conditions seem to go on for ever (e.g. dementia)!

Wellbeing / Ability

What the resident is able to do, their functional status, has been shown to have a significant bearing on their predicted survival.

Several scales have been developed to categorise people according to their level of need and this in turn can help to predict how long they might be expected to live for. One such scale is the Palliative Performance Scale (PPS).

PALLIATIVE PERFORMANCE SCALE (PPS)

%	Ambulation	Activity / evidence of disease	Self care	Intake	Level of consciousness
100	Full	Normal activity No evidence of disease	Full	Normal	Full
90	Full	Normal activity Some evidence of disease	Full	Normal	Full
80	Full	Normal activity with effort Some evidence of disease	Full	Normal or reduced	Full
70	Reduced	Unable to do normal job/work Some evidence of disease	Full	Normal or reduced	Full
60	Reduced	Unable to do hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or confusion
50	Mainly sit/lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or confusion
40	Mainly in bed	As above	Mainly assistance	Normal or reduced	Full or drowsy or confusion
30	Totally bed bound	As above	Total care	Reduced	Full or drowsy or confusion
20	As above	As above	Total care	Minimal sips	Full or drowsy or confusion
10	As above	As above	Total care	Mouth care only	Drowsy or coma
0	Death	-	-	-	-

All of the aspects in the PPS should be easy to assess by staff working in a care home.

PPS rating has been shown to be quite accurate in people dying with cancer e.g. a study has shown that only about 10% of people with a score of 50% or below would be likely to survive for more than 6 months. However the majority of patients looked after in care homes are not dying of cancer and may well have a very low PPS and yet live for many months. To be useful in the care home population the person's level of need must be linked to the speed of their decline.

Speed of Deterioration / How Quickly a Resident is Failing

By and large if patients / residents seem to be failing quite quickly then the decline is likely to continue at that pace whereas a slow decline continues quite slowly - rapid changes tend to continue rapidly and slow changes tend to continue slowly. All care home staff will know residents who have required virtually total care for many months and also frail residents who suddenly go down hill, deteriorate on an almost daily basis decline and die within a very few days e.g. a pneumonia in someone suffering with dementia.

The Surprise Question

Another matter to consider is quite simply the 'feeling' that the various people involved in the care of the resident have about that persons approximate length of survival. This is often referred to as the 'surprise question' - e.g. 'Would you be surprised if the person was to die within the next six months?'. Though this might seem slightly casual there is evidence that it can be quite accurate and again that it is something that everyone can make an attempt at.

Stabilisation

In categorising your residents / patients what is important is speed of change. If someones deterioration is moderate then they would be in the 'amber' category. If they then stabilise and their deterioration is minimal they would move back to 'green' even if there care needs remained high. SPAR is about recognising change in need.

Team Involvement

As with all important clinical matters it is important that as many of the professional care team as possible are involved in assessing the patients changing needs and likely survival time - all the care home staff have a significant role in this process.

The Liverpool Care Pathway for the Dying (LCP)

Finally mention must be made of the Liverpool Care Pathway for the Dying. This is a specific tool designed to help predict and then aid the management of a persons last few days of life. This is currently being implemented throughout NHS Greater Glasgow and Clyde Board area. The full implementation of this pathway is beyond the scope of this project. However the use of the Supportive and Palliative Register can assist identification of deterioration that may ultimately result in the use of the LCP.

Summation

Using your knowledge of how different conditions usually progress, combined with an assessment of the resident's needs and an awareness of how rapidly the resident is failing should ensure that the supportive and palliative care needs of each resident is assessed. This raised awareness then allows these needs to be addressed.

PROCESS

Initial Categorisation

- Review all residents
- Consider
    - Their functional condition
    - Their rate of change / how quickly they appear to be failing
    - The 'surprise question'
- Discuss with all staff involved with the residents care
- Assign them to one of the three categories
    - Green - Those whose condition and their need for palliative care is not changing - may also be expected to live for six months or more
    - Amber - Those whose condition is deteriorating (probably due to irreversible causes) and whose need for palliative care is clearly changing - may be expected to live for a few months
    - Red – Those who have had sustained irreversible decline or sudden severe irreversible decline – may be expected to live for a few weeks
- Code their care plan records

What to do next

Clearly the highest priority group are likely to be those whose survival is thought to be measured in weeks.

- **Rate of deterioration nil / minimal - Green:**
    - Reassess monthly or
    - If any sudden change
- **Rate of deterioration moderate – 'Amber':**
    - Discuss with Care Home Liaison Nursing Service / General Practitioner
    - Consider need for OOH handover form
    - Discuss deterioration and implications with family
    - Preferred priorities of care - Advance/Anticipatory Care Plan
        - Capacity issues
        - Most appropriate place for care
        - DNA CPR status
    - Reassess every week or
    - If any sudden change
- **Rate of deterioration rapid / major – 'Red':**
    - Discuss with Care Home Liaison Nursing Service / General Practitioner
    - Consider need for OOH handover form
    - Discuss deterioration and implications with family
    - Awareness of likely survival length / possibility of imminent death / possibility of improvement
    - Preferred priorities of care - Advance/Anticipatory Care Plan
        - Capacity issues
        - Most appropriate place for care
        - DNA CPR status
    - Preferred priorities of care
        - Are the resident's wishes known?
        - Are the family / loved one's / next of kin's wishes known?
        - Who might be best placed to look into this issue?
    - Review daily or more frequently according to clinical need
    - Consider possible need for Liverpool Care Pathway for the Dying

Appendix 3: Palliative Performance Scale

3

Victoria Hospice

Palliative Performance Scale (PPSv2) version 2

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity with Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

Instructions for Use of PPS (see also definition of terms)

1. PPS scores are determined by reading horizontally at each level to find a 'best fit' for the patient which is then assigned as the PPS% score.

2. Begin at the left column and read downwards until the appropriate ambulation level is reached, then read across to the next column and downwards again until the activity/evidence of disease is located. These steps are repeated until all five columns are covered before assigning the actual PPS for that patient. In this way, 'leftward' columns (columns to the left of any specific column) are 'stronger' determinants and generally take precedence over others.

   Example 1: A patient who spends the majority of the day sitting or lying down due to fatigue from advanced disease and requires considerable assistance to walk even for short distances but who is otherwise fully conscious level with good intake would be scored at PPS 50%.

   Example 2: A patient who has become paralyzed and quadriplegic requiring total care would be PPS 30%. Although this patient may be placed in a wheelchair (and perhaps seem initially to be at 50%), the score is 30% because he or she would be otherwise totally bed bound due to the disease or complication if it were not for caregivers providing total care including lift/transfer. The patient may have normal intake and full conscious level.

   Example 3: However, if the patient in example 2 was paraplegic and bed bound but still able to do some self-care such as feed themselves, then the PPS would be higher at 40 or 50% since he or she is not 'total care.'

3. PPS scores are in 10% increments only. Sometimes, there are several columns easily placed at one level but one or two which seem better at a higher or lower level. One then needs to make a 'best fit' decision. Choosing a 'half-fit' value of PPS 45%, for example, is not correct. The combination of clinical judgment and 'leftward precedence' is used to determine whether 40% or 50% is the more accurate score for that patient.

4. PPS may be used for several purposes. First, it is an excellent communication tool for quickly describing a patient's current functional level. Second, it may have value in criteria for workload assessment or other measurements and comparisons. Finally, it appears to have prognostic value.

Palliative Performance Scale (PPSv2) version 2. *Medical Care of the Dying, 4th ed.*; p. 120. ©Victoria Hospice Society, 2006.

Victoria Hospice

Palliative Performance Scale (PPSv2) version 2

Definition of Terms for PPS

As noted below, some of the terms have similar meanings with the differences being more readily apparent as one reads horizontally across each row to find an overall 'best fit' using all five columns.

1. Ambulation

The items '**mainly sit/lie**,' '**mainly in bed**,' and '**totally bed bound**' are clearly similar. The subtle differences are related to items in the self-care column. For example, 'totally bed 'bound' at PPS 30% is due to either profound weakness or paralysis such that the patient not only can't get out of bed but is also unable to do any self-care. The difference between 'sit/lie' and 'bed' is proportionate to the amount of time the patient is able to sit up vs need to lie down.

'**Reduced ambulation**' is located at the PPS 70% and PPS 60% level. By using the adjacent column, the reduction of ambulation is tied to inability to carry out their normal job, work occupation or some hobbies or housework activities. The person is still able to walk and transfer on their own but at PPS 60% needs occasional assistance.

2. Activity & Extent of disease

'**Some**,' '**significant**,' and '**extensive**' disease refer to physical and investigative evidence which shows degrees of progression. For example in breast cancer, a local recurrence would imply 'some' disease, one or two metastases in the lung or bone would imply 'significant' disease, whereas multiple metastases in lung, bone, liver, brain, hypercalcemia or other major complications would be 'extensive' disease. The extent may also refer to progression of disease despite active treatments. Using PPS in AIDS, 'some' may mean the shift from HIV to AIDS, 'significant' implies progression in physical decline, new or difficult symptoms and laboratory findings with low counts. 'Extensive' refers to one or more serious complications with or without continuation of active antiretrovirals, antibiotics, etc.

The above extent of disease is also judged in context with the ability to maintain one's work and hobbies or activities. Decline in activity may mean the person still plays golf but reduces from playing 18 holes to 9 holes, or just a par 3, or to backyard putting. People who enjoy walking will gradually reduce the distance covered, although they may continue trying, sometimes even close to death (eg. trying to walk the halls).

3. Self-Care

'**Occasional assistance**' means that most of the time patients are able to transfer out of bed, walk, wash, toilet and eat by their own means, but that on occasion (perhaps once daily or a few times weekly) they require minor assistance.

'**Considerable assistance**' means that regularly every day the patient needs help, usually by one person, to do some of the activities noted above. For example, the person needs help to get to the bathroom but is then able to brush his or her teeth or wash at least hands and face. Food will often need to be cut into edible sizes but the patient is then able to eat of his or her own accord.

'**Mainly assistance**' is a further extension of 'considerable.' Using the above example, the patient now needs help getting up but also needs assistance washing his face and shaving, but can usually eat with minimal or no help. This may fluctuate according to fatigue during the day.

'**Total care**' means that the patient is completely unable to eat without help, toilet or do any self-care. Depending on the clinical situation, the patient may or may not be able to chew and swallow food once prepared and fed to him or her.

4. Intake

Changes in intake are quite obvious with '**normal intake**' referring to the person's usual eating habits while healthy. '**Reduced**' means any reduction from that and is highly variable according to the unique individual circumstances. '**Minimal**' refers to very small amounts, usually pureed or liquid, which are well below nutritional sustenance.

5. Conscious Level

'**Full consciousness**' implies full alertness and orientation with good cognitive abilities in various domains of thinking, memory, etc. '**Confusion**' is used to denote presence of either delirium or dementia and is a reduced level of consciousness. It may be mild, moderate or severe with multiple possible etiologies. '**Drowsiness**' implies either fatigue, drug side effects, delirium or closeness to death and is sometimes included in the term stupor. '**Coma**' in this context is the absence of response to verbal or physical stimuli; some reflexes may or may not remain. The depth of coma may fluctuate throughout a 24 hour period.

Palliative Performance Scale (PPSv2) version 2. *Medical Care of the Dying, 4th ed.*; p. 121. ©Victoria Hospice Society, 2006.

Appendix 4: PEPSI COLA Aide Memoire

4

PEPSI COLA Aide Memoir – Palliative Care monthly checklist

SCR4

Patients Name ______________________ **Completed by** ______________________ **Date started** __________ **Lead GP** ______________

	Date	Date	Date	Date	Date	Date
P -Physical Symptom control Medication - regular & PRN Compliance / stopping non-essentials Complementary therapies						
E -Emotional Understanding expectations Depression and adjustment Fears /Security Relationships						
P -Personal Spiritual / religious needs Inner journey Quality of life Pt/carer's agenda						
S -Social Support Benefits/Financial Care for carers Practical support						
I –Information/ Communication Within PHCT Between professionals To and from patient To and from carers						
C -Control Choice, dignity Treatment options/ Management Plan Advanced directive Place of death						
O -Out of Hours/ Emergency Continuity Communication to out of hours/pts/carers Carer support Medical support Drugs and equipment						
L -Late End of life/Terminal care Stopped non-urgent Rx Patient and family aware Comfort measure Spiritual care Rattle, agitation						
A -Afterwards Bereavement Follow-up/others informed Family support Assessment/Audit Support team						

Appendix 5: Journal Article

5

Appendix 6: Interview Schedule

6

Toward understanding how palliative care is organised for older adults with dementia who are living and dying in residential care homes in Scotland

Semi- Structured Interview Schedule

Introduction and explanation of the purpose of the interview

Thank you for being willing to take part in this interview. The interview is part of a research project I am doing in partial fulfilment of a Master of Research award, with the University of the West of Scotland. I am trying to understanding how palliative care is organised for older adults with dementia who are living and dying in residential care homes in Scotland.

Can I first of all assure you that you will remain completely anonymous and no records of the interview will be kept with your name on them.

I am trying to understand the work of organising palliative care in residential care homes. I have never worked in a residential care home, and so I don't know how that comes about. You are the expert. You may find some of the questions silly, or difficult to answer, but you are not to worry about trying to tell me the "right" answer. I am not testing you; and so I am only interested in your personal experience and thoughts.

Please feel free to interrupt, to ask for clarification if you don't understand what I am asking you, or criticise the line of questioning.

Tell interview participant about myself:

- *Background*
- *Training*
- *Interest in area of enquiry*

What I would like to find out about today falls under three categories:

- *Admission to (name of care home),*
- *Organising care for a resident whose health is deteriorating,*
- *Organising care for a person who is dying.*

I will ask you first to describe the work you do. Then I will ask you about the documents that are used to help you plan and organise care.

Toward understanding how palliative care is organised for older adults with dementia who are living and dying in residential care homes in Scotland

Warm up questions

1. Can I first of all ask you to tell me a bit about your role here at (name of care home)?
2. Can you describe a typical day here at (name of care home)?

Admission to the service

3. Can you tell me how a person comes to live here at (name of care home)?
    a. What texts/documents are used?
    b. How to they come to the participant?
    c. Where does it go after the participant is finished with it?
    d. What does the participant need to know to fill the document out?
    e. How this document intersects with/depends on other documents and written processes as sources of information?

4. Can you explain the work which is involved when a person first comes to live here at (name of care home), including assessment of symptoms which could cause discomfort?
    a. What documents are used?
    b. How do they come to the participant?
    c. Where does it go after the participant is finished with it?
    d. What does the participant need to know to fill the document out?
    e. How does this document intersect with/depend on other documents and written processes as sources of information?

5. Can you tell me about any future planning, or thinking ahead, that is done on admission to (name of care home)?
    a. What documents are used?
    b. How do they come to the participant?
    c. Where does it go after the participant is finished with it?
    d. What does the participant need to know to fill the document out?
    e. How does this document intersect with/depend on other documents and written processes as sources of information?

Health deterioration

6. Can you describe the work involved in noticing deterioration in a resident's health?
    a. What documents are used?
    b. How do they come to the participant?
    c. Where does it go after the participant is finished with it?
    d. What does the participant need to know to fill the document out?
    e. How does this document intersect with/depend on other documents and written processes as sources of information?
7. Can you describe the work involved in responding to deterioration in a resident's health, including making sure residents are not experiencing uncomfortable symptoms?
    a. What documents are used?
    b. How do they come to the participant?
    c. Where does it go after the participant is finished with it?
    d. What does the participant need to know to fill the document out?
    e. How does this document intersect with/depend on other documents and written processes as sources of information?

8. Can you tell me about any future planning, or thinking ahead, that is done when a resident's health begins to deteriorate?
    a. What documents are used?
    b. How do they come to the participant?
    c. Where does it go after the participant is finished with it?
    d. What does the participant need to know to fill the document out?
    e. How does this document intersect with/depend on other documents and written processes as sources of information?

Dying

9. Can you describe the work that is involved in recognising that a resident may be dying?
    a. What documents are used?
    b. How do they come to the participant?
    c. Where does it go after the participant is finished with it?
    d. What does the participant need to know to fill the document out?
    e. How does this document intersect with/depend on other documents and written processes as sources of information?
10. Can you describe the work that is involved in responding the signs of dying, including making sure that residents are not experiencing uncomfortable symptoms?
    a. What documents are used?
    b. How do they come to the participant?
    c. Where does it go after the participant is finished with it?
    d. What does the participant need to know to fill the document out?
    e. How does this document intersect with/depend on other documents and written processes as sources of information?

11. Can you describe a case when you were satisfied that a resident was supported to achieve a dignified death?

12. On reflection can you say what made it a good experience?
13. Can you describe a case when you were not satisfied that a resident was supported to achieve a dignified death?
14. On reflection, can you say what made it a difficult experience?

Cooling down

15. What aspects of palliative care – from admission, through the period when a person's health is declining, and into the dying phase - do you think you do well here at (name of care home)?
16. Is there something else that you would like to tell me about the experience of organising palliative care for older adults with dementia that we have not covered in this interview?

Close

Thank you very much for helping me, and giving up your time. Your responses have been very helpful.

Outline next steps:

- *Gathering data from other participants*
- *Analysing data*
- *Presenting findings – invitation to attend meeting for research participants*
- *Contact details*
- *Permission to contact participant again if necessary*
- *Thanks and close*

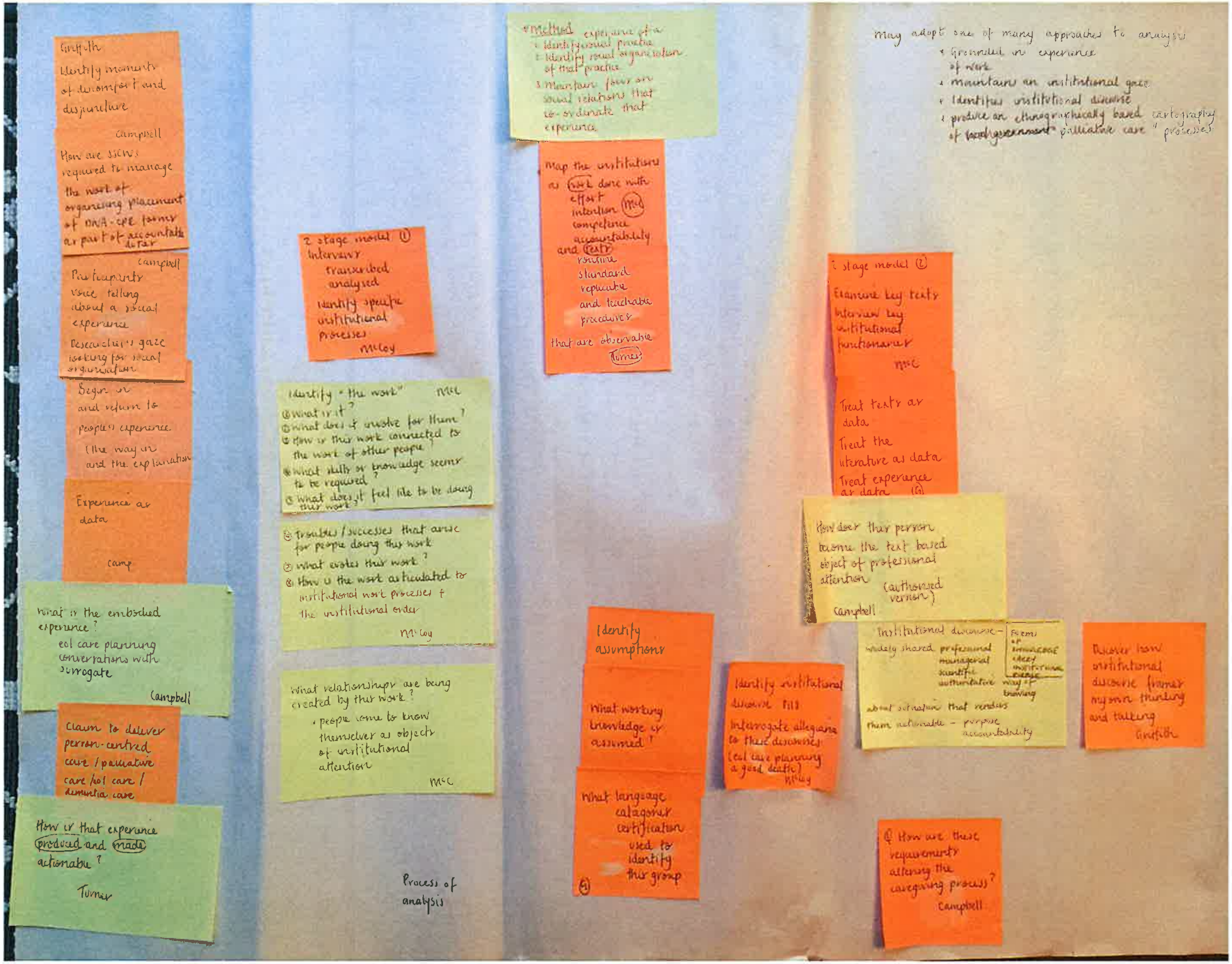
Appendix 7: Do Not Attempt Cardiopulmonary Resuscitation (DNACPR): Integrated Adult Policy

Scottish Government. (2010) *Do Not Attempt Cardiopulmonary Resuscitation (DNACPR): Integrated Adult Policy*. Available from: http://www.healthcareimprovementscotland.org/our_work/person-centred_care/dnacpr.aspx [accessed June 2016)].

7

Appendix 8: Developing a Protocol

8



Griffith
Identify moments of discomfort and disjuncture

Campbell
How are SICWs required to manage the work of organising placement of DNA-CPR forms as part of accountable duties

Campbell
Participants voice telling about a social experience
Researcher's gaze looking for social organisation

Begin in and return to people's experience
(the way in and the explanation

Experience as data

camp

What is the embodied experience?
eol care planning conversations with surrogate

Campbell

Claim to deliver person-centred care / palliative care / eol care / dementia care

How is that experience produced and made actionable?

Turner

2 stage model ①
Interviews
transcribed
analysed
identify specific institutional processes
McCoy

Identify "the work" McC
① What is it?
② What does it involve for them?
③ How is this work connected to the work of other people?
④ What skills or knowledge seems to be required?
⑤ What does it feel like to be doing this work?

⑥ Troubles / successes that arise for people doing this work
⑦ What evokes this work?
⑧ How is the work articulated to institutional work processes & the institutional order

McCoy

What relationships are being created by this work?
• people come to know themselves as objects of institutional attention

McC

Process of analysis

*Method experience of a
1 identify actual practice
2 identify social organisation of that practice
3 maintain focus on social relations that co-ordinate that experience

Map the institutions as work done with effort intention (McC) competence accountability
and texts routine standard replicable and teachable procedures
that are observable
Turner

Identify assumptions

What working knowledge is assumed?

What language categories certification used to identify this group
⑤

Identify institutional discourse [illegible]
Interrogate allegiance to these discourses
(eol care planning a good death)
McCoy

May adopt one of many approaches to analysis
• Grounded in experience of work
• maintains an institutional gaze
• Identifies institutional discourse
• produce an ethnographically based cartography of ~~local government~~ palliative care "processes"

2 stage model ②
Examine key texts
Interview key institutional functionaries
McC

Treat texts as data
Treat the literature as data
Treat experience as data (6)

How does this person become the text based object of professional attention (authorised version)
Campbell

Institutional discourse – widely shared professional managerial scientific authoritative way of knowing
Forms of knowledge ideas institutional [illegible]
about situations that renders them actionable – purpose accountability

Discover how institutional discourse frames my own thinking and talking
Griffith

Q How are these requirements altering the caregiving process?
Campbell

What is it?

STEP ONE

Pre-assessment visit: generated by family request or social work request for admission.

Connected to the work of other people

Social worker
CARENAP document from social worker to assess and document care needs prior to admission process

Legislator / medics
ADULTS WITH INCAPACITY (2000) ACT SCOTLAND
- Section 47

Legislator
THE REGULATION OF CARE (SCOTLAND) ACT 2001

Regulator (service)
NATIONAL CARE STANDARDS
Registered with the regulator

Regulator (individuals)
SCOTTISH SOCIAL SERVICES COUNCIL
(registered as supervisor)

What does it involve?

Visit [illegible] at home, hospital or other care home to assess suitability for admission

- confirmed diagnosis of dementia
  - "all need to have a "Section 47"
- [illegible]
- consent from family + [illegible]

"the main point is the family want them to come ... it's their decision"

- arrange a date for admission for 4 week period of assessment
- family
- social worker

What skills are required?

Skills required

- Read and understand
  - CARENAP
  - Admissions Procedure
  - Checklist
  - Admission Policy
- Initiate, build and manage relationships
  - potential resident
  - family
  - social worker
  - care home colleagues
- Complete paperwork and supervise others to complete paperwork
  - assessment documents and checklists
- Initiate and manage complex conversations
  - potential resident
  - family
  - health and social care professionals
- Judge what to discuss and when based on knowledge
  - of family
  - of resident
  - of presenting needs and issues
  - of service based requirements as contained in documentation
- negotiate with
  - family
  - resident
  - other Health and social care professionals
- ~~[illegible]~~
- support decision making

THE WORK

[illegible]

What knowledge is required?

Knowledge required

condition of dementia

pre-admission process
- referral from family supported by social worker through completion of CARENAP
- eligibility for admission to this care home
  - mobility
  - behaviour
  - family wishes
  - diagnosis
- policies and procedures - internal
  - regulatory

"relevant" information to gather on pre-assessment visit

- admission process
  - how to arrange

STEP TWO

Admission into SCH for 4 week assessment period

- spiritual needs discussed / recorded
- equal opportunities explained
- dietary arrangements
- structure of day + activities discussed

contact details
- personal care, advocacy needs + health and safety discussed
- risk assessments
  - mobility
  - dependency
  - MUST
  - falls

personal belongings
choices, preferences requirements + aspirations
- private / public space discussed
- brochure given

- review process
- visiting arrangements
- medical records and information
- photo taken for file and medication chart

What does it involve?

- Arrange date for admission
- Assign a key worker
- Follow checklist (4 weeks to complete)

- Gather assessment records
- Arrange room viewing
- Identify needs
- Discuss reason for admission
- Discuss and sign contract

- Discuss complaints procedure
- Give copy of above
- Initial goals discussed agreed and set
- rights and responsibilities explained

- Copy of service user charter supplied
- Timescales for admission recorded
- Key worker identified + role explained

- Service explained
- Drug and alcohol policy explained
- charges and other T+C discussed
- Social networks recorded

- Appointees and Trustees determined and recorded
- Quality Assurance explained
- Communication systems explained

STEP THREE

Arrange a review meeting
- Family
- Key worker
- SSCW
- Social Worker

Prepare review document
- sight
- teeth
- food
- bowel / bladder control

- sleep
- daily living
- mental health
  - orientation
  - behaviour
  - previous psych involvement
- sociability

- activities
- social work input
- health service input
- community support
- assessment of needs

- planning

"being pushed to discuss" on the word of resuscitation at this point

What is it like to do this work?

"[illegible] staff [illegible] [illegible] worried about some of the new [illegible] [illegible] do it" [illegible]

"might only have met the daughter once or twice" (SSCW)

"it's a really hard thing to talk about" (SSCW)

"easier when you know the family been in for respite a lot" (SSCW)

"I told her it's a really hard decision" (SSCW)

"might need to sort something else out like a personal problem ... [illegible] transition ... now let's talk about dying"

"I hate doing it ... I'm not comfortable with it like some of the others" ([illegible])

Appendix 9: Ethics Application Form

9

Application Form for University Ethical Approval REAG1

Research Ethics Advisory Group

APPLICATION FORM FOR ETHICAL APPROVAL
(FORM REAG1)

1. Name of principal investigator(s)
Lorna Margaret Reid
BSc in Nursing Studies (Distinction), Registered General Nurse
[redacted]

School/Address
School of Nursing and Midwifery

Position
Master of Research Student/ possible progression to PhD

2. Name of supervisors
Dr. Angela Kydd Senior Lecturer [redacted]

Dr. Austyn Snowden Research Fellow [redacted]

School/Address
School of Health, Nursing and Midwifery, UWS, Paisley Campus, High Street, Paisley PA1 2BE

3. Title of study:

Towards understanding how palliative care is organised for older adults with dementia who are living and dying in residential care homes in Scotland using the principles of institutional ethnography.

4. Summary

More than 55,000 people die in Scotland each year (General Register Officer of Statistics 2006). Unlike the past, when dying was a relatively rapid response to an infectious disease, childbirth or accident, most of those who die in Scotland now will be over 65, and the majority will experience a period of illness and/or frailty before dying (Living and Dying Well 2008). For example, the number of older people who are living and dying with progressive and incurable long term conditions, like dementia, is increasing (World Health Organisation 2005). The period of decline for people with dementia often takes place over a number of years, and may lead to an increased need for support. For some this will mean admission to a nursing care home, or a residential care home, for formal long-term care.

There are three levels of care home provision in the UK. Nursing care homes provide accommodation and access to 24 hour nursing care, they are intended for those who have health needs and require regular nursing care (Bejekal 2002; Froggatt 2004). In contrast, residential care homes provide accommodation and access to 24 hour personal and social care, they are intended for those who have social needs and require social care (Dudman 2007). The third level of care home provision is NHS continuing care, which provides more complex nursing care in a care home or a long-stay institution.

In the past older people who lived in residential care homes were less dependent and had fewer health needs than those older people who lived in nursing care homes. However, recent research suggests that this is no longer the case. Residents in both settings are becoming increasingly frail and disabled, with complex co-morbidities and often high levels of cognitive impairment (Bowman et al 2004; Froggatt et al 2009; Laing and Buisson 2009). Indeed one study highlights that older adults living in residential care homes now have health needs which are broadly equivalent to those who would more traditionally have been cared for in nursing care homes (Goodman et al 2010).

Most decisions to move into a care home are not based on a need for end of life care, nevertheless 21% of all deaths in the over 65 age group in the UK take place in a care home (Froggatt 2004; Social Care Institute for Excellence (SCIE 2000). As people approach the final phase of life they may experience symptoms such as pain, breathlessness, fatigue, anxiety and depression (Royal College of Physicians 2007). This suggests that, there could be a significant number of older adults who are living and dying in care homes with increased health needs as they reach the end of their lives. Health needs include palliative needs.

Palliative care is defined by the World Health Organisation (WHO) as an:

> "approach that improves the quality of life for patients and their families facing the problems associated with life-threatening illnesses, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual" (WHO 2004b, p14).

Originally, palliative care was focussed on patients, and their families, in the final stage of a cancer journey, but it has been broadened to include anyone who has a life-threatening illness which cannot be cured. This includes non-malignant conditions like dementia, heart failure and stroke among others. Palliative care can be provided at any stage of a person's illness; it is not limited to those who are imminently dying.

Palliative care could include a range of interventions such as symptom control, psychological and emotional support, physiotherapy and complementary therapies. These interventions aim to support patients and their families to obtain the best quality of life possible throughout the course of their illness. They also aim to promote the best possible conditions for a good death. A good death is conceptualised as one in which the wishes of the patient and his/her family are honoured and respected (Audit Scotland 2008).

The contemporary literature embraces a broad definition of palliative care, however, in clinical practice it is often only associated with end stage cancer care. This leads to significant confusion about who could benefit from this approach to their care, and when. Some of this confusion comes from misunderstanding about related concepts which include: hospice care, general palliative care, specialist palliative care, end of life care, terminal care, and supportive care. The term "palliative care" is often interchanged with the terms "end of life care" or "terminal care". This can lead to associating palliative care only with the care of the dying person, which in turn produces delays in carrying out the practical tasks of organising pro-active care for people who are not imminently dying (Meghani 2004), but who could benefit from the promotion of comfort through effective symptom management. For example, retrospective research suggests that during the final six months of life people with dementia may experience pain and other distressing symptoms in similar degrees to those who are in the final six months of life with cancer. A significant number of care home residents have dementia. But, often people who are living and dying with dementia do not have access to the same level of support as people who are living and dying with cancer (McCarthy et al 1997; Hirakawa et al 2006). Despite a growing body of evidence about symptom burden, people with dementia are not always recognized as having a life-limiting condition which could benefit from a palliative approach (Mitchell et al 2004). Jacqueline Morris (Chair of the British Geriatrics Society Policy Committee) et al (2007) comment in the British Medical Journal that:

> 'Both health and palliative care are often poorly organised in these settings and are associated with out of hours' crises and resultant high anxiety and unpredictability for staff and residents. The lack of clarity around clinical leadership for care homes may result in GPs only visiting when called'
> (Morris et al 2007 opinion rapid response online journal).

Failure to recognise palliative needs in this patient group will obviously deny them access to any potential advantages which a palliative approach to their care could offer. This may lead to unnecessary suffering, dignity violation and reduced quality of life (WHO 2004b) and suggests that there is a disconnect between the ideal and actual palliative care provision for older people, who are living and dying in care homes in the UK. It also raises significant concern that some of the most vulnerable members of our society are receiving sub-optimal care in the final phase of their life (Hall et al 2002; Hockley 2006).

5. What is the primary purpose of this study? (e.g. original research, audit, undergraduate dissertation, post-graduate dissertation,)

Post graduate dissertation for Master of Research award with potential progression to PhD.

6. Has the proposed study submitted to any other ethics committee?
Has approval been given?

Letter from NHS West of Scotland Ethics Research Service is included in this application (Appendix 1).

The tile of the study has changed since advice was sought, but the sample and the focus of the study is the same.

The letter states that as the quantitative data to be collected is obtained as part of usual care, and as the qualitative data seeks the views and opinions of staff on a service, this study is not intended to assess or pass judgement on professional competency. Therefore, it could be considered as a service evaluation. This means that this project does not require ethical review under the terms of the Governance Arrangements of Research Ethics Committees (REC) in the UK.

7. Scientific background to the study

Rationale for the current proposal, and its relation to other's work

It is predicted that by 2016 there could be an additional 23,000 older people who need some kind of formal care in Scotland; a figure which could rise to 83,000 by 2013. This is almost double the number of older people who were receiving formal care services in 2009 (Age Concern and Help the Aged 2009). Due to the connection between increased age and numbers with dementia a significant percentage of these people will have dementia. There are currently (in 2011) approximately 82,000 people with dementia in Scotland; again those figures are expected to rise, to 164,000 by 2036 (Alzheimer's Scotland 2011).

McCarthy et al (1997) reported a host of symptoms which are commonly experienced by people with dementia in the last year of life: confusion (83%), urinary incontinence (72%), pain (64%), low mood (61%), constipation (59%), and loss of appitite (59%). These symptoms were similar to those experienced by people with cancer in the last year of life. But, people with dementia were found to experience these difficult symptoms for longer. The implication is that the symptoms experienced in the last year of life by people with dementia are not as well managed as the symptoms experienced by people with cancer. Although neither is an easy dying, Froggat et al (2007) highlights that dying with dementia is a protracted and unglamorous affair when contrasted with the heroic "fighting against the odds" kind of dying typically associated with a cancer diagnosis. Simard (2007) comments that by the time they reach the advanced stage of the disease people with dementia become increasingly "silent and invisible" (p.484) and urges healthcare professionals to become the voice for people who have become the "voiceless ones" (p.485). So, although it is not straightforward, there is an ethical imperative to minimise the symptom burden and improve quality of life for people who are living and dying with dementia (Hughes et al 2007). This includes those who are living and dying in residential care homes.

The rising costs associated with caring for an aging population at a time of global financial uncertainty is challenging to say the least, however, the current situation leaves much to be desired. Scandals about the quality of care that is available to older adults who are living and dying in UK care homes surface with troubling regularity. The blame for this is often laid at the feed of particular practitioners, or individual care homes. This may be part of the issue, but it seems that many difficulties, such as the provision of sufficient palliative dementia care, are bigger than isolated episodes. Beliefs and routine institutional practices could be adding to the gap between what care home residents need, and what they get, from the health and social care system (Seymour et al 2011). Gaps may well extend across both nursing care and residential care settings; but it could be argued that those who are living and dying in residential care homes are potentially more at risk. There may not be significant differences between the population of older adults who are being cared for in nursing and residential care homes, but there are significant differences in the care settings. These include the healthcare knowledge and experience of the staff. However, after the publication of the "National Care Standards for Care Homes for Older People" (Scottish Executive 2001) both settings became known simply as: care homes, which has caused varying degrees of confusion among support staff who are external to the care home.

In the student's experience residential care home staff are often highly motivated and caring individuals, but it has to be remembered that their expertise lies in *social* rather than *health* care. Residential care home staff cannot be expected to recognise and manage the wide variety of complex physical and psychosocial palliative healthcare needs of residents and families in isolation. Nevertheless, most healthcare practitioners do not routinely visit residential care homes, and so residents with palliative needs are dependent upon staff recognising and accurately reporting problems to healthcare staff. However, even if problems are identified Audit Scotland (2008) report that lack of GP services to care homes in some areas may affect the quality of general palliative care which is available to care home residents.

Improving palliative dementia care for older adults in residential care homes is both an academic and a clinical challenge for health and social care professionals. There have been a number of UK studies since the 1990's which have focused on the provision of palliative care in care homes. A high percentage of these have been carried out in nursing care homes, where there is access to a nurse 24 hours a day. There are limited studies which focus on palliative dementia care in residential care homes. Additionally, many of the studies in care homes with a palliative focus have been carried out in England. England has different regulatory frameworks, funding streams and policy initiatives to guide and support palliative care than those in Scotland. This means that the findings from previous studies of palliative care for older adults living and dying in care homes may not be directly transferable to residential care homes in Scotland. For this reason research that explores how palliative care is organised for older adults with dementia who are living and dying in residential care homes in Scotland is urgently needed.

8. Aims

This project aims to explore how palliative care is organised for older people with dementia who are living and dying in residential care homes in the west of Scotland.

9. Sample (including criteria for subject inclusion/exclusion):

It is difficult to know beforehand exactly who will be involved in data collection. DeVault and McCoy (2002) emphasise the open-ended nature of the process of inquiry by stating that:

“Institutional Ethnography investigations are rarely planned out fully in advance, identifying research sites, informants, texts to analyse, or even questions to pursue with informants. Instead the process of inquiry is rather like grabbing a ball of string, finding a thread, and then pulling it out; that is why it is difficult to specify in advance exactly what the research will consist of. The researcher knows what she wants to explain, but only step by step does she know who she needs to interview, or what texts and discourses she needs to examine.” (DeVault and McCoy 2002, p. 755).

Snowball sampling will be employed that is, one participant may recommend another person to interview That said, participants for this study will most likely be from among the following group:

- residential care home staff of all grades working in care homes in the west of Scotland,
- health and social care staff who support these care homes, including District Nurses and General Practitioners.
- health and social care staff from the wider system which may include General Practioners, District Nurses, Care Commission staff, Specialist Palliative Care staff, Community Psychiatric Nurses, NHS 24 staff, Service Directors, Community Health Partnership staff and selected others who are recommended as key stakeholders by any interviewees.

The residential care home staff who will be approached to participate in this study are workers from two local authority residential care homes, and one private residential care home. All of the homes are staffed by social - rather than health - care staff.

What is discovered will then be used to move on and situate those experiences in the organisation of health care work among those who support residential care home residents.

There will be no nursing care home staff approached for inclusion in this study.

10. Procedure

Access

A top down approach will be adopted to gain permission to access the site and so permission to access to the research site will be sought from:

- the services manager, and care home manager for older adults to access the local authority care homes,

- the care home owner and manager of the private care home to access the private care home.

An introductory poster (Appendix 2) will be displayed in homes which opt to participate. Information leaflets (Appendix 3) and response cards (Appendix 4) will be left for all members of staff. The information sheet will include:

- expectations of what participation will mean to willing participants,
- any foreseen disadvantages and risks to the participant,
- any predicted benefits from participating in the study,
- assurances about confidentiality and security of data storage,
- who will have access to information taken,
- what will happen to the results of the study
- and what to do/who to contact if there are further questions or concerns.

The student is a registered nurse with 14 years experience working in palliative care, and 5 years working in nursing care homes. For the past 2 years she has been working on an outreach project with a number of the care home staff who will be approached to participate in this study. This work has included leading education and practice development projects. This could mean that she was seen as having a higher status than some potential participants. It is acknowledged that this could affect decision-making because staff may opt to participate because respondents want to please her, or because they feel pressured by her position. However, the topic for investigation has arisen from the concerns which have been voiced to her by care home staff during the education and practice development work. Informal discussion with care home staff suggests that many would like an opportunity to share their experiences.

Contact will also be made with the care home regulatory body and the Community Health Partnership to make them aware of the details and purpose of this study.

Interviews

Semi- structured, in-depth interviews (Appendix 6) will be held with residential care home staff and staff from the wider heath and social care system. Semi-structured interviews will be sought initially with 9 residential care home staff (It is hoped that interviews could be held with 3 managers, 3 day staff and 3 night staff) to develop understanding of the work which is involved in organising palliative care for residents.

The interview procedure will be open ended, and participants will be treated as experts who are knowledgeable about the organisation of their local setting. The purpose of the interview is to have participants share their knowledge with the student.

The interview will address the organisational knowledge of those who are active participants in the organisation of palliative care for residential care home residents. The interviews will normally last no longer than 1 hour, and will be conducted either in person or by telephone according to the preference of the participant.

Interviewing will involve two main strategies:

1. Investigating participants' working knowledge of the organisational work processes they are part of to gain practical knowledge and greater insight into how things work.
2. Interviews will also try to uncover what participants can tell the student about how documents enter into the routine practices of their daily work.

Thapar-Bjorkert and Henry (2004) have highlighted concerns about how power is exercised in research interviews, particularly in terms of the potential of research relationship itself becoming exploitative. Rhodes (2000) comments that exploitation can come about through what is, and what is not, represented by the researcher in the interview transcript. Walby (2007), an institutional ethnographer, cites Bourdieu and Wacquant (1992) who claim that misrepresentation in research could be thought of as a form of "symbolic violence, a soft form of violence whereby cultural forms or theoretical frameworks are pushed on a social group" (p. 167). Walby (2007) then goes on to suggest institutional ethnographers need to consider the role such "violence" has in their own work.

Rhodes (2000) has advanced an interesting method of minimising the authority of the researcher to "shape and construct meaning out of interviews" (p. 519) through the practice of ghost-writing. Ghostwriting is a process of interviewing where instead of recording and transcribing the interview; the researcher creates a narrative from memory and from notes taken during the interview(s). The researcher allows the participant to read the narrative account which has been constructed, and correct any misrepresentations. This process could serve to ensure more accurate representation of research participants' dialogue, maintain awareness of the presence of the researcher/writer within the narrative, and break the authority which the researcher has over how the participant is portrayed within the research.

Taking these concerns into account a pilot study will be undertaken. 6 interviews (from 2 residential care homes) will be transcribed and analaysed from recordings of the interview and 3 interviews (from the same residential care home) will be written up and analysed using the ghost-writing technique. The ghost-writing technique normally relies on the memory of the researcher, but as the student is a novice researcher she will also tape record the interviews to minimise the risk of losing the detail of the interview and being overly distracted by note-taking.

Text analysis

IE involves analysis of texts and discourses to enable an examination of how ideas, knowledge and actions come into being. It also explores how ideas, knowledge and actions are replicated by their use. The data for this study will include sets of texts which are used to guide and direct care. These are not known beforehand, but may include documents like care plans, referral documents, and admission criteria.

11. Is the power of the study sufficient to answer the question that is being asked? Please indicate the power calculations used for the required sample size, including any assumptions you may have made. If you think that power calculations are not appropriate, please explain.

This proposal is to conduct a study of the social world of the health and social care system as it interacts with older adults who have palliative needs. It is a qualitative research project which will use a purposive sample. As such it is not suitable for power testing and so power calculations are not appropriate.

12. What statistical tests will you apply?

Not applicable

13. Does the research involve any physically invasive procedures? Are there any known hazards associated with these procedures?

There are no invasive procedures involved in this study.

14. Does the research involve any procedure that might psychologically distress the participants? How long is this likely to last?

Some data will be collected through semi structured interviews (Appendix 6). These interviews will be undertaken to understand the work which is done to organise palliative and end of life care for older adults living and dying in residential care homes. The process of interviewing will normally follow a sequence. The sequence will be:

- Introduction and explanation of the purpose of the interview.

- Assurance of confidentiality and gaining consent to tape the interview.
- A period of warm-up - where neutral questions are asked to settle the student and the participant.
- The main body of the interview where questions will be asked to shed light on what work the participant does in relation to organising palliative care for older adults who are living and dying in residential care homes.
- A period of cooling-down – where neutral questions are asked.
- Closure of interview, with thanks to participant (Robson 2002).

The subject matter under discussion could be distressing to participants and there is a risk of participants becoming emotional as a result. This is a particular risk if work connected with the episodes of care which participants choose to discuss did not go well. Emotion is a natural reaction to difficult issues, managing emotions may be an important aspect of the work of caring for an older adult with palliative and end of life needs. The student's role is not to act as a counsellor to research participants, but she will be prepared to be supportive and understanding. As a palliative care nurse, the student has significant experience in offering patients, relatives, colleagues and students supportive and active listening. These skills are transferable to the proposed research project.

Further support will be offered after the interview if participants are distressed at the end of the interview. Follow up sessions will also be offered to all participants if they wish to discuss their experience further. If there was reason to believe that a participant was experiencing undue distress the interview would be terminated.

15. What arrangements have been made to compensate subjects in the event of injury?

Data will be collected by conversation and looking a texts. There is no anticipation of injury as an outcome.

16. (a)Does the research involve any deception regarding aims and objectives?

There is no plan to involve deception regarding aims and objectives.

(b) Will the research participants be de-briefed? When? How? By whom?

Research participants will be de-briefed after the interview by the student. Follow up sessions will be offered, as previously outlined. There will be an opportunity to attend a feedback event which will outline the findings and give the participants a second opportunity to discuss their thoughts, experiences and feelings about participating in this study.

17. Please describe any expected benefits to the research participant.

Potential benefits could include the opportunity to express feelings and raise concerns about palliative and end of life care in residential care homes.

Findings will be communicated to the health and social care community through publications and an open meeting with opportunity for discussion at the conclusion of the project. Participants will be invited to this meeting. This could give participants the opportunity to contribute their views and offer practical guidance about palliative and end of life care in residential care homes. It may also result in wider networking opportunities with colleagues who share similar challenges and concerns.

18. Who will have access to the data and what steps will be taken to keep data confidential?

Written information and recording will be secured in a digital safe in the student's home. The student will be the only one with access to the password. All information will be destroyed on completion of the student's studies - this may be after the Master of Research project is complete, but may be after progression to PhD.

The information will be entered and saved in an encrypted data base on the students' pass-word protected computer for analysis. This computer belongs to the student and is not used by any other party.

The names of all who take part will be changed, so individuals will not be recognised.

Any extracts being used in published reports will have all personal details and identifiable characteristics removed so participants cannot be identified in any published work.

19. How is consent to be obtained? A copy of the subject information sheet and consent forms should be attached. If the applicant is of the opinion that a consent form and/or information sheet are not required the reasons for this must be given.

Informed consent

Meetings will be arranged and invitations sent to staff from participating care homes. The purpose and the process of the research will be explained to potential participants at this meeting. People will have the opportunity, if they wish, to opt to participate in some aspect of the research.

Informed consent will be sought from all staff who opt to become participants. This process will include explanation of the aims of the research and their potential role in the research. An information sheet will also be given and explained. An introductory poster (Appendix 2) will be displayed in homes which opt to participate. Information leaflets (Appendix 3) will be left for all members of staff. The information sheet will include:

- expectations of what participation will mean to willing participants,
- any foreseen disadvantages and risks to the participant,
- any predicted benefits from participating in the study,
- assurances about confidentiality and security of data storage,
- who will have access to information taken,
- what will happen to the results of the study

and what to do/who to contact if there are further questions or concerns

Written and verbal explanation will be offered to maximise understanding. There will be an opportunity to ask questions and time will be given to reflect on the decision to participate. After a period of consideration participants will be asked to sign two copies of consent form (Appendix 5). One will be attached to the information sheet and given to the participant for their own records. One will be kept by the student. It will be emphasised that participation is voluntary and that participants are free to withdraw from the study at any time with no negative consequence.

20. Does subject recruitment require the permission of a GP/Consultant/other involved in clinical care? If so, how will this be obtained?

This study will focus on collecting data from health and social care staff through interview and from texts which are used to guide and direct care. As no patients will be directly involved in this study there is no need to gain permission from clinical staff.

21. Will subjects be informed that they can withdraw at any time from the study?

As detailed in the informed consent section, participants will be informed in writing and verbally that they can withdraw from the study at any time, with no negative consequences.

22. Will the study result in financial payment or payment in kind to the applicants? to the department? Please specify, including the amounts involved.

No payment will be received by the student. This project is being carried out as part of the requirement of the Master of Research award at the University of the West of Scotland. There is potential for progression to PhD.

23. Are there any special pressures that might make it difficult for people to refuse to take part in the study (e.g. the potential participants are students of the investigator)?

The potential participants could be colleagues of the student who works as Education Liaison Nurse at a Hospice in Central Scotland. This role includes supporting local care homes through education and the supported implementation of palliative and end of life frameworks and tools. As such she has established professional relationships, which are based on trust, with many of the potential participants.

Some of the participants will be at the same, or higher, level of social power as the student. The assumption will be made that those individuals will feel at liberty to answer, or refuse to answer, questions posed. Other participants, such as residential care home social care workers, will be at a lower level of social power, which may result in a power differential. The student takes note of other researchers concerns about the potential for exploitation when such a power differential occurs. However, in this instance it is vital to include the knowledge and experience of all grades of residential care home staff if the work of organising palliative care is to be explored and understood. As previously outlined, the topic of this research project came out of informal discussion with all grades of care home staff, and preliminary exploratory conversation suggests that some staff would welcome the opportunity to share their experiences. This is particularly the case if there is a prospect of those experiences being heard and noted within the wider health and social care system.

24. How will you ensure that participants are competent to consent to take part in this study?

Participants will be staff who work in the health and social care system. The assumption will be made that if they are competent to work in that capacity, they are competent to consent, or refuse to consent, to take part in this study.

25. Where will this research take place?

At a location of the participants choice - either their place of work or the place of work of the student or a neutral location. The option to participate by telephone will also be offered.

References

Age Concern and Help the Aged (2009) Age Concern and Help the Aged Scottish Government Debate: Reshaping the Future Care of Older People: Wednesday 28 October 2009. [online]. Available from: http://www.ageconcernandhelptheagedscotland.org.uk/our_work/policy/parliamentary_debate_briefings [Accessed 22 April 2011].

Alzheimer Scotland (2011) Statistics: Number of people with dementia in Scotland 2011. [online] Available from: http://dementiascotland.org/news/statistics-number-of-people-with-dementia-in-scotland-2011/?page=statistics.htm (Accessed 22 June 2011).

Audit Scotland (2008) Review of Palliative Care Services in Scotland. Edinburgh: Audit Scotland.

Bejekal, M. (2002) Health Survey for England 2000. Care Homes and their residents. London: The Stationary Office.

Bowman, C., Whistler, J. & Ellerby, M. (2004) A national census of care home residents. Age and aging. Vol. 33(6), pp. 561- 566.

Dudman, J. (2007) Context and concepts. In: Help the Aged (2007) My Home Life: Quality of Life in Care Homes. A review of the literature. Prepared for Help the Aged by The National Care Homes Forum. London: Help the Aged.

Froggatt, K. (2004) Palliative Care in Care Homes for Older People. London: The National Council for Palliative Care.

Froggatt, K., Davies, D. & Meyer, J. (2009) Research and Development in Care Homes: Setting the Scene. In: Froggatt, K., Davies,S. And Meyer, J. (ed.) Understanding Care Homes: A Research and Development Perspective. London: Jessica Kingsley Publishers.

General Register Office for Scotland (2007) Scotland's Population 2006 – The Registrar General's Annual Review of Demographic Trends. Edinburgh: General Register Office for Scotland.

Goodman, C., Mathie, E., Crang, C., Wright, J., Handley, M., Barclay, S., Froggatt, K., Thompson, D., Cowe, M., Fenner, P., Gage, H., Garlick, R., Iliffe, S., Manthorpe, J., Mendoza, A., Munday, D. & Westwood, D. (2010) The Experiences and Expectations of Older People Resident in Care Homes, Their Carers and Professionals of End of Life Care and Symptom Relief Needs: A Prospective Study. A report for the National Institute for Health Research for Patient Benefit Programme PB PG 0906 11387. NHS Hertfordshire.

Hall, P., Schroder, C. and Weaver, L. (2002) The last 48 hours of life in long-term care: a focused chart audit. Journal of the American Geriatric Society. Vol. 50(3), pp. 501-506.

Hirakawa, Y., Masuda, Y., Uemura, K., Kuzuya, M., Kimata, T. & Iquchi, A. (2006) End of life care at group homes for patients with dementia in Japan. Findings from an analysis of policy related differences. Archives of Gerontological Geriatrics. Vol. 42(3), pp. 233-245.

Hockley, J. (2006) Developing High Quality End-of Life Care in Nursing Homes: An Action Research Study. Unpublished Thesis: University of Edinburgh.

Hughes, J.C., Jolley, D., Jordan, A. & Sampson, E.L. (2007) Palliative care in dementia: issues and evidence. Advances in Psychiatric Treatment. Vol. 13, pp. 251-260.

Laing and Buisson. (2009) Care of Elderly People UK Market Survey 2009. In. Hockley, J., Watson, J., Oxenham, D., Murray, S.A. (2010) The integrated implementation of two end-of-life tools in nursing care homes in the UK: an in-depth evaluation. Palliative Medicine. Vol24(8), pp. 828-838.

McCarthy, M., Addington-Hall, J. & Attmann, D. (1997) The experience of dying with dementia: a retrospective study. International Journal of Geriatric Psychiatry. Vol. 12(3), pp. 404-409.

Meghani, S.H. (2004) A concept analysis of palliative care in the United States Journal of Advanced Nursing. Vol. 46(2), pp. 152-161.

Mitchell, S.L., Kiely, D.K. & Hamel, M.B. (2004) Dying with advanced dementia in the nursing home. Archives of Internal Medicine Vol164(3), pp.321 – 326.

Morris, J., Barret, J., Tadd, W., Chambers, N., Hurst, P., Wardle, PJ., Wagg, A., Gladman, J. & Holmes, P. (2007) Better-targeted health care will ensure care home residents human rights and dignity. British Medical Journal. Vol. 334(913) [online]. Available from: http://www.bmj.com/content/334/7600/913/reply (Accessed 23rd November 2010).

Royal College of Physicians (2007) Palliative Care Services: Meeting the Needs of Patients. [online]. Available from: http://bookshop.rcplondon.ac.uk/contents/ec579e02-64fd-4f36-bb5d-5159a276077f.pdf (Accessed 23 November 2010).

Scottish Executive (2001) National Care Standards: Care homes for older people. Edinburgh: Scottish Executive.

Scottish Government. (2008) Living and Dying Well: a national action plan for palliative and end of life care in Scotland. Edinburgh: The Scottish Government.

Seymour, J., Kumar, A. & Froggatt, K. (2011) Do nursing homes for older people have the support they need to provide end-of-life care? A mixed methods enquiry in England. Palliative Medicine. [online]. Available from: http://www.nottingham.ac.uk/nmp/documents/open-access-publication-eol-in-nursing-homes.pdf (Accessed 2 June 2011).

Simard, J. (2007) Silent and invisible; Nursing home residents with advanced dementia. Journal of Nutrition, Health and Aging. Vol. 11(6), pp. 484-488.

Small, N., Froggatt, K. & Downs, M. (2007) Living and Dying with Dementia: Dialogues about palliative care. Oxford: Oxford University Press.

Social Care Institute for Excellence (SCIE) (2004) Terminal Care in Care Homes. Report 10. [online]. Available from: www.scie.org.uk/publications/briefings/breifing10 (Accessed 30 November 2010).

World Health Organisation (2004) Palliative Care: the solid facts. Geneva: World Health Organisation.

World Health Organisation (2005) Preventing Chronic Diseases: A vital investment: Global Report. Geneva: World Health Organisation.

Appendix 10: Letter from West of Scotland Research Ethics Committee

10

WoSRES
West of Scotland Research Ethics Service

NHS
Greater Glasgow
and Clyde

West of Scotland Research Ethics Service
Ground Floor – The Tennent Institute
Western Infirmary
38 Church Street
Glasgow G11 6NT

Ms Lorna Reid
Education Liaison Nurse
ACCORD Hospice

Date 08 December 2010
Your Ref
Our Ref WoS ASD 480
Direct line
Fax
E-mail
[redacted]

Dear Ms Reid

Full title of project: A case study of 3 social care homes as a care setting for older adults with palliative and end of life needs

You have sought advice from the West of Scotland Research Ethics Service Office on the above project. This has been considered by the Scientific Officer and you are advised that it does not need ethical review under the terms of the Governance Arrangements for Research Ethics Committees (REC) in the UK. The advice is based on the following.

- The project involves an audit using only data obtained as part of usual care. All data should be anonymised.
- The project is an opinion survey seeking the views of medical NHS staff on a service delivery.
- It is not intended to assess or pas judgement on professional competency.
- Recruitment is invitational and the transcripts from face to face interviews will be irreversibly anonymised so that the respondent's identity is fully protected.
- It is not possible to identify the individual from any direct quotation used in the reporting of your project.

If during the course of your project the nature of the study changes and starts to generate new knowledge and thereby inadvertently becoming research then the changing nature of the study would necessitate REC review at that point, before any further work was undertaken. A REC opinion would be required for the new use of the data collected.

Note that this advice is issued on behalf of the West of Scotland Research Ethics Service Office and does **not** constitute a favourable opinion from a REC. It is intended to satisfy journal editors and conference organisers and others who may require evidence of consideration of the need for ethical review prior to publication or presentation of your results.

However, if you, your sponsor/funder or any NHS organisation feels that the project should be managed as research and/or that ethical review by a NHS REC is essential, please write setting out your reasons and we will be pleased to consider further.

Continued...

Where NHS organisations have clarified that a project is not to be managed as research, the Research Governance Framework states that it should not be presented as research within the NHS. This letter has been copied to NHS Greater Glasgow & Clyde R&D Department for their information.

Kind regards

[redacted]

Dr Judith Godden
WoSRES Scientific Officer/Manager

Austyn

Dr. Austyn Snowden
Research Fellow in Psychological Care and Therapies and Lecturer in Mental Health Nursing School of Health Nursing and Midwifery University of the West of Scotland Paisley campus
PA1 2BE

[redacted]

From: Godden, Judith [redacted]
Sent: 24 August 2011 12:53
To: Austyn Snowden
Subject: RE: Application for Ethical Approval from University Ethics Committee for MRes/PhD study: Lorna Reid

Dear Austyn
As the study has not been classed as research then you will not hear from the R&D Dept. You need to ensure permission to work in the hospital has been granted from the local heads of department and those responsible for the staff taking part in the study.

If you are finding it difficult to get the appropriete permission then get back in touch and I will try to help.

Regards
Judith

Dr Judith Godden
Manager/Scientific Officer
West of Scotland Research Ethics Service Tennent Institute Western Infirmary Glasgow G11 6NT

Tel: [redacted]
Mobile: [redacted]
e-mail: [redacted]

From: Austyn Snowden [redacted]
Sent: 22 August 2011 10:44
To: Godden, Judith
Cc: 'Lorna Reid'; Angela Kydd
Subject: FW: Application for Ethical Approval from University Ethics Committee for MRes/PhD study: Lorna Reid

Dear Judith

I am supervising Lorna Reid, who has already been in contact with you regarding WosRes submission as enclosed. You kindly copied your response to R&D. However, we haven't yet had confirmation from NHS GG&C that this is ok with them. Could you please advise us who we could contact to chase this up

Thanks very much for your help with this

Austyn

Dr. Austyn Snowden
http://www.mendeley.com/profiles/austyn-snowden/

Lorna Reid

From: Austyn Snowden [redacted]
Sent: 20 September 2011 13:22
To: Lorna Reid
Subject: FW: Application for Ethical Approval from University Ethics Committee for MRes/PhD study: Lorna Reid

Follow Up Flag: Follow up
Flag Status: Flagged

Sorry. You mean this one Lorna?

Dr. Austyn Snowden
Research Fellow in Psychological Care and Therapies and Lecturer in Mental Health Nursing School of Health Nursing and Midwifery University of the West of Scotland Paisley campus
PA1 2BE

[redacted]

From: Godden, Judith [redacted]
Sent: 24 August 2011 14:06
To: Austyn Snowden
Subject: RE: Application for Ethical Approval from University Ethics Committee for MRes/PhD study: Lorna Reid

Hi Austyn
You are right about the changes to GAFREC this doesn't alter the fact that managers would want to know what is being asked of their staff particularly if it is in work time.

Regards

Judith

-----Original Message-----
From: Austyn Snowden [redacted]
Sent: 24 August 2011 13:34
To: Godden, Judith
Cc: Angela Kydd; [redacted]
Subject: RE: Application for Ethical Approval from University Ethics Committee for MRes/PhD study: Lorna Reid

Thanks Judith

Lorna's interviews will take place in care homes, but some of the interviewees will be NHS staff. Does she need these staffs' managers permission? This could get complex! However, does the following apply?

Governance Arrangements for Research Ethics Committees which comes into effect from September 2011 states that "Research involving staff who are recruited by virtue of their professional role, does not therefore require REC review except where it would otherwise require REC review (for example the research involves patients etc)"

This seems to suggest that from next month NHS staff can be interviewed without ethics approval as long as no NHS patients are involved. Could you clarify?

It's really important we get this right as criteria for ethics permissions seem to move so quickly. Thanks very much for your help here

Appendix 11: University Ethics Permission Letter

11

UWS UNIVERSITY OF THE
WEST of SCOTLAND

Paisley Campus
Paisley
PA1 2BE
Scotland

[redacted]

[redacted]

23rd August 2011

Dear Lorna

REF. EC/130711/Reid

The School of Health, Nursing and Midwifery Ethics Committee of the University of the West of Scotland has considered the application for your project: Towards understanding how palliative care is organised for older adults with dementia who are living and dying in residential care homes in Scotland using the principles of institutional ethnography.

I am pleased to inform you that ethical approval has been granted.

Please keep the Committee informed should there be any changes to your study which may require further ethical consideration.

Yours sincerely

[redacted]

Charlie Fielding
Secretary to the University Ethics Committee
Innovation and Research Office

[redacted]

Innovation and Research Office
Ian Bishop, Director

Appendix 12: E-mail Permission to Proceed

12

Lorna Reid

From: Lorna Reid [redacted]
Sent: 16 January 2016 15:56
To: Lorna Reid
Subject: Fw: Ethics Approval Form
Attachments: Appendix B Letter confiming ethical approval from UWS.pdf; 230811L_Reid[1].pdf; Appendix 1 letter.pdf; Appendix 3 information leaflet revised.pdf; Appendix 5 consent form ammended.doc; Appendix 5 consent form ammended.doc; Appendix 7 Supervisior's CV.doc; Appendix 9 Reference list.doc; Appendix 2 information poster.pdf

Importance: High

From: Lorna Reid
Sent: 08 January 2014 13:50
To: Austyn Snowden
Subject: FW: Ethics Approval Form

Here it is again, remember I sent it to you after our meeting in December...

Hope this is ok,
Lorna

From: Lorna Reid
Sent: 16 December 2013 16:46
To: Austyn Snowden
Cc: Angela Kydd; [redacted]
Subject: Ethics Approval Form

Austyn,

Further to our conversation today, I confirm that I intend to recommence the study that I originally intended to work on before becoming ill and needing to take time out. I attach the ethical approval letter from the University (EC/130711/Reid) for your information and for your records (Appendix B). I also attach the original application form and appendices for information.

Please let me know if I can send you anything else that would be helpful in order to re-start the process.

Very best wishes,
Lorna

From:	Lorna Reid [redacted]
Sent:	16 January 2016 15:57
To:	Lorna Reid
Subject:	Fw: an interesting ie of ER "waiting times"

From: Austyn Snowden
Sent: 09 January 2014 12:06
To: Angela Kydd
Cc: Lorna Reid; Claire Chalmers
Subject: Re: an interesting ie of ER "waiting times"

Just had a chat to Claire. Please go ahead as originally planned Lorna. We will record the decision for our records but nothing else to do ethics wise unless you amend your original protocol

Apologies again for any unnecessary anxiety and see you soon

Austyn

Professor Austyn Snowden
Chair in Mental Health
UWS
KA8 0SX
[redacted]

http://www.mendeley.com/profiles/austyn-snowden/

On 9 Jan 2014, at 07:12, Angela Kydd [redacted]
wrote:

> also the BIG problem with targets... thanks for sending this it is very interesting. Austyn - give us a shout when you have had a chat with Claire about the ethics fr Lorna..
> Angela
>
> Dr Angela Kydd
> Senior Lecturer Research, Institute of Older Peoples Health and Well-being
> School of Health, Nursing and Midwifery
> University of the West of Scotland, Hamilton Campus
> Hamilton, Lanarkshire, ML3 0JB
> [redacted]

Appendix 13: Poster

13

Toward understanding how palliative care is organised for older adults with dementia who are living and dying in residential care homes in Scotland

You are invited to take part in a research study.

Your knowledge and experience is important.

Would you consider taking part in my research study?

The age and health of older people who are being admitted to residential care homes is changing. People tend to be older when they come to live in the care home now. They also tend to have more health problems.

It is important to make every day as comfortable and meaningful as possible for residential care home residents. This is important from the day of admission, through changes in a residents health, right up to the final days of life. Care that focuses on these issues is called palliative care.

The problem is that we do not know very much about how palliative care is organised for older people with dementia who are living and dying in residential care homes. This study aims to improve our understanding.

I would like to interview 3 people from (name of home) care home. 2 care staff members who work day shift, and 1 care staff member who works night shift.

Before you decide whether or not to take part, it is important to understand why the research is being done, and what it will involve. Take time to decide whether or not you wish to take part. Please read the information leaflet carefully, and discuss it with friends and colleagues if you wish.

This study is being conducted by Lorna Reid. Lorna is a registered nurse who is currently working on an educational outreach project to care homes from ACCORD Hospice in Paisley.

This research project, in association with the University of the West of Scotland, is related to that work.

The project is being undertaken in partial fulfillment part of a Higher Degree. It is being supervised by an experienced team of researchers which includes: Dr. Angela Kydd, Dr. Austyn Snowden and Professor John Atkinson, from the University of the West of Scotland.

Contact me

ACCORD Hospice:

Telephone: [redacted]

E-mail: [redacted]

OR

University of the West of Scotland:

E-mail: [redacted]

Appendix 14: Information Leaflet

14

Confidentiality:

All information about you and your care home will be strictly confidential. It will be destroyed on completion of my studies. Under no circumstances will your name or any identifying features be included in any report or publications.

All information collected during the course of the research will be kept on a password protected database on my personal computer.

Will there be any benefits for you and your care home?

You may find that taking part in the project allows you to share you experiences and express your feelings and concerns about the way palliative care is organised for residents.

What will happen to the results?

The results of this research will be made more widely available through journal publications and conference presentations.

This study is being conducted by Lorna Reid. Lorna is a registered nurse who is currently working on an educational outreach project to care homes from ACCORD Hospice.

This research project, in association with the University of the West of Scotland, is related to that work.

The project is being supervised by an experienced team of researchers which includes: Dr. Angela Kydd, Dr. Austyn Snowden and Professor John Atkinson, from the University of the West of Scotland.

*

UNIVERSITY OF THE WEST of SCOTLAND
UWS

Contact me

ACCORD Hospice :
Telephone [redacted]
OR
The University of the West of Scotland:
E-Mail: [redacted]

Toward understanding how palliative care is organized for older adults with dementia who are living and dying in residential care homes in Scotland.

You are invited to take part in a research study

Your knowledge and experience is important. Would you consider taking part in my research study?

You are being invited to be involved in a research study.

Please read the following information carefully, and discuss it with friends and colleagues if you wish. Do feel free to ask if there is anything that is not clear, or if you would like more information.

Information about the study

The age and health of older people who are being admitted to residential care homes is changing. People tend to be older when they come to live in the care home now. They also tend to have more health problems.

It is important to make every day as comfortable and meaningful as possible for residents. This is important from the day of admission, through changes in a residents health, right up to the final days of life.

Care that focuses on these issues is called palliative care.

One aspect of palliative care is the care that is given when a person is dying.

The problem is that we do not know very much about how palliative care is organised for older people with dementia who are living and dying in residential care homes.

This study aims to improve our understanding.

What will taking part involve?

An interview

You are an expert in the work you do. Your knowledge and experience is very important.

I am particularly interested in finding out about:

- The work you do during a typical day in (name) care home.
- The work you do when a resident with dementia is admitted to (name) care home.
- The work you do when a resident with dementia is experiencing a change in their health.
- The work you do when a resident with dementia is dying.

Our conversation will last no longer than 1 hour.

I would like to speak with you in person, but would be happy to speak with you by telephone if you prefer.

With your permission, I would like to record our conversation so I don't miss any of the important information you have kindly agreed to share with me.

Toward understanding how palliative care is organised for older adults with dementia who are living and dying in residential care homes in Scotland.

Are there any disadvantages to participating in the project?

You will have to spend some time reading this information leaflet , reading and signing the consent form and talking with me.

Thinking and speaking about the work of caring for people who are living and dying with dementia can remind you of difficult situations. This could make you feel sad or uncomfortable.

However, please be assured that you do not have to answer all my questions. If there is one you would rather not discuss, just tell me and we will move on.

Appendix 15: Response Cards

15

Toward understanding how palliative care is organised for older adults with dementia who are living and dying in residential care homes in Scotland.

Research Participant Response Card

I **would** like to take part in this research study:

Your signature

Your name:

Your position at (name) care home:

Your contact details:

Toward understanding how palliative care is organised for older adults with dementia who are living and dying in residential care homes in Scotland.

Research Participant Response Card

I **would** like to take part in this research study:

Your signature

Your name:

Your position at (name) care home:

Your contact details:

If you would like to take part, please place your response card in the box provided.

I will collect the responses by (date).

I will be in touch with you by (date) to arrange a time for the interview.

Thank you for agreeing to share your knowledge and experience with me.

If you would like to take part, please place your response card in the box provided.

I will collect the responses by (date).

I will be in touch with you by (date) to arrange a time for the interview.

Thank you for agreeing to share your knowledge and experience with me.

Appendix 16: Consent Forms

16

Towards understanding how palliative care is organised for older adults with dementia who are living and dying in residential care homes in Scotland

Informed Consent Form for Research Participants

Thank you for agreeing to be interviewed for my study. Dr. Angela Kydd, Senior Lecturer in Gerontology, University of the West of Scotland, is supervising the study.

This interview will be kept strictly confidential and will be available only to members of the research team. Excerpts from the interview may be included in the final research report, but under no circumstances will your name or any identifying characteristics be included in the report.

Please sign below after you have read the following:

- I confirm that I have read and understood the information sheet which has been given to me.
- I understand that my participation is voluntary, that I can refuse to answer any questions, and am free to withdraw at any time from the interview and from the study.
- I agree to the interview being recorded for the purpose of the research. I understand that I can ask for the recording to be stopped at any time.
- I agree to the use of extracts from the interview being used in published reports and presentations resulting from the research. I understand that all personal details will be removed and that I will not be identified in any published work.
- I agree to take part in this study.

----------------------------------	------------------	------------------------------------
Name of research participant	Date	Signature
----------------------------------	------------------	------------------------------------
Name of student researcher	Date	Signature

Appendix 17: Standards for Dementia in Scotland

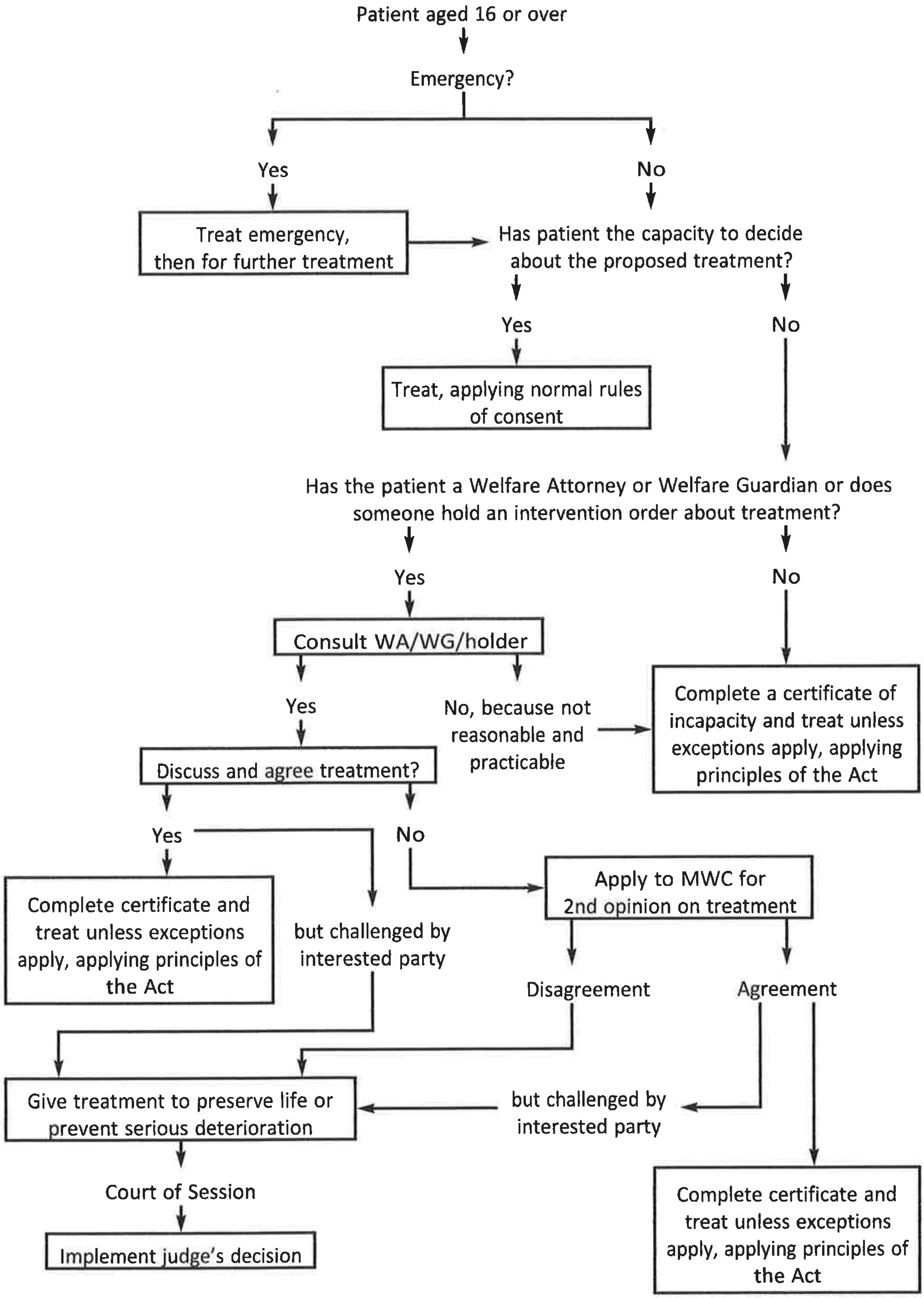
Scottish Government. (2011) *Standards of Care for Dementia in Scotland*. Available from: http://www.gov.scot/resource/doc/350188/0117212.pdf [accessed June 2016].

17

Appendix 18: Adults with Incapacity Certificate

18

ADULTS WITH INCAPACITY (SCOTLAND) ACT 2000
PART 5 – MEDICAL TREATMENT – FLOWCHART



ADULTS WITH INCAPACITY
(SCOTLAND) ACT 2000

Certificate of Incapacity under Section 47 of the AdultswithIncapacity (Scotland) Act 2000

I(name)

of(address)

*am the medical practitioner primarily responsible for the medical treatment of; or

*am a person who is *a dental practitioner/an ophthalmic optician/a registered nurse and who satisfies such requirements as are prescribed by the Adults with Incapacity (Requirements for Signing Medical Treatment Certificates) (Scotland) Regulations 2007 and who is primarily responsible for treatment of the kind in question of:

(name)

of(address) (date of birth)

for whom the *guardian/welfare attorney/person appointed by intervention order/nearest relative/carer

is

I have examined the patient named above on (date). I am of the opinion that *he/she is incapable within the meaning of the Adults with Incapacity (Scotland) Act 2000 ("the 2000 Act") in relation to a decision about the following medical treatment:

because of (nature of incapacity)

This incapacity is likely to continue for months.

*I therefore consider it appropriate for the authority conferred by section 47(2) of the 2000 Act to subsist from:

(date of examination) until , being a period which does not exceed one year from the *date of the examination on which this certificate is based/date of revocation of the certificate issued previously by me; or

*I am of the opinion that (a) *he/she is suffering from *a severe or profound learning disability/dementia/a severe neurological disorder; and (b) *what he/she is suffering from is unlikely to improve within the meaning of the Adults with Incapacity (Conditions and Circumstances Applicable to Three Year Medical Certificates) (Scotland) Regulations 2007/ and therefore consider it appropriate for the authority conferred by section 47(2) of the 2000 Act to subsist until:

Appendix 19: Power of Attorney Certificate

19

SCHEDULE 1

Regulation 2

CERTIFICATE UNDER SECTIONS 15(3)(c) AND/OR 16(3)(c) OF THE ADULTS WITH INCAPACITY (SCOTLAND) ACT 2000 TO BE INCORPORATED IN A DOCUMENT GRANTING A POWER OF ATTORNEY

1. This certificate is incorporated in the document subscribed by

Insert name of granter

2. On

Insert date subscribed

3. That confers a

Tick appropriate box – tick one box only

☐ • Continuing power of attorney (i.e. confers property or financial powers only)

☐ • Welfare power of attorney (i.e. confers welfare powers only)

☐ • Combined power of attorney (i.e. confers both property or financial and welfare powers)

4. Appointing as Attorney(s)

Insert name(s) of Attorney(s)

5. Declaration of Certifier

Note: any person signing this certificate should not be the person to whom this power of attorney has been granted.

I certify that

1. I interviewed the granter ***immediately*** before he/she subscribed this power of attorney;

2. I am satisfied that, at the time this power of attorney was granted, the granter understood its nature and extent; and

   I have satisfied myself of this:
   Please tick appropriate box. (Both may apply but one must apply)

   ☐ (a) because of my own knowledge of the granter;

   and/or

   ☐ (b) because I have consulted the following person who has knowledge of the granter on the matter

   Insert name, address and relationship with granter, of person consulted

3. I have no reason to believe the granter was acting under undue influence or that any other factor vitiates the granting of this power of attorney.

Signed: ....

Print name: ....

Profession: ....

Address: ....

....

....

Date: ....

Appendix 20: Single Shared (Care Needs) Assessment Document

20

East Dunbartonshire Council
www.eastdunbarton.gov.uk

East Renfrewshire
working for you

Glasgow
CITY COUNCIL

NHS
Greater Glasgow
and Clyde

Inverclyde
council

Renfrewshire
Council

West Dunbartonshire Council

Greater Glasgow and Clyde Data Sharing Partnership

Standardised Shareable Assessment (SSA)

Person Name			
Reference No.		**Reference No. Type***	
Assessor Name			
Date of Assessment			

Basic Information

Person Details			
Forename(s)		Surname	
Title*		Preferred name	
Date of Birth		Gender*	
Marital Status*			

Reference No		**Reference No Type***	

Home Address*	
Postcode	
Start Date	
End Date	

Current Address* (if different)	
Postcode	
Start Date	
End Date	

Person Contact Details		
Does the person have a telephone?	Yes	No
Tel (Day)		
Tel (Night)		
Mobile		
Email		

Person Contact Details		
Does the person have a telephone?	Yes	No
Tel (Day)		
Tel (Night)		
Mobile		
Email		

Describe specific entry or access arrangements (including any known risks or concerns)

Basic Information at Referral

Referral Information			
Date of referral			
Referrer Name			
Designation/Relationship*			
Organisation			
Address (inc postcode)			
Tel (day)		Tel (night)	
Referral Method*			

Has the person been informed that a referral has been made?	**Yes**	**No**
Provide Details:		

Has the person agreed to the referral?	**Yes**	**No**
Provide Details:		

Reason for Referral

Outcome of Referral

If referral results in an assessment, please complete the following

Assessor Details	
Name	
Designation	
Agency	
Address	
Contact Tel No.	

Has the person been informed who the Assessor is?	Yes	No
Provide Details		

Personal Contact Details (including all Dependents)

Main Contact					
Title		Forename(s)		Surname	
Relationship*		Gender			
Date of Birth (if applicable)		ID No.			
Address (inc postcode)					
Tel (day)		Tel (night)			
Mobile		email			
Contact Arrangements or Limitations					
Key Holder	Yes		No		
Emergency Contact	Yes		No		

Main Unpaid Carer					
Title		Forename(s)		Surname	
Relationship*		Gender			
Date of Birth (if applicable)		ID No.			
Address (inc postcode)					
Tel (day)		Tel (night)			
Mobile		email			
Contact Arrangements or Limitations					
Key Holder	Yes		No		
Emergency Contact	Yes		No		

Is the main carer a young carer?	Yes	No

Other Personal Contact					
Title		Forename(s)		Surname	
Relationship* / Role*		Gender			
Date of Birth (if applicable)		ID No.			
Address (inc postcode)					
Tel (day)		Tel (night)			
Mobile		email			
Contact Arrangements or Limitations					
Key Holder	Yes		No		
Emergency Contact	Yes		No		

No Contact Requested

Name	
Relationship* / Role*	
Reason Why*	
Provide Details:	

Professional Contact Details

GP			
Practice Name		GP Practice Code	
Forename(s)		Surname	
Address (inc postcode)			
Tel (day)		Out of Hours	
Contact Arrangements or Limitations			

Other Professional Contact					
Title		Forename(s)		Surname	
Organisation Name					
Designation / Role					
Address (inc postcode)					
Tel (day)		Tel (night)			
Mobile		email			
Contact Arrangements or Limitations					

Other Professional Contact					
Title		Forename(s)		Surname	
Organisation Name					
Designation / Role					
Address (inc postcode)					
Tel (day)		Tel (night)			
Mobile		email			
Contact Arrangements or Limitations					

Housing Details

Accommodation Type*	
Tenure Type*	
Dwelling Type*	
Household Composition*	

Living Arrangements		
Does the person live alone?	Yes	No
Comments (where applicable)		

Landlord Details (where applicable)					
Organisation Name					
Title		Forename(s)		Surname	
Address (inc postcode)					
Contact Tel No		Contact Times			

Personal Details

Ethnicity *	
Immigration Status (where applicable)	
Religion / Spiritual Belief *	

Language and Communication Information

First Language*	
Preferred Language*	
Person's preferred communication method*	

Is an interpreter required?	**Yes**	**No**
Provide Details:		

Are there issues with communication?	**Yes**	**No**
Provide Details:		

Does the person require advocacy / person representation?	Yes	No
Provide Details:		

Assessment Information

Reason for Assessment

Assessment Type*	
Assessment Legal Status*	

Personal Profile

Perspectives

What is the person's view of the current situation? (including feeling safe)

What is the carer's view of the current situation?

What are the views of additional contributors to care?

Are there any issues with safety, protection and vulnerability?	**Yes**	**No**	**Not Known**
Provide Details:			

Health Details

Relevant Health Information (including any impairments, disabilities, long term conditions & diagnoses)*	
Source of Information	

Are there any addiction issues?	Yes	No	Not Known
Provide Details:			

Does the person suffer from any allergies or sensitivities?	Yes	No	Not Known
Provide Details:			
Has the person had any hospital admissions	Yes	No	Not Known

within the last 12 months?			
Provide Details: (including details of planned or unplanned admissions and frequency):			

Has the person attended a clinic, A&E, outpatient or treatment centre in the last 12 months?	Yes	No	Not Known
Provide Details:			

Has the person had a fall in the last 12 months?	Yes	No	Not Known
Provide Details:			

Medication

Is the person currently on any medication?	**Yes**	**No**
Provide Details:		

Describe any issues (including taking and obtaining medication):

Physical Health and Wellbeing

Describe Situation		
Are there issues with physical health and wellbeing?	**Yes**	**No**
Provide Details:		

Personal Care		
Describe Situation		
Are there issues with personal care?	**Yes**	**No**
Provide Details:		

Mobility		
Describe Situation		
Are there issues with mobility?	**Yes**	**No**
Provide Details:		

Socialising		
Describe Situation		
Are there issues with socialising?	**Yes**	**No**
Provide Details:		

Employment, Education and Training		
Is the person currently in work, training or education?	**Yes**	**No**
Describe Situation		
If not in work, is the person interested in finding out more about their options about employment, education, training or lifelong learning?	**Yes**	**No**
Provide Details:		

Mental Health		
Describe Situation		
Are there issues with mental health?	**Yes**	**No**
Provide Details:		

Accommodation		
Describe Situation		
Are there issues with accommodation?	**Yes**	**No**
Provide Details:		

Housecare		
Describe Situation		
Are there issues with housecare?	**Yes**	**No**
Provide Details:		

Finances		
Describe Situation		
Are there issues with finances?	**Yes**	**No**
Provide Details:		
Has the person been offered an income maximisation assessment?	**Yes**	**No**
Provide details:		

Current Activities and Support

	Mon	Tues	Wed	Thurs	Fri	Sat	Sun
Getting Up							
Breakfast							
Morning							
Lunch							
Afternoon							
Tea							
Evening							
Settle							
Overnight							

Summary of Intended Outcomes (including any risks identified)

Action/s from Assessment

Assessment Related Information

Assessment Start Date	
Assessment End Date	

Those Consulted During the Assessment		
Name	**Designation / Role**	**Contact Details**

Was person involved in assessment?	**Yes**	**No**
Provide Details:		

Is there an unpaid carer (including young carers)?	**Yes**	**No**
If Yes, was the unpaid carer involved in the assessment?	**Yes**	**No**
Provide Details:		

Does the unpaid carer feel able to continue the caring role?	**Yes**	**No**
Provide Details:		

Has the unpaid carer been offered an assessment?	**Yes**	**No**
Provide Details:		

Has the person been informed of single point of contact?	**Yes**	**No**
Has the carer been informed of single point of contact?	**Yes**	**No**
If single point of contact different from assessor, provide details:		

Signatures

Name	**Signature**

Appendix 21: Mobility Assessment Document

21

Client Handling Mobility Assessment Chart

Name:		Address:						
Body Build:	Obese	Above Average	Average	Below Average	Stature:	Tall	Medium	Short
Weight (if known)			History of Falls		Y	N	Risk of Falls	High	Low

Problems with comprehension, communication, behaviour, co-operation (identify)

Handling Constraints: e.g. disability, pain, weakness, skin lesions. Infusions (identify)

Assessment Number	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**Comments**
Date Assessed									
Forward in chair									
Sit to stand									
Stand to sit									
Walking									
Back in chair									
Toileting									
Bathing/Showering									
Into bed									
Lying to sitting									
Rolling/Turning									
Moving up the bed									
Out of bed									
Into car									
Out of car									
Stairs / Kerbs									
Up from floor									

Mobility Code

BR	Bed Rest	A2	Assistance of 2		
Ind	Independent	NM	Not to be mobilised		
Sup	Supervision	NWB	Non-weight bearing		
A1	Assistance of 1	PWB	Partial weight bearing		

Equipment

RL	Rope Ladder	HBL	Hand-blocks		
RS	Roller Sheet	BL	Bed Lever		
TF	Transfer Board	PS	Patslide		
FT	Fabric Turntable	SA	Stand-Aid		
HB	Handling Belt	H	Hoist		

Mobility Aids

S	Stick	ZF	Zimmer Frame	W	Wheelchair
C	Crutches	R	Rollator		
T	Tripod	D	Delta Walker		

Appendix 22: Four Week Assessment Document

22

PERSONAL INFORMATION

Name ____

Address ____

Date of Birth __________

Admission date ________

✓ ? Reviews __________ ______________ ______________

__________ ______________ ______________

Name and address
of social worker ____

________________________ Tel: __________

✓ ? Demission date ________________

Reason ____

GENERAL INFORMATION

Name and address
of next of kin ____

____________________________ Tel: __________

Person to be contacted
in emergency ____

________________________ Tel: __________

General practitioner ____

________________________ Tel: __________

Minister ____

______________________________ Tel: __________

✓ Burial arrangements ____

Supplementing authority ____

BRIEF PERSONAL HISTORY:	
MOBILITY:	**LEVEL OF SUPPORT / PREFERRED SUPPORT**
WASHING & DRESSING:	**LEVEL OF SUPPORT / PREFERRED SUPPORT**

CONTINENCE MANAGEMENT NEEDS:	**LEVEL OF SUPPORT / PREFERRED SUPPORT**
NUTRITION & DIETARY REQUIREMENTS: **(Likes / Dislikes, Tea, Coffee etc, Food Allergies)**	**LEVEL OF SUPPORT / PREFERRED SUPPORT**
ACTIVITIES / INTERESTS:	**LEVEL OF SUPPORT / PREFERRED SUPPORT**

SPIRITUAL NEEDS:	**LEVEL OF SUPPORT / PREFERRED SUPPORT**
MORNING ROUTINE:	**LEVEL OF SUPPORT / PREFERRED SUPPORT**
EVENING ROUTINE:	**LEVEL OF SUPPORT / PREFERRED SUPPORT**
NIGHT ROUTINE / SLEEP PATTERN:	**LEVEL OF SUPPORT / PREFERRED SUPPORT**

[redacted] **4 WEEK ASSESSMENT RECORDS**

Residents Name: Keyworker:

CARE NEED: PERSONAL NEEDS / CONTINENCE (Please record level of support required)	Date & Sign

[redacted] 4 WEEK ASSESSMENT RECORDS

Residents Name:

Keyworker:

CARE NEED: PARTICIPATION IN ACTIVITIES AND INTERESTS (Please record likes & dislikes)	Date & Sign

[redacted] 4 WEEK ASSESSMENT RECORDS

Residents Name: Keyworker:

CARE NEED: PHYSICAL HEALTH – Including – Nutritional Needs & Mobility issues (Please record level of support required)	Date & Sign
what kind of information is recorded here?	

[redacted]

4 WEEK ASSESSMENT RECORDS

Residents Name:

Keyworker:

CARE NEED: Communication Skills & Social Interaction with others (Please record level of support required)	Date & Sign

[redacted] 4 WEEK ASSESSMENT RECORDS

Residents Name: Keyworker:

CARE NEED: PERSONAL HYGIENE (Please record level of support required)	Date & Sign

xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx
xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx
xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx
xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx
xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx
xxxx

RESIDENTIAL ASSESSMENT REVIEW HELD ON

PERSONAL DETAILS

SURNAME		**FORENAMES**		
MR ☐	MRS ☐	MISS ☐	DATE OF BIRTH	AGE

Referred by:	
Date and Time of Review	
Date of Admission	
Home Address:	
NEXT OF KIN Name	
Address	
Telephone Number	
Relationship to Client	
Name, Address and Telephone Number of Social Worker	

Name, Address and Telephone Number of GP	

1. BRIEF PERSONAL HISTORY

2. PHYSICAL CONDITION (treatment/medical/details of medical condition - diabetes etc.)

3. PHYSICAL ABILITIES

a) Mobility

	Delete as appropriate
Is the client able to get in and out of bed?	Yes/No
Is the client able to get in and out of a chair?	Yes/No
Is the client able to walk into the next room?	Yes/No
Can the client go up and down stairs? Requires supervision or lift.	Yes/No
Is the client unstable when walking?	YesNo
Does the client use a zimmer frame?	Yes/No
Would chiropody help? Routine appointments	Yes/No
Has medical advice been sought as to the cause of this immobility?	Yes/No

b) Hearing

Does the client use a hearing aid?	Yes/No
Does the client require a hearing test?	YesNo

What is the client able to hear?	Nothing Only loud conversation Ordinary conversation	☐ ☐ ☐

Comments:	

c: **Sight**

Does the client wear glasses?	Yes/No
Can the client: (i) see the TV at a distance of 20 ft? (ii) recognise people some distance away? (iii) read ordinary print? (iv) see to write?	 Yes/No Yes/No Yes/No Yes/No

d) **Teeth**

Are dentures worn? Top and bottom.		Yes/No
Is treatment required?		Yes/No
Comments		

e) **Food**

Does the client require assistance when eating? Supervision		Yes/No
Does the client require special diet? Food needs to be cut up		Yes/No
If yes, give details		
Please give details of likes/dislikes		

f) **Bladder/Bowel Control**

Does the client have full bladder control by day? by night?	Yes/No Yes/No
Comments	
Does the client have full bowel control by day? by night?	Yes/No Yes/No
Occasionally constipated, receives medication for this?	
Comments	
If the client has a problem with incontinence, please give details:	
Has the incontinence been medically assessed?	
Comments	

g) **Sleep Pattern**

At night is the person	almost never asleep ☐ occasionally asleep ☐ always asleep ☐
Comments	
During the day is the person	almost never asleep ☐ occasionally asleep ☐ always asleep ☐
Comments	

h) **Daily Living**

Can the person:

(i) get to and use WC?	Yes ☐ With some assistance ☐ No ☐
Comments	
(ii) feed himself/herself	Yes ☐ With some assistance ☐ No ☐
Comments	
(iii) dress himself/herself	Yes ☐ With some assistance ☐ No ☐
Comments	
(iv) have an overall wash or bath	Yes ☐ With some assistance ☐ No ☐
Comments	
(v) wash hands and face	Yes ☐ With some assistance ☐ No ☐
Comments	

4. MENTAL HEALTH

Does the client show disorientation to:	
Time? Comments:	Yes ☐ No ☐ Sometimes ☐
Place? Comments:	Yes ☐ No ☐ Sometimes ☐
Person? Comments:	Yes ☐ No ☐ Sometimes ☐
Orientation to own surroundings? Comments:	
Orientation to assessment unit? Comments:	
Does the client exhibit any behaviour which requires special attention? If yes, give details	Yes ☐ At times ☐ No ☐
Has psychiatric assessment ever been carried out or has the client been seen by a psychiatrist in the previous year? If yes, give details:	Yes ☐ No ☐

5. SOCIABILITY

Does the client help other residents? Comments:	Often ☐ Occasionally ☐ Never ☐
Are relationships with other residents: Comments:	Good ☐ Satisfactory ☐ Difficult ☐ Poor ☐
Has the client a special friendship with other residents? Comments:	Yes/No
Is the client willing to participate in activities? Comments:	Usually ☐ Seldom ☐
Is conversation with others initiated? Comments:	Frequently ☐ Never ☐ Seldom ☐
Is communication with others easily understood? Comments:	Frequently ☐ Never ☐ Seldom ☐

6. ACTIVITIES

Note any interest in the following by ticking as relevant:

bed making or similar household task	
making tea	
reading	
letter writing	
watching TV and/or radio	
hobbies	
outings	
comments, enjoys one-to-one conversation	

7. SOCIAL WORK AND HEALTH SERVICE SUPPORT GIVEN PRIOR TO ASSESSMENT:

Social Work: (tick relevant services received)

casework/family support	
home help	
meals on wheels	
day care	
aids/helps	
respite care	
others, specify	

Comments:

Health Services: (tick relevant services received)

hospital visits – long term admission	
day hospital attendance	
district nurse	
health visitor	
GP	
community psychiatric nurse	
others, specify	

Comments:

8. COMMUNITY SUPPORT

Give details of continuing support being given by, and comment on the frequency of visits:

Friends:

Neighbours:

Community or Church Groups:

Others (specify):

9. ASSESSMENT OF NEEDS AND PLANNING

List any other residential or hospital experience the client has had:

What was the applicant's response to residential care assessment?

Is this an appropriate resource for the applicant? (If so, why? If not, why not?)

Brief summary of the client's situation prior to assessment:

Identify how we could assist the client to retain a quality of life:

Signatures of workers participating in assessment:

____

____

____

____

ACTION TO BE TAKEN:

DATE:

Appendix 23: Admission Checklist

23

ADMISSION PROCEDURES CHECKLIST

This Checklist is an *aide memoire* to ensuring that information is given to, and received from, service users. This information will help to establish the structure of personal service which individual service users can expect from the Board. The Checklist is also helpful in providing a list of preliminary work carried out by the service and the service user in relation to individualised practice and service delivery. In should also be helpful to auditors when implementing the Board's Quality Assurance, as it provides clear indication of areas covered during the admission process.

Guidance for Completing the Admission Procedures Checklist

The Grid

- **Requirements**: These are to remind you of the items you should cover during the admission process
- **Completed**: Please indicate the date this part of the process was completed
- **Reason Incomplete**: Please say why the requirement was incomplete – this may be, for example, because the requirement is "not applicable" to your particular service
- **Comment**: This should direct the reader to other documents or records for additional information e.g. "See Care Plan, *or* Medical Records, *or* Activity Database, etc.

(Please make sure that all boxes are completed)

Additional Boxes

Additional boxes are included to provide space for any other items you wish to incorporate which may relate to your specific services. This allows for customisation of the admission process

Timescales

It is expected that all the information required to complete the admission process be collated within four weeks of the service user coming into the Board's service. Should any item not be completed, it should be recorded in the *"Reason Incomplete"* and *"Comment"* Boxes

Signatures

The service user, Service Manager, and Divisional Manager, should all sign the completed Checklist

ADMISSION CHECKLIST

REQUIREMENT	COMPLETED (DATE)	REASON INCOMPLETE	COMMENT
Background Reports Received			
Assessments Records Available			
Service User Views Room Prior to Admission			
Needs Identified			
Service User Understand Reasons for Referral			
Contract Discussed			
Contract Signed			
Complaints Procedures Discussed and Explained			
Copy of the Board's Complaints Procedures Given to the Service User			
* **Initial Goals Discussed, Agreed and Set with Service User**			

ADMISSION CHECKLIST

REQUIREMENT	COMPLETED (DATE)	REASON INCOMPLETE	COMMENT
Rights and Responsibilities Explained			
Service User Charter Given to Service User			
Timescales for Admission Recorded			
Key Worker Identified and Role Explained			
Key Worker Introduced to Service User			
Structure of the Service and Service Delivery Explained			
Board's Drug/Alcohol Policy Explained			
Details of any Charges, Terms and Conditions, Discussed/Agreed			
Social Networks Recorded			
* Appointees and Trustees Determined and Recorded			

ADMISSION CHECKLIST

REQUIREMENT	COMPLETED (DATE)	REASON INCOMPLETE	COMMENT
Explanation of Quality Assurance given to Service User			
Communications Systems Explained to Service User and Relatives/Carers			
Contact Arrangements Discussed and Recorded			
Relatives/Carers Involved			
Personal Care Aspects Discussed and Agreed			
Special Arrangements for Personal Care Recorded			
* Advocacy Needs Discussed, Agreed and Recorded			
Health and Safety Discussed with Service User			
Spiritual Needs and Requirements Discussed and Recorded			
Board Equal Opportunities Policy Explained			

ADMISSION CHECKLIST

REQUIREMENT	COMPLETED (DATE)	REASON INCOMPLETE	COMMENT
Dietary Arrangements Recorded			
Explanation of the Structure of the Day in the Service			
Community Activities Discussed and Recorded			
Service User's Personal Belongings Discussed and Agreed			
Service User's Choices, Preferences, Requirements and Aspirations Recorded			
Private and Public Space Clearly Explained			
Service Brochure Given to Service User			
Review Process Discussed			
Visiting Arrangements Discussed			
Medical Records and Information Discussed and Recorded			
Explanation given re photos that require to be taken for files and marr sheets.	Permission Granted (Tick)	Permission not Granted (Tick)	

Appendix 24: National Care Standards

Scottish Government. (2007) *National Care Standards: Care Homes for Older People*. Available from:

http://www.gov.scot/resource/doc/205928/0054733.pdf [accessed Oct 2015].

24

Appendix 25: SSSC Code of Practice

Scottish Social Service Council. (2016) Codes of Practice for Social Service Workers and Employers. Available from: http://www.sssc.uk.com/about-the-sssc/multimedia-ibrary/publications?task=document.viewdoc&id=239 [accessed June 2016].

25

Appendix 26: Personal Plan

26

PERSONAL PLANNING GUIDANCE NOTES

who ?

Introduction The documentation for Care Files, incorporating the Personal Plan, has been drafted in the context of the Board's drive not only to have quality services, but also to be able to be transparent and *prove* that it has quality services.

copy

It, therefore, takes account of the Board's Service Standards, the National Standards and is also compatible with Care Nap assessment.

what is this ?

Furthermore, the documents are reflective of good practice with a person centred focus, taking account of the S.P.I.C.E.S. and exceeding them.

what does this mean ?

Additionally, it applies the good management and Quality assurance practice of 'closing the loop' through a recording system that confirms, with checks, that the ambitions of the plan are accomplished.

The completion of these documents should be considered as part of each service's admission protocol.

The documentation comes in four sections:

- The admission phase paperwork covering the period of entry into the service until the first full assessment
- The person focussed Assessment and the Personal Plan
- The Monitoring section, this includes daily recording.
- Review section, including six weekly and six monthly reviews.

Completing the Documents At all times, workers should bear in mind what the service user will experience when being asked intimate questions about their life. With that in mind, it is important that a balance is struck by workers undertaking gathering information that they neither make presumptions nor do they ask obvious questions, the information on which is already available.

The document should be completed as a partnership exercise with the service user, where the Key Worker spends time with the person, building relationships and explaining that good information allows the Board to offer professional care uniquely influenced by the person's own individual circumstances.

Conclusion The Care File documents have been designed in such a fashion that they are consistent with each other, with the Board's Standards and the accomplishment of S.V.Q.s. They support staff through the Personal Planning process, although the

which ones ?

paperwork should never be seen as a replacement for good practice and sensitive work, but rather as a facilitator of that work as well as a vehicle for communication. However, armed with good information, the skilled worker will be enabled to provide a higher quality of service.

ADMISSION PHASE

GUIDANCE NOTES

Admission Phase

During the Admission Phase (which extends from the initial referral and includes the settling in period), information may come from a variety of sources: the person themselves; their carer; the referring Social Worker; etc.

Within this section, it is important that basic details such as the next of kin and G.P. are included, not only for good professional practice, but also to refer to quickly in a crisis situation.

Any omissions to information should be addressed on admission in dialogue between the Key Worker and the person or their carer where possible.

Important Details

Name **Title** **Preferred name** **DOB** **NI number**	**Home Address Adams House**	**Admit from:** **(Date)** **Demit to:** **(Date)**
Presenting Issues Diagnosed with what kind of information here?	**Support Needs** **24 hour specialist Dementia care**	**Agencies Involve**

Contacts	**Name**	**Address**	**Telephone**	**Details**
Next of Kin				
In emergency				
GP				
DN				
Solicitor				
Spiritual				
Other Agencies involved if any				
SW				
Supplementing LA				
CPN				
OT				
Physio				
Podiatrist				
Dentist				
Optician				
Day/Home Care				

Others				
Brief social history (Including working life, special dates, events etc.)				

Brief medical history (Note any allergie Where does this information come from ? +	Medication:	Dosage:	Frequency:
	+		

PERSONAL PLAN

PERSONAL PLANNING GUIDANCE NOTES

Personal Plan

This section of the documentation has been written in a style that confirms that it is the service user-s agenda which has primacy, thus endorsing the Board-s principle of *Empowering People.* what does this mean ?

The document invited key workers to engage with Service Users on their own agenda through systematically assessing the areas of support they might need.

Key Workers are encouraged to use language appropriate to the Service User to discuss relevant information and then to enter dialogue with them to establish negotiated and agreed goals..

Having agreed these solutions it is important that the plan allocates tasks to individuals as well as establishing any prevalent risks. Should the risk assessment be more complex than the paperwork permits, a more full risk assessment should be compiled and attached to the personal plan.

comfort …

At all times the service user-s comfort with the process is paramount and it is important that they should sign a copy of the plan confirming their consent to its contents and suggesting that it is jointly owned by the individual and the Key Worker.

how!

In accord with good quality assurance practice, there should be a monitoring of performance of the Plan, usually by managers, and the paperwork facilitates this, requiring their signature at the 6 weekly summary stage which has been carefully aligned to correspond to Board supervision timetables.

Quick Guide

Also included in the Personal Plan documentation is a Quick Guide or easy reference to the person-s Personal Plan. This serves four functions:

- To record any information forthcoming from the carer or Social Worker about needs
- To give the service user a concise overview of their Personal Plan when it has been completed (previous versions should be redundant)
- For services with short timescale interventions such as Home Support and some Day Care provision, the Quick

Guide offers an opportunity to draw up an abbreviated Personal Plan without requiring to reference the more comprehensive document.

- To facilitate the understanding of service users in respect of relief staff and newly appointed staff members.

The Quick Guide to the Personal Plan should be signed by both the Key Worker and the person or their advocate. Should the person not wish a full copy of their Care Plan (as demanded by Care Commission requirements), a copy of the Quick Guide should then be given to the person or their advocate for ongoing reference.

In Board Services where there are short interventions, such as Home Support, only the Quick Guide to the Personal Plan should be completed, albeit with a similar focus to the headings in the Person Centred Assessment section.

PERSONAL PLAN (SOCIAL)

I may need your help to	Negotiated/ Agreed Goals	Code	Who Does What And When	How Will Risks be Managed
		SO1.		
		SO2.		
		SO3.		
		SO4.		
Here is a list of the areas you should consider (Tick box as you eliminate them): Outings ☐ ; My friends ☐ ; My family ☐ ; Clubs ☐ ; Transport ☐ ; My favourite places ☐ ; My money ☐ ; Shopping ☐ ; My communicating with others ☐ ; My education ☐ .				

PERSONAL PLAN (PHYSICAL)

I may need your help to	Negotiated/ Agreed Goals	Code	Who Does What And When	How Will Risks be Managed
		PH1.		
		PH2.		
		PH3.		
		PH4.		
Here is a list of the areas you should consider (Tick box as you eliminate them): Walking ☐ ; Toileting ☐ ; Hearing ☐ ; Seeing ☐ ; Continence ☐ ; Weight ☐ .				

PERSONAL PLAN (INTELLECTUAL)

I may need your help to	Negotiated/ Agreed Goals	Code	Who Does What And When	How Will Risks be Managed
		IN1.		
		IN2.		
		IN3.		
		IN4.		

Here is a list of the areas you should consider (Tick box as you eliminate them): Interests ☐ ; Newspapers ☐ ; Games ☐; Memory ☐ ; Radio/T.V. ☐ ; Films ☐ ; Arts/Crafts ☐ ;Theatre ☐ ; Skills ☐ ;

PERSONAL PLAN (CULTURAL)

<table>
<tr><th>I may need your help to</th><th>Negotiated/ Agreed Goals</th><th>Code</th><th>Who Does What And When</th><th>How Will Risks be Managed</th></tr>
<tr><td></td><td></td><td><u>CU1.</u></td><td></td><td></td></tr>
<tr><td></td><td></td><td><u>CU2.</u></td><td></td><td></td></tr>
<tr><td></td><td></td><td><u>CU3.</u></td><td></td><td></td></tr>
<tr><td></td><td></td><td><u>CU4.</u></td><td></td><td></td></tr>
<tr><td colspan="5"><i>Here is a list of the areas you should consider (Tick box as you eliminate them): My background ☐ ; My personal tastes ☐ ; My cultural activities ☐ ; My physical characteristics ☐ ; My clothing ☐ ; My special diet ☐ ; My ethnicity ☐ ;</i></td></tr>
</table>

PERSONAL PLAN (EMOTIONAL)

I may need your help to	Negotiated/ Agreed Goals	Code	Who Does What And When	How Will Risks be Managed
		EM1.		
		EM2.		
		EM3.		
		EM4.		

Here is a list of the areas you should consider (Tick box as you eliminate them): My fears ☐ ; My relationships ☐ ; My distress ☐ ; My happiness ☐ ; My bereavement ☐ ;

'What goes in here ...

PERSONAL PLAN (SPIRITUAL)

I may need your help to	Negotiated/ Agreed Goals	Code	Who Does What And When	How Will Risks be Managed
Namaste Care.		**SP1.**		
		SP2.		
		SP3.		
		SP4.		

Here is a list of the areas you should consider (Tick box as you eliminate them): My chosen beliefs or none ☐ ; My religious background ☐ ; My attending worship ☐ ; My ways of relaxing ☐ ; My celebration of festive occasions ☐ ; [✓ My living will ☐] ; My funeral arrangements ☐ .

What goes in here?

Who discusses this?

Is this "spiritual"? (Physical / Health)

PERSONAL PLAN (HEALTH)

I may need your help to	Negotiated/ Agreed Goals	Code	Who Does What And When	How Will Risks be Managed
		HE1.		
		HE2.		
		HE3.		
		HE4.		

Here is a list of the areas you should consider (Tick box as you eliminate them): My medication ☐ ; My visits to the Doctor ☐ ; My visits to hospital ☐ ; My feet ☐ ; My skin ☐ ; My digestion ☐ ; My hearing ☐ ; My balance ☐ ; My mobility ☐ ; My pain ☐ ; My use of aids ☐ ; My substance abuse ☐ ;

How is this organised?

No nurse input?

PERSONAL PLAN (PERSONAL HYGIENE)

I may need your help to	Negotiated/ Agreed Goals	Code	Who Does What And When	How Will Risks be Managed
		HY1.		
		HY2.		
		HY3.		
		HY4.		

Here is a list of the areas you should consider (Tick box as you eliminate them): My washing myself ☐ ; My bathing ☐ ; My mouth ☐ ; My eating and drinking ☐ ; My nails ☐ ; My hair ☐ ;

PERSONAL PLAN (NUTRITION AND DIET)

I may need your help to	Negotiated/ Agreed Goals	Code	Who Does What And When	How Will Risks be Managed
		NU1.		
		NU2.		
		NU3.		
		NU4.		
Here is a list of the areas you should consider (Tick box as you eliminate them): My own ability to prepare food and drink ☐ ; My eating preferences ☐ ; My drinking preferences ☐ ; Helping me to make appropriate dietary choices ☐ ;				

PERSONAL PLAN (NIGHTS)

I may need your help to	Negotiated/ Agreed Goals	Code	Who Does What And When	How Will Risks be Managed
		NI1.		
		NI2.		
		NI3.		
		NI4.		

Here is a list of the areas you should consider (Tick box as you eliminate them): My personal clothing ☐ ; My personal hygiene ☐ ; My refreshments ☐ ; My night medication ☐ ; My room temperature/ fresh air ☐ ; My lighting ☐ ; My sleep pattern and comfort ☐ ; My toilet arrangements ☐ ; My observation requests ☐ ; My bed clothes ☐

QUICK GUIDE TO PERSONAL PLAN

Care Codes	Negotiated Outcome	Who does what, how and when	Risks	Priority Code 1,2,or3

SIGNATURES: **Individual/ Advocate:** ____________

Keyworker: ____________ **Date:** __________

Copy of personal Plan Offered	Accepted
Signature	Rejected

PERSONAL PLAN (ON THE OCCASION OF ME HAVING A SERIOUS ILLNESS)

I may need your help to	Negotiated/ Agreed Goals	Code	Who Does What And When	How Will Risks be Managed
		SI1.		
		SI2.		
		SI3.		
		SI4.		

SIGNATURES: **Individual/ Advocate:** ____________

Keyworker: ____________ **Date:** ______

What is discussed here ?
who is involved ?

Appendix 27: On the Occasion of Serious Illness

27

PERSONAL PLAN (ON THE OCCASION OF ME HAVING A SERIOUS ILLNESS)

I may need your help to	Negotiated/ Agreed Goals	Code	Who Does What And When	How Will Risks be Managed
		SI1.		
		SI2.		
		SI3.		
		SI4.		

SIGNATURES: **Individual/ Advocate:** ________________

Keyworker: ________________ **Date:** ______

What is discussed here?
who is involved?

Appendix 28: Weekly Work Plan

28

WEEKLY WORK PLAN

With reference to the Care Plan, write in what needs to be done this week

Week Beginning:

Support Issue	Personal Progress	Action Required	Action Taken
Social			
Physical			
Intellectual			
Cultural			
Emotional			

Spiritual	what here ?		
Health	what here ?		
Personal Hygiene			
Nutrition and Diet			
Nights			
Serious Illness	what here ?		

Appendix 29: Daily Log Sheets

29

PERSONAL PLAN DAILY LOG

Date	Daily Log	Code	Signatur

Appendix 30: Monthly Summary Sheet

30

PERSONAL PLAN MONTHLY SUMMARY COVERING MONTH OF-

SUMMARISE CHANGES FROM LAST MONTH IN RELATION TO THE CARE PLAN & DISCUSS WITH LINE MANAGER

Support Issue	Changes in Person's Progress	Negotiated Alterations to Personal Plan (Update Risk Assessment)
Social		
Physical		
Intellectual		
Cultural		
Emotional		
Spiritual		

Health		
Personal Hygiene		
Nutrition and Diet		
Nights		
Serious Illness		

MULTIFACTORIAL FALLS RISK ASSESSMENT UPDATE: (3 MONTHLY UNLESS SIGNIFICANT CHANGES)

NOT REQUIRED ☐ **CHECKED/UPDATED- NO CHANGES** ☐ **CHECKED/UPDATED WITH CHANGES** ☐
SEE CARE PLAN/RISK ASSESSMENT

Signatures: Person/ Advocate____________ **Keyworker:**____________ **Line Manager:**______________

Date:_________

Appendix 31: Six Monthly Review Document

31

REVIEW

PERSONAL PLANNING GUIDANCE NOTES

Review

As part of your Kew Worker session, every 6 weeks, Keyworkers should summarise changes, both positive and negative in the service user as they impact on the Personal Plan and take the opportunity to discuss matters with their Manager in scheduled supervision.

In accord with Board Standards, twice per year, a more full review of the Personal Plan should be undertaken, involving the service user and other pertinent stakeholders in a case conference setting. On such occasions, the agreed conclusion should be confirmed by the signatories of the service user or their advocate, the Keyworker and a member of management staff.

Skilled workers will be aware that the information gathered should be done so in a sensitive fashion, with language appropriate to the Service User's situation.

example ?

who attends ?
what is talked about ?

PERSONAL PLAN 6 MONTHLY REVIEW

Support Issue	Person's Progress on Previous Negotiated Outcomes	New Negotiated Outcomes (Update Risk Assessment)
Social		
Physical		
Intellectual		

Cultural		
Emotional		
Spiritual	Living Will ?	

~~What happened to other domains ... how is information allocated~~ ?

Nights		
Serious Illness	What issues are discussed? Examples …	

Signatures **Individual (Or Advocate):** ________________ **Keyworker:** ________________

Line Manager: ________________ **Date:** ________________

List of those invited:	Attended	Did not attend

List of those invited:	Attended	Did not attend

Please document below the discussion that took place.

Example, if appropriate ...

Appendix 32: Prognostic Indicator Guidance

The Gold Standards Framework. (2011) *The GSF Prognostic Indicator Guidance: the national GSF Centre's guidance for clinicians to support earlier recognition of patients nearing the end of life*. Available from: http://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf [accessed June 2016].

32

Appendix 33: Palliative Care Register

33

[redacted]

Care matrix for end-of-life care

(adapted from GSFCH, Thomas et al 2006)

	Goal	Activity
A = years	• Adjustment to living well in a new home, with regular review of care. • Assessment of disease progression to optimise care	• Assessment of residents needs in relation to: co-morbidities, dependency, frailty • Address 'losses' of individual with family & staff team • Introduction & preparation for GSF by staff & relatives • Advance care plan + preferred place of care + DNAR discussion with resident, family or advocate • Communication opportunities to discuss issues as they present themselves • *Holistic care*: nutrition, hydration, mobility, continence assessments. Pain & symptom assessment. Spiritual and social needs assessment – 'what is important to you'
B = months	• Regular proactive review of individual resident's needs & care	• Monthly communication with MDT/staff (e.g. GP, CNS, psychologist etc) • Review of Advance Care Plan e.g. DNAR, preferred place of care/death • Monthly assessment of pain/symptom control (POS; Doloplus2) & assessment of family needs as frailty of resident increases • Assessment and/or Continuing Care Funding review
C = weeks	• Preparing for final stage • Focus on comfort care • Regular contact and discussion with family	• Continue regular pain & symptom control assessments (POS; Doloplus2) as appropriate (may need to be weekly) • Increased proactive review by GP, CNS etc • Send OOHs form to NHS24 re 'end-stage' if not already done • Increased contact with family – discuss prognosis – consider 'unfinished business' within family • Advance care plan rechecked + preference of place of care (not admitting to hospital) reassessed + inappropriate use of antibiotics discussed
D = days	• Preparation for death in preferred place – resisting transfer to hospital	• Diagnosing dying • Remember resident is likely to be aware that they are dying – be prepared to answer their questions – do not 'fob them off' • Use of 'care pathway' e.g. *Liverpool Care Pathway for the Dying* with 4hrly assessment/recording • Close contact with GP (check they have sent OOHs form to NHS24) • Consider spiritual care aspect of holistic care • Contact with family increased – discuss prognosis
Aftercare		• Verification of death procedure clarified • Staff protocol for after death care • Guidance for family for funeral arrangements + awareness of bereavement emotions: additional loss, guilt issues • Openness about death with other residents – their need for support • Staff support – debriefing • Audit of care provision – 'After Death Analysis'

[redacted]

The GSFCH Supportive / Palliative Care Register

Register Prompts for Discussion at Case Management Meeting

Name of Resident + age & date of admission	Diagnoses	Code A-D	GP	Key Worker: named nurse /carer	DNAR Status completed + date	Advance Care Plan completed Y or N (date)	Problems / concerns: i.e. pain, depression, family difficulties	Other Specialists? Y or N	SPC Involvement ? Y or N	OOHs' form – Confirm date sent	Actual place death + date	Further bereavement support : 'Y' (yes) or 'N' (no)	Any gaps in care/ crises/ other notes

Appendix 34: After Death Analysis Form

34

[redacted]

Proforma of Retrospective Review of Notes

2 cohorts:
Pre-implementation: June 2006 – May 2007
Post-implementation: June 2007 – May 2008

NH Code	Initials of resident	Gender - F/M	DOB	DOA	DOD	Length of time in NH	Diagnoses	Presence of dementia Y/N	DNAR form Y/N	Doc. evidence of ACP	No. of hospital admissions in last 8wks of life	No. hosp. days appropriate /inappropriate		No. of OOHs contact in last 8 wks:	LCP: Y or N	Place of death: NH or hospital	Type of death: D, S, A, T[2]

---

[2] **D** = dwindling; **S** = sudden (totally unexpected ie heart attack in dining room); **A** = after ‘acute’ episode (ie extension of stroke; fractured femur); **T** = diagnosed terminal condition

Appendix 35: Quality and Outcomes Framework Guidance Document

Quality and Outcomes Framework (QOF). (2014) *Guidance for NHS Boards and GP Practices 2014/15*. Available from: http://www.sehd.scot.nhs.uk/publications/DC20140502QOFguidance.pdf. [accessed June 2016].

35

Appendix 36: DNACPR Form

The Scottish Government. (2010) *Appendix 1: The DNACPR Form*. Available from: http://www.gov.scot/Publications/2010/05/24095633/15 [accessed June 2016].

36

Appendix 37: DNACPR Decision Making Framework

The Scottish Government. (2010) *Appendix 11: The Decision-Making Framework.* Available from: http://www.gov.scot/Publications/2010/05/24095633/15 [accessed June 2016].

37

Appendix 38: Care Inspectorate Self-Assessment Form

Care Inspectorate. (2016) *Self Assessment Form: Care Homes for Older People*. Available from: http://www.careinspectorate.com/images/documents/125/SAF%20Care%20Homes%20for%20Older%20People.pdf [accessed June 2016].

Appendix 39: Making Good Care Better: national practice statements

Care Commission and Scottish Partnership for Palliative Care. (2006) *Making Good care Better: National Practice Statements for General Palliative Care in Adult Care Homes in Scotland*. Available from: https://www.palliativecarescotland.org.uk/content/publications/Makinggoodcar-bette--CareHome-PracticStatements.pdf [accessed June 2016].

39

Appendix 40: Annual Return Form

40

care inspectorate

Annual Return December 2013: Care Homes for Adults

Section – Service Profile

Service Providers are asked to note that the annual return for Care Home for Adults caters for a wide range of care services including those for older people, people with alcohol and drug misuse problems, and people with learning disabilities. As a result, you may be asked questions which may not be relevant to your service. We have provided a not applicable option to minimise any inconvenience.

Read Only	Name of provider:
	Is the name of the Service Provider above correct? *Select one only:* Yes No Don't Know
	If 'No', you must formally notify the Care Inspectorate of the correct details – this can be done using the Care Inspectorate's online eForms system.
Read Only	Address of provider line 1:
Read Only	Address of provider line 2:
Read Only	Address of provider line 3:
Read Only	Address of provider line 4:
Read Only	Town / City:
Read Only	Provider postcode:
	Is the care home contained in one or more buildings? *Select one only:* Single building or site Multiple buildings or sites
	What type of services are provided? *Select all that apply:* Long Term Placement Rehabilitation or Preventative Respite Care and Short Breaks

	Please indicate what service user age groups your service caters for: *Select all that apply:* 16 to 17 years old 18 to 24 years old 25 to 64 years old 65 and over
	Please indicate whether your service caters for both sexes of service user: *Select all that apply:* Female Male
	Please indicate whether your service is equipped to provide for: *Select all that apply:* Alcohol Dependency Alcohol Related Brain Injury Acquired Brain Injury Autism Spectrum Disorders Blood-Borne Viruses Dementia Drug Dependency Hearing Impairment Korsakoff's Syndrome Learning Difficulties Mental Health Problems (other than Dementia) Mothers and Children Older People Palliative and End of Life Care Physical Disability or Illness Sensory Impairment Visual Impairment
	Please indicate which one of the services you provide you regard as your main area of provision: *Select one only:* Alcohol Dependency Alcohol Related Brain Injury Acquired Brain Injury Autism Spectrum Disorders Blood-Borne Viruses Dementia Drug Dependency

	Hearing Impairment Korsakoff's Syndrome Learning Difficulties Mental Health Problems (other than Dementia) Mothers and Children Older People Palliative and End of Life Care Physical Disability or Illness Sensory Impairment Visual Impairment
	Please provide a brief description of your main area of service provision *Text*

Section – Service Capacity

Number is automatically calculated	Total number of beds as at 31 December: *Number*
	Total Number of single bedrooms as at 31 December: *Number*
	Number of service users occupying single bedrooms as at 31 December: *Number*
	"Ensuite" means that the bedroom has a toilet and a washbasin for the exclusive use of the occupant of the bedroom (but no bath or shower). "Ensuite plus Bathing" means that the bedroom has a toilet and a washbasin and a bath or shower for the exclusive use of the occupant of the bedroom.
	Number of single bedrooms which are Ensuite plus Bathing as at 31 December: *Number*
	Number of single bedrooms which are Ensuite as at 31 December: *Number*
	Number of beds occupied in single bedrooms which are Ensuite with Bathing as at 31 December: *Number*
	Number of beds occupied in single bedrooms which are Ensuite as at 31 December: *Number*
	Total Number of beds in double bedrooms as at 31 December: *Number*

	Number of beds occupied in double bedrooms as at 31 December: *Number*
	"Ensuite" means that the bedroom has a toilet and a washbasin for the exclusive use of the occupant of the bedroom. "Ensuite plus Bathing" means that the bedroom has a toilet and a washbasin and a bath or shower for the exclusive use of the occupant of the bedroom.
	Number of beds in double bedrooms which are Ensuite plus Bathing as at 31 December: *Number*
	Number of beds in double bedrooms which are Ensuite as at 31 December: *Number*
	Number of beds occupied in double bedrooms which are Ensuite as at 31 December: *Number*
	Number of beds occupied in double bedrooms which are Ensuite as at 31 December: *Number*
	Total Number of beds in bedrooms for three or more service users as at 31 December: *Number*
	Number of beds occupied in bedrooms for three or more occupants as at 31 December: *Number*
	"Ensuite" means that the bedroom has a toilet and a washbasin for the exclusive use of the occupant of the bedroom. "Ensuite plus Bathing" means that the bedroom has a toilet and a washbasin and a bath or shower for the exclusive use of the occupant of the bedroom.
	Number of beds in bedrooms for three or more service users which are Ensuite plus Bathing as at 31 December: *Number*
	Number of beds in bedrooms for three or more service users which are Ensuite as at 31 December: *Number*
	Number of beds occupied in bedrooms for three or more service users which are Ensuite plus Bathing as at 31 December: *Number*
	Number of beds occupied in bedrooms for three or more service users which are Ensuite as at 31 December: *Number*
	How many of your beds were unavailable at 31 December? A bed which is unavailable is, for example, in a room that cannot be used due to refurbishment. A bed that is occupied should not be counted as unavailable.: *Number*
	How many beds were vacant at 31 December? *Number*

	How many emergency places were being provided at 31 December? Emergency places are places that are kept solely for very short / emergency use. *Number*
	How many respite places were being provided at 31 December? *Number*
	Are the respite places provided in single rooms? *Select one only* Yes No Not Applicable

Section – Service Usage

	Do you provide nursing care to service users? *Select one only:* Yes No
	If "Yes", how many service users were receiving nursing care from the care service's own nursing staff as at 31 December? *Number*
	How many service users were receiving nursing care from Community Healthcare or Health and Social Care Partnership nursing staff as at 31 December? *Number*
	Do all service users in the care home have access to an enhanced GP service? Enhanced GP services are services which are provided over and above the basic GMS (General Medical Service) contract. For example, some Health Board areas have set up local schemes where GPs receive payments to provide extra services to care home residents *Select one only:* *Yes* *No*
	If "Yes" does the enhanced service include:
	The allocation of a single GP practice to deal with all service users? *Select one only:* *Yes* *No*

	Regular, planned GP visits to the service? *Select one only:* No Yes - Weekly Yes - Fortnightly Yes - Monthly Yes - Three monthly Yes - Six monthly
	Which local authorities, if any, buy places or services from your service? If your service is operated by a local authority, please identify all local authorities which buy places, including your own local authority). Include any local authorities that you have a formal partnership agreement with. *Select all that apply from list of Local Authorities*
	Do you support people whose care package is funded, or partially funded, through 'Self Directed Support' arrangements? 'Self Directed Support' is an approach where people have more control over the support they wish to receive. Funding sources vary but they include Direct Payments and Personalised Budgets. These arrangements are different from the standard contracts in place between services and local authorities for individuals or block contracts. *Select one only:* Yes No Don't know
	If 'Yes', how many people are you currently supporting where the package is funded through 'Self Directed Support' arrangements? *Number*
	How many service users received the following levels of care and support, through 'Self Directed Support' arrangements, during the last full working week before 30 November? (Note that this should include all hours provided for a full seven days ending 30 November) Enter 0 if applicable.
	0 up to 4 hours *Number*
	From 4 hours up to 10 hours *Number*

	From 10 hours up to 20 hours *Number*
	From 20 hours up to 40 hours *Number*
	40 hours or more *Number*
	Please describe how you are developing your service's approach to self-directed support. *Text*
	Please describe how you are supporting your workforce to deliver self-directed support. *Text*
Question removed	~~How many service users have a current Adults with Incapacity (Scotland) Act 2000 (AWI), Section 47 consent to treatment certificate?~~ ~~*Number*~~
	How many service users did you have at 31 December who have needs in relation to the following: (Note – only include those service users who were actually using the service at 31 December) *Text*
	Diagnosed Dementia *Number*
	Mental Disorder (other than dementia) *Number*
	Visual Impairment *Number*
	Hearing Impairment *Number*
	Mobility Impairment *Number*
	Use of Equipment to assist mobility (e.g. wheelchairs and walking aids) *Number*
	Complex Conditions? Examples of complex conditions include: epilepsy, respiratory disease, heart disease; or, conditions which require the use of PEG feeding, oxygen therapy, suction, nebulisers, etc. *Number*
	Treatment of Infection *Number*
	Pressure Ulcers / Wounds *Number*

	Use of Pressure Reducing Equipment to promote pressure reduction comfort and support (e.g. pressure reducing active or static mattresses or pressure cushions) *Number*
	Urinary Catheter *Number*
	Diet to increase or maintain weight such as food fortification *Number*
	Prescribed medication for constipation *Number*
	PEG feeding or other tube feeding *Number*
	Prescribed dietary supplements such as sip feeds or energy supplements (for example: Ensure, Fortisip, Pro-Cal, Shot, Forticreme) *Number*
	Total assistance with eating and drinking *Number*
	Partial assistance with eating and drinking (e.g. cutting up food, intermittent assistance or prompting) *Number*
	Modified textured food such as a finely mashed or thick pureed diet *Number*
	Diabetes – on insulin *Number*
	Diabetes – not on insulin *Number*
	Assistance with Washing / Bathing / Showering *Number*
	Behavioural Support and Management *Number*
	Intravenous / Intramuscular/ Subcutaneous / pen devices medication *Number*
	Medication Administered Rectally *Number*
	How many service users had a body mass index less than 20 as at 31 December? *Number*
	How many service users had a body mass index of 20 to 25 as at 31 December? *Number*
	How many service users had a body mass index of over 25 but less than 30 as at 31 December? *Number*

	How many service users had a body mass index of 30 or over as at 31 December? *Number*
	How many service users were on a food monitoring chart as at 31 December? *Number*
	How many service users were on a fluid monitoring chart as at 31 December? *Number*
	Do you use a formal tool to assess the dependency levels of service users? *Select one only:* Yes No
	Please provide a description of the tools you use and whether their use has influenced staffing levels. *Text*
	If your service cares for people diagnosed with dementia, have you used the 'Dementia Skilled – Improving Practice' (NHS Education for Scotland 2012) learning resource document? *Select one only:* Yes No
	If 'Yes', how many staff have completed:
	All the modules? *Number*
	Some of the modules? *Number*
Help Text Using the falls management resource pack and following the guidance can help reduce falls and the serious problems caused by falls – such as: pain and suffering, disability, loss of independence and decline in quality of life.	Do you use the 'Managing Falls & Fractures in Care Homes for Older People' resource pack? *Select one only:* Yes No Not applicable – service does not provide care for older people
	If yes, have you completed the self-assessment and compiled an action plan to address any gaps? *Select one only:* Yes No

Help Text: As a fall is nearly always due to one or more 'risk factors', identifying them and removing or altering an individual's risk factors can often prevent a fall. The multi-factorial falls risk assessment helps you to tackle this.	Has every resident in your care home had a multi-functional falls risk assessment completed – Tool 5. *Select one only:* Yes No
	What methods do you use to provide training in falls and fracture prevention and management? *Select all that apply:* Falls awareness DVD issued with resource pack In-house training Attend local training provided by Multi-Disciplinary Team Falls leads in local Health Boards Other
	If 'Other', please provide details. *Text*
	Do you have support from the wider health and social care team in relation to falls & fracture prevention and management? *Select one only:* Yes No
	How many people in your service have had a fall in the past year? *Number*
	How many people in your service were admitted to hospital due to a fall in the past year? *Number*
Help Text: Strength, balance and walking are key programme components for interventions in older adults - it is helpful to think about this when encouraging older people to be active.	How many service users take part in physical activities where strength, balance and walking are key aspects? (This can include any everyday tasks that they like to do.) *Number*

Help Text: As physical activity can improve the physical and psychological health of older adults it is useful to ensure that their needs are detailed in their care plan to help staff to facilitate this.	How many service users have their physical activity needs and choices noted in their care plan? *Number*
Question reworded Help Text: There are various community supports that can help support you to engage older people in physical activity - such as Falls Leads, Physical Activity Leads, Gyms, etc.	**Do you have support to encourage day-to-day activity in your service which supports the physical wellbeing of service users?** *Select one only:* Yes No
	If 'Yes', please provide details of the support provided? *Text*

Section – Continence Care

Question removed - already exists in another section	~~How many service users do you have at 31 December who are incontinent?~~ ~~*Number*~~
New question	**How many service users did you have at 31 December who were only incontinent of urine (enter 0 if none)?** ***Number***
New question	**How many service users did you have at 31 December who were only incontinent of faeces (enter 0 if none)?** ***Number***
New question	**How many service users did you have at 31 December who were incontinent of urine and faeces (enter 0 if none)?** ***Number***
	How many service users used containment products to help in the management of continence (e.g. pads, pants) at 31 December? *Number*
New question	**How many service users had a urinary catheter in place at 31 December (enter 0 if none)?** ***Number***
	How many staff have completed continence management training? *Number*

Section – Palliative Care

Help Text: A copy of this document can be found on the Scottish Government website at: http://tinyurl.com/d66hyqs	Do you have a copy of the NHS Scotland 'Do not attempt cardiopulmonary resuscitation' (DNACPR) integrated adult policy (2010) *Select one only:* Yes No
	Have you implemented the NHS Scotland 'Do not attempt cardiopulmonary resuscitation' (DNACPR) integrated adult policy (2010) *Select one only:* Yes No
	If 'Yes', when was the above DNACPR policy implemented in your service? *DDMMYYYY*
	How has the DNACPR policy been implemented in your service? Please describe any education and training provided and who delivered the education. The dates on which the training and education was provided should also be included. *Text*
	When did you last review any local DNACPR policy? *DDMMYYYY*
	How many of the residents who died in your care home between 1 January and 31 December had a NHS Scotland DNACPR form? *Number*
	Do you have a verification of expected deaths policy for allowing nurses, once they have had appropriate training, to confirm deaths that General Practitioners have considered likely to happen? *Select one only:* Yes No
	When did you review the verification of expected deaths policy? *DDMMYYYY*
	Has your service implemented the Liverpool Care Pathway (LCP) or equivalent)? *Select one only:* Yes No
	If 'Yes' to the above question, how many of the residents who died in your service between 1 January and 31 December were supported by the LCP or equivalent? *Number*

	Please provide any comments regarding your use of the LCP, number of deaths and/or any details of equivalent integrated care pathway used) *Text*
	Which assessment methods for pain do you use? *Select all that apply:* Abbey Pain Scale Disability Distress Assessment Tool Doloplus 2 Scale Other None
	If "Other" or "None" please provide details/comments *Text*
	Please indicate all the methods you use to provide education to staff on palliative and end of life care? *Select all that apply:* Macmillan Foundation Pack Work with nurse specialists in palliative care Attend local palliative care link nurse meetings Educational course at hospice E-learning course Practice development facilitators for palliative care come to the care home None Other
	If "Other" or "None" please provide details/comments *Text*
	Do you have a bereavement policy, including a procedure for Last Offices? *Select one only:* Yes No
	Do you have a copy of 'Shaping bereavement care – a framework for action (2011)'? *Select one only:* Yes No

Help Text The ePCS improves communication between patients, carers and professionals at all stages of the patient journey by allowing data to be sent automatically and on a daily basis from GP systems to Out of Hours (OOH) services.	Of the residents who died in your care service, between 1 January and 31 December, did the GP use Electronic Palliative Care Summary (ePCS) *Select one only:* Yes – in all or most cases Yes – in a few cases Not Used Not aware whether used or not Not applicable – no deaths in the service
Help Text: Information about anticipatory care plans can found on the Scottish Government website at: http://tinyurl.com/ceeggst	How many of the residents who died in your care home between 1 January and 31 December had an anticipatory care plan (ACP)? *Number*

Section – Pressure Area Care

	How many service users had wounds which were classified as pressure ulcers at 31 December? *Number*
	Using the Scottish adapted European Pressure Ulcer Advisory Panel (EPUAP) grading tool, please record the number of pressure ulcers on 31 December by grade below:
	Grade 1 (non blanching erythema) *Number*
	Grade 2 (partial thickness skin loss) *Number*
	Grade 3 (full thickness skin loss) *Number*
	Grade 4 (tissue damage extends to muscle and bone) *Number*
Question removed	~~How many service users were admitted to the service with pressure ulcers over the year to 31 December?~~ ~~*Number*~~
	Do you use the 'NHS Scotland pressure ulcer safety cross' to monitor pressure ulcers? *Select one only:* Yes No

Section – Staff Members

Please provide the information below for each member of your staff who has worked for you over the past year to 31 December. **Please note only staff who are on your payroll should be included**. Students or trainees on placement, and volunteers must not be included in this section.

	Staff initials:
	Please provide details in the section for each staff member who has worked for you over the last year, to 31 December. Only include staff who are on your payroll. Students or trainees on placement must not be included in this section The information in this Section will be shared with the Scottish Social Services Council and the Scottish Government, and used for developing, monitoring and evaluating policies about the social care workforce. We may use information about ethnicity and disability to monitor the impact of our policies and ensure they do not discriminate. We will share this information with the Scottish Government and the Scottish Social Services Council who will use it for workforce planning purposes. Our Inspectors will not be able to view this information
	Gender: *Select one only:* Female Male Other Not Known
	Date of Birth: *DDMMYYYY*
	Date employment commenced with current employer *DDMMYYYY*
	Date employment commenced in current post: *DDMMYYYY*
	Where was the employee recruited from: *Select one only from list of Entry Sources*
	Contract Type: *Select one only from list of Contract Types*
	Have they completed induction training: *Select one only:* Yes No Not Known

	Have they completed manual handling training: *Select one only:* Yes No Not Known Not Applicable
	Have they completed health and safety training: *Select one only:* Yes No Not Known Not Applicable
	Have they completed infection prevention and control training: *Select one only:* Yes No Not Known Not Applicable
	What are the typical hours worked (including overtime) per week (Please complete this as a decimal e.g. 30 minutes = 0.5 hours). *Number*
	What is their typical working pattern? (Select as many as are applicable to the post. To select multiple options from the list, hold down the "Ctrl" key and make your selection). *Select all that apply from list of Working Patterns*
	Job title: *Text*
	Job Function: *Select one only from list of Job Functions*
	This information will be passed to the Scottish Government and the Scottish Social Services Council for workforce planning purposes. What is the ethnic group of the staff member? *Select one only from list of Ethnic Groups*