CHAPTER 1: INTRODUCTION

1.1 CONTEXT

"We know how to deal with the technology. It's the people that are the problem."

IT Manager; Oil and Gas Supply Chain. (CP12)

The theme of this thesis developed in response to the concerns of the many managers interviewed by the author in different contexts, from energy to health and to financial services - all involved in managing the migration of local work processes to a more global platform.

Their training had prepared them to solve technical problems, rather than the sociotechnical and socio-political ones that characterised infrastructure at such scale. They pointed to the lack of support or professional development for addressing these issues, together with the impact they had on the performance of systems, and the businesses that relied upon them. Subsequent research interviews with senior managers in some of the largest international companies in different fields reflected similar experiences of the issues in aligning standardised digital infrastructure with the aims and modus operandi of very diverse and distributed local communities. Yet because of reasons of commercial sensitivity, classical problems and failures were not shared. The vision underpinning the funding of extended enterprise systems, global portals and international safety software was much more problematic on the ground than might have been anticipated from what was available in the public domain.

I was a relatively new researcher, in an emerging field, where theory, practice and terminology had not coalesced. Digital technology was reconfiguring the relationships between people, processes and technologies in new ways that impacted on economic, professional, political and organizational relationships in often unanticipated ways. My background in developmental psychology and educational research may have contributed to a preference for viewing technology in the wider social context in which it is embedded, and to then explore the

impact of different alignments of the two from a sociotechnical perspective, as outlined in Chapter 2.

The publications presented derive from a series of nationally-funded projects in eLearning, eBusiness and eHealth over ten years, in the evolution of the digital infrastructure from more static, technology inspired paradigms such as databases, to more user centred paradigms such as social networking media. The issues that arise in developing and implementing digital infrastructure at scale were explored iteratively across domains.

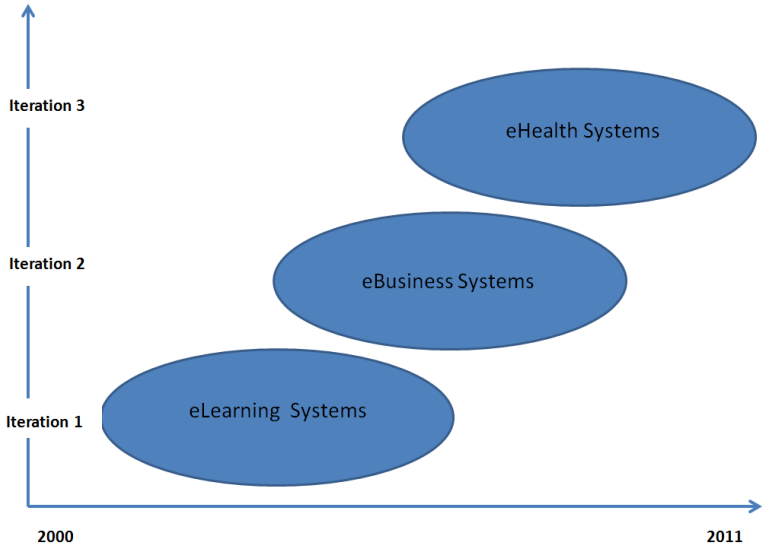

Fig.1.1 Three iterative cycles of research over a 10 year period.

The publications also explore the evolution of strategy in addressing these issues, and the implications for minimising cost and risk in these large scale public and commercial investments. These issues were under-represented at the time. The failure of many large-scale, flagship ICT-projects, such as the NPfIT [1] in the NHS, have since raised awareness of the more sociotechnical and socio-political issues in the design and implementation of ICT at scale, and the lack of transfer of knowledge of such issues from other projects and other sectors (Peltu 2008, Eason 2007, NHS23b 2007b).

1 National Programme for IT in the National Health Service

The thesis points to the implications of this for research and professional development at a time where education, business, health and economic markets increasingly depend on digital infrastructure at scale.

The Research Themes section scopes these underpinning issues in three different domains (eLearning, eBusiness and eHealth). It draws on the insights of stake holding users to identify a range of recurring issues with implications for cutting cost and risk in the design of large scale infrastructure.

1.2 RESEARCH THEMES:

The thesis is constructed around the issues in aligning the technical and the social at scale, and the potential to learn from the evolution of strategy in other domains.

- How do designers and managers align standardised digital infrastructure with the needs of different user communities?
- Are there recurring issues and strategies across domains?
- How has sociotechnical infrastructure evolved to address these?
- What are the implications for design, research and development?

These questions run through the research across three different domains.

How do Designers and managers align global infrastructure with the local needs of disparate user communities?

Large scale IT systems need to resolve the tensions between a standardised digital infrastructure that provides interoperability and economies of scale, and the local requirements of very different communities on which adoption and use depend.[2] In addition to being diverse, these needs are often emergent, unpredictable, and change over time.

Taking one example from in the implementation of a tele monitoring service (CP7) , the requirements of GPs, nurses, patients and researchers in a monitoring service served very different purposes, requiring different levels of access and security, and different formats. There were requirements for new ethical and legal agreements with regard to who could now have access to what data, which had the potential to prevent use of the system altogether, or to invoke fundamental changes to the roles and risks involved.

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2 Goguen (1994) was an early proponent of the view that requirements engineering was about reconciling social and technical issues.

The emergent and often unanticipated impact of such systems on roles, risks and resource allocation requires significant renegotiation at a professional, an ethical, an organisational and often a legal level, and the thesis argues for the value of involving stake-holding users in this process if these issues are to be identified and addressed effectively.

The move towards increasingly large scale online collaborations across multiple sites has exacerbated the problems in managing the competing needs of different user groups.

- Should ‘one size fit all, for example?
- Should some services be generic, with some services managed locally to meet local needs?
- What models are there?
- What has worked in other domains?

This is one of the most pressing tensions in the design of networked systems at scale (Edwards et al 2007). The thesis argues that there has been little transfer of the lessons from other domains, and looks at the experience of addressing these problems across three disciplines.

Many of the more recurring issues in aligning this new digital infrastructure with the working practices of different communities are evident in the early eLearning papers, and re-appear in subsequent eBusiness and eHealth papers, where they are explored and developed.

Are There Recurring Problem/Solution Scenarios Across Domains?

Nationally funded research in eLearning, eBusiness and eHealth provided the opportunity to look at the response to these recurring problems in very different domains, as they moved towards greater use of digitally mediated information and collaborative working. Migrating the work processes of a multiplicity of different user communities to standardised digital systems at scale has created tensions which are evident across eLearning, eBusiness and eHealth. The value of the

research derives in part from engagement with stakeholding users in these communities experiencing these issues at first hand, and teasing out some of the more recurring problems, and solution strategies developed to minimise cost and risk.

Chapter 3 – ‘Building Constituency; Developing Strategy’, highlights a process of engaging with other communities addressing similar issues. This involved organizing International Conference Tracks on sociotechnical issues, publishing an overview of the kinds of issues most cited by managers for the British Computer Society (CP2) and carrying out a series of invited lectures for IT managers through the BCS. The publications cover sociotechnical issues in projects carried out in the oil and gas supply chain, in renewable energy clusters, (CP3) and in procurement systems in the automotive supply chain. These activities underlined the concerns of managers, and their perceptions about the lack of accessible research and professional development on the non-technical aspects of project development that occupied most of their time.

The papers look at these issues in most detail in Chapter 4, in the context of eHealth and telehealth systems in the HealthGrid papers (CP4, 5) and the telehealth publications (CP7, 8). This Chapter frames them more explicitly in the literature, with more rigorous and transparent research methods, and with more formal impact in terms of citations.

In Chapter 4, Informing Theory and Practice (eHealth) the process of engagement with other international programmes was extended to eHealth, validating shared issues as part of a European roadmap, and informing strategy for joint working on shared standards in the same domain. This was subsequently included as part of a European White Paper on the challenges facing HealthGrids in this context, (CP4) and is one of the two most frequently cited papers in the thesis.

Combining research and development

Figure two highlights the way this is framed in the research papers - as stages in a developmental process, where different strands come together at key interfaces, and where there are optimal opportunities for intervention to mitigate risk. Mapping key issues at key interfaces provides a basis for intervention, but also, at times, to create synergies.

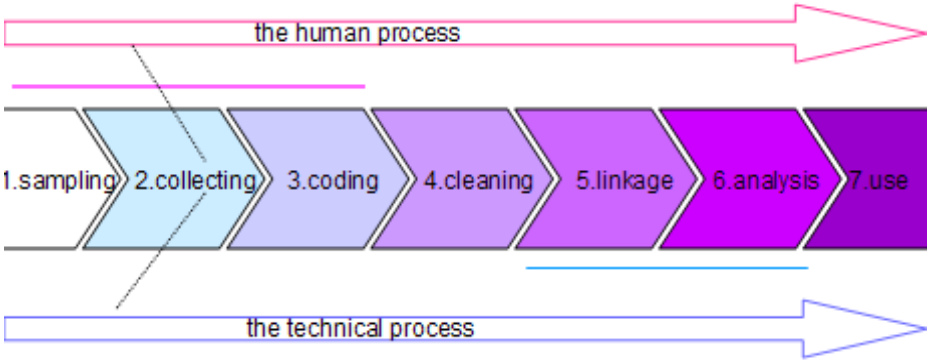

Fig. 1.2. Data sharing issues in HealthGrids. (Ure et al. 2007c)

This is resonates with the approach adopted by the NIHR [3] in the reconfiguration of care pathways by stakeholding users (Bate & Robert, 2006; 2007), and was also familiar in business contexts as collaborative process re-engineering (Hammer and Champy 1993). One theme that runs through the thesis is the extent to which participatory methodology is a catalyst for engagement and change.

How has sociotechnical infrastructure evolved to address these issues?

The thesis highlights recurring sociotechnical (as opposed to technical) problems which arise from the way people, processes and technologies are aligned (or misaligned) at different stages in development or use, and points to successive visions of how the social and the technical can most usefully be aligned.

[3] NHS Institute for Innovation and Improvement(NIHR): Experience Based Design http://www.institute.nhs.uk/quality_and_value/introduction/experience_based_design.html

It presents a framework for understanding developments, contextualized in the literature and in recent practice. All the papers deal with the design and implementation of large scale infrastructure in terms of the way distributed technical and human systems are aligned.

The mind map in Fig. 1.3 is intended to give a flavour of some of the recurring issues and approaches that characterised the eHealth papers (CP4-8) and were also evident in the eBusiness papers.

What are the implications for design, research and development?

The thesis discusses the implications of the research for research and professional development. In particular, it points to the lack of professional development in addressing recurring design and implementation issues in large scale infrastructure which brings together complex digital and human systems in new ways.

It also reflects on the importance of a more rapid and responsive feedback loop from emerging practice on the ground, to professional development and to policymaking. It highlights approaches which have been adopted to leverage the knowledge of stake-holding users in practice, and feed back more rapidly into policy & professional development.

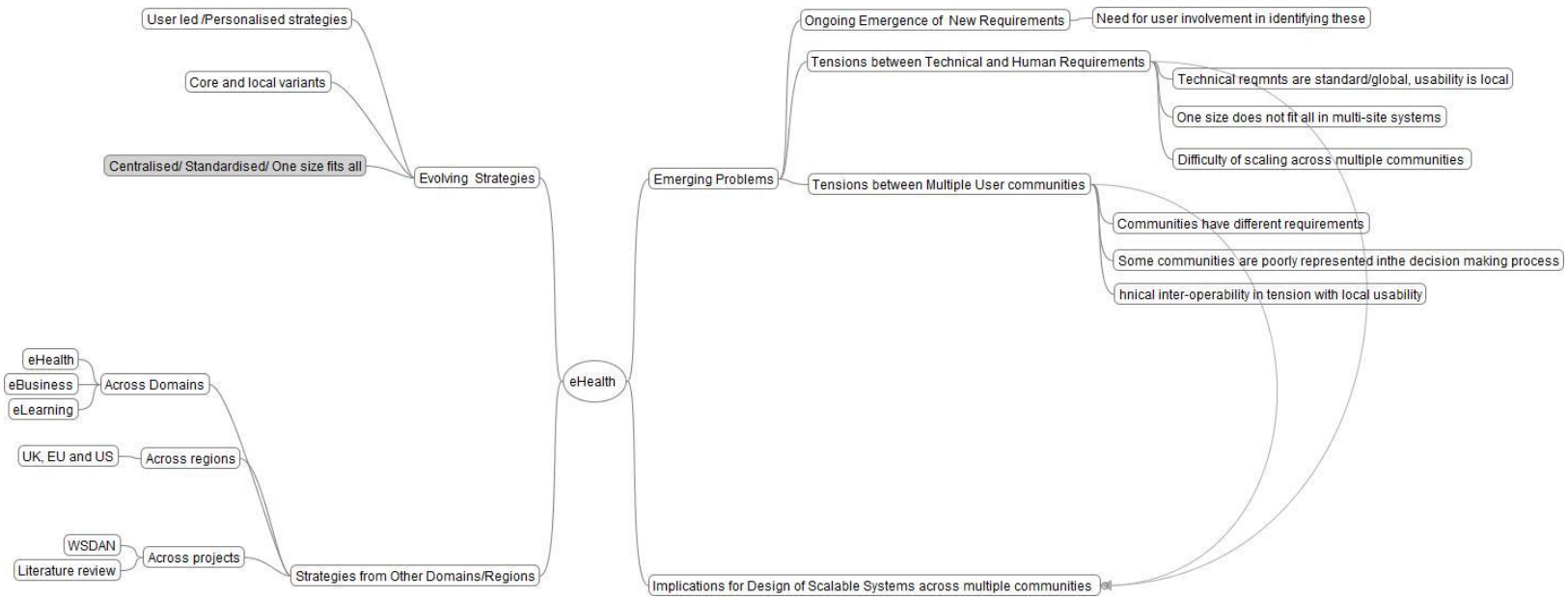

Fig.1 3. Thematic Overview: recurring problems and strategies in a tele-monitoring project. (CP4.5)

1.3 RESEARCH METHODS

This project shaped my view of (a) the kinds of research methods that would unpick such issues on the ground, and (b) the ways in which this could be developed to extend the role of users in co-designing systems. This is a theme which is developed throughout the thesis.

In almost all the papers presented, qualitative research methods were used (Denzin et al 2000; Guba et al 1989) particularly grounded theory (Corbin and Strauss et al 2008; Glaser 1999) and collaborative action research (Carr and Kemmis 1986).These were the main vehicle for exploring the issues with users of the systems in question, whether eLearning, eBusiness or eHealth. This means that issues and concerns are not pre-determined, but emerge and are validated successively over time. The research space itself can also provide a catalyst for discussion and change in that it allows users (often for the first time) to share a diversity of concerns, and negotiate different possible scenarios, as exemplified in CP, 8 in particular. Collaborative and iterative approaches provide advantages where research raises issues which then require development, negotiation and change management,

Complex healthcare interventions impact on clinical, organisational and care processes in ways that cannot always be adequately explored using quantitative methods alone (Levin et al. 2009). Nested qualitative work that brings users together around emerging issues, as for example in collaborative action research/participatory research, grounded theory, or in realistic evaluation (Pawson 2001), can refine or raise new research questions as well as illuminating possible barriers of an operational, technical, clinical, ethical, organisational, contextual or patient specific issues.

Fig. 1.4 provides an example of the approach taken in a research project evaluating the issues in implementing a new telemonitoring service with patients with chronic obstructive pulmonary disease (COPD) at home. (CP7, 9)

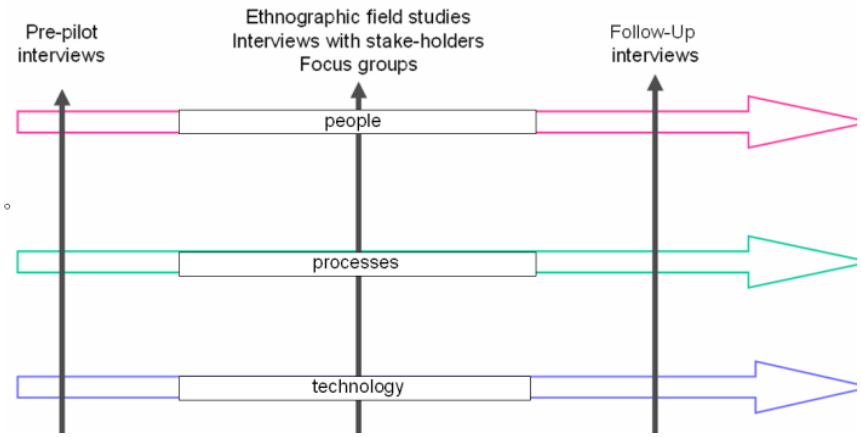

Fig.1. 4. Using collaborative action research as part of the research and design process (CP4).

Analysis

Typically, coding of interviews was iteratively refined using paired analysis of transcripts by two researchers and further refined in collaboration with the wider group. These issues, together with the outcomes of recorded observation studies provided a basis for feedback to the wider team, and in the context of the workshop, to stimulate discussion in order to refine the emerging issues.

Focus groups provide a means of validating, refining and taking forward the issues arising from interviews or ethnographic observation. Stakeholder analysis (Fletcher et al 2003) can also be facilitated through these activities. As this suggests, this kind of approach also provides a vehicle for engaging users in the process of change management (May et al 2003), such as the renegotiation of care pathways or business processes. Here problems emerge unpredictably in practice, and their resolution requires negotiation of new roles and risks with users as an integral part of the process.

Much of the development in the latter publications has been on the economic and the democratic argument for involving users as a an indispensable resource in the process of designing, implementing and maintaining systems that reconfigure the services they use, their roles in them, and the roles, risks and responsibilities afforded by different arrangements (Ure 2011c).

Recent MRC Guidance for Clinical Trials (Anderson 2008) now recommends the inclusion of this kind of research to inform large scale trials and service developments, and identifies this as a means of cutting cost and risk, and ensuring that the investment in system and service design is usable in practice.

Design at scale arguably requires the redesign of work practices themselves, with stake-holding users able to bring local knowledge and agency to bear – not only as a reflection of their rights, but also as a means of ensuring cost-effective outcomes. This view is increasingly evident in new government recommendations that reflect a changing view of users as a resource in the co-production of services (Loeffler 2012; Boyle and Harris 2009).

1.4 CRITICAL ANALYSIS

The thesis aims to demonstrate how the publications form a coherent body of work, how they contribute to theoretical and practical knowledge in this area, and how the author has developed her thinking in the course of the journey.

As the eLearning, eBusiness and eHealth publications were developed chronologically around nationally funded projects (SHEFC[4], ESRC[5], MRC[6] and CSO[7]), the published final reports provide a chronological backbone for the thesis, with journal papers illustrating the development of the themes in context, for different disciplinary audiences.

The Core Papers (CP 1-9) reflect a process of discovery and development in three successive cycles – in the design and implementation of infrastructure in national projects on eLearning, eBusiness and eHealth. The final project reports provide core staging posts in the process of synthesis and reflection, and the other publications are summaries of this (or aspects of this) for particular audiences and particular purposes.

The first cycle (Chapter 2) highlights the exploratory phase of understanding emerging issues through dialogue and reflection with colleagues in an eLearning project, in the course of interviews, observations and reviews of the literature.

The second cycle (Chapter 3) highlights the process of synthesis and development through engagement with other communities- re-discovering and reflecting on the issues in the context of extended business and engineering enterprises.

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4 SHEFC Scottish Higher Education Funding Council

5 ESRC Economic and Social Research Council

6 MRC Medical Research Council

7 CSO Chief Scientists Office (Scotland)

Chapter 4, on Health, shows the more formal development and dissemination of the theoretical frameworks (CP6), the synthesis of the recurring sociotechnical alignment issues with implications for design and implementation strategy (CP 4, 7).

Chapter 5 pulls these together in relation to the over-arching research questions. It reflects on the strengths, weaknesses and contribution of the research and the implications for future eInfrastructure. It also points to the potential to rethink research and training infrastructure itself if this is to bridge the gap between theory and practice, given the speed of change on the ground, and the scale of investment in high risk infrastructure projects.

The natural geography of the landscape has been used here, since the evolving themes and the associated journal papers flow naturally from and through them. The challenges of aligning distributed technical and human systems are evident in each of these contexts, and they provided recursive opportunities to observe the recurrent nature of the problems that can arise, and the different ways in which these challenges are addressed.

They also highlight the lack of transfer between disciplines (and across borders) in the design and implementation of high cost, high risk systems at scale. This thesis, like the publications it discusses, has a focus on raising awareness of the recurring issues, and of the potential to re-use rather than re-invent some of the solutions that have evolved.

The approach by Coghlin and Brannick (2005) seemed to extend and encapsulate this cyclical process in a way that lent itself to the narrative of this thesis as a revisiting of ideas in successive domains. Coghlin and Brannick (2005), like Kolb (1984) and Schön (1983), were influential approaches in the context where of design research, and educational research where CP1 was written, and provided an intuitive way forward within that community.

Aims and Research Questions

The papers all provide theoretical and/or empirical evidence for the role of different underpinning visions of the alignment of technical and human systems. They all look to some extent at the way in which interdependencies between technical and human systems reconfigure costs, risks and resource allocation in eInfrastructure, and highlight the implications of that for design, for implementation 'in the wild', (Hutchins, 1995) and for the reconfiguring of work practices, and more widely, the role of users.

In the Chapter 6, the Discussion Section, I reflect on the personal journey, on the strengths and weaknesses of different approaches, and on my perception of the impact and implications of this series of research cycles for

- advancing theory (particularly in relation to sociotechnical systems theory and the move to more user-centric models)
- the use of methodology (particularly in relation to complex, dynamic contexts)
- practice (identifying strategies for optimizing the design/management of infrastructure at scale and minimising cost and risk)

Selection of Papers

The choice of papers reflects their role as signposts in my own journey, identifying these issues in practice, through collaborative action research with users. The earlier work, (focused on awareness-raising and dissemination of these sociotechnical issues) was strongly oriented towards those International Conferences with most impact in the international fora for eBusiness, eScience and eHealth communities, in an as yet emergent field. The book chapters cited are all double or triple reviewed, and have a high impact on a very wide audience in

emerging areas of particular interest. As awareness of more sociotechnical and socio-political tensions in infrastructure design and implementation have been fore-grounded (Star 1999; Edwards et al 2003, 2007; Ribes & Finholt, 2009; Ribes and Lee 2010; Bowker et al 2010), often in the context of project failure, there has been more scope for publication in mainstream journals.. [8]

Evidence of Impact

In addition to the use of journal publications, other indications of impact have been included, along the lines suggested by Duryea (2007), including indications of engagement with professional communities, impact on policy and practice, and evidence of added value or changes in policy or practice. Workshops, invited lectures and testimonials are included as part of this.

The publications follow a natural progression from initial personal engagement with/ reflection on the issues in eLearning. In the second phase in eBusiness there is more focus on dissemination to/ engagement with other communities at an international level. Impact here is evidenced by papers, but also by engagement with a wide range of professional communities using technology at scale, and addressing similar challenges. International Workshops and Conference Tracks and Invited Lecture Series are also covered to evidence impact on the academic and the professional engineering, computing, business, design and education communities in several countries.

[8] The Journal of Computer-Supported Collaborative Work (Springer) increasingly covers these topics, and the Journal of the Association for Information Systems has included more sociotechnical articles in recent years.

Structure

Each paper looks at the context and the audience, given a brief overview of the Content, evaluated the strengths and weaknesses of the approach and sought to identify the contribution of the publication to theory and/or practice, with an indication of impact. Developing and emerging themes are also evidenced through core and supporting publications. The core and supporting papers have been chosen to show the progression of the main cross-cutting themes across the three domains.

Core Publications were chosen in terms of their ability to signpost that progression (i.e. impact on my own development as well as impact on the field).

The proposal and the PhD by Publication are constructed around

Core Publications	9
ISBN conference papers	10
Book chapters	11

Table 1 provides a two page overview of the papers which are the core of the thesis.

Table 1		
eHealth 2006-2012		
CP 9	Ure, J., Hanley, J., Irshad, T., Whyte, A. Pagliari, C., Pinnock, H., McKinstry, B. (2011) Curating Complex, Dynamic and Distributed Data: Telehealth as a Laboratory for Strategy.	[**Journal**] *International Journal of Digital Curation.* 6, (2):128-145. ISSN 1746-8256 http://www.ijdc.net/index.php/ijdc/article/view/187/267
CP 8	Ure, J., Hanley, J., Pinnock, H., Pagliari, C., and McKinstry, B. et al (2012) Piloting telemonitoring in Chronic Obstructive Pulmonary Disease: a mixed methods exploration of issues in design and implementation.(Accepted 2011)	[**Journal**] *Primary Care Respiratory Journal (PCRJ)* International Journal of the Primary Care Respiratory Group. 21(1):57-64. ISSN 1759 58X http://www.thepcrj.org/journ/vol21/21_1_57_64.pdf
CP 7	Ure, J., Kydd, G., Tarling, A., McKinstry, B., et al (2009) Reconfiguring Care for Chronic Disease with Home Monitoring: A Pilot Study Report on Telemetry-Supported Care for COPD Patients in the Lothian Region.	**[Report]** Final Report to Intel UK, and the Scottish Centre for Telehealth. *Edinburgh University Centre for Population Health Sciences.* Ed. Res. Archive : http://hdl.handle.net/1842/5828 www.telescot.org/uploads/4/5/9/4/4594120/telescot-copd-pilot-report.pdf
CP 6	Ure, J., Rakebrandt, F., Lloyd, S., Khanban, A., Procter, R. et al. (2009) Giving Them Something to Hate: Using Prototypes as a Vehicle for Early Engagement in Virtual Organizations.	*[**Journal**] Social Science Computer Review,* 27(4):569-582 ISSN: 0894-4393. Sage. http://ssc.sagepub.com/content/27/4/569.abstract
CP 5	Ure, J., Procter, R., Lin, Y., Hartswood, M., Anderson, S., Lloyd, S., Wardlaw, J., Gonzalez-Velez, H. and Ho, K. (2009) The Development of Data Infrastructures in eHealth: A Sociotechnical Perspective.	[**Journal**] *Journal of the Association For Information Systems (JAIS),* 10 (5) Art. 3.ISSN: 1536-9323 http://aisel.aisnet.org/jais/vol10/iss5/3/
CP 4	Ure, J., Procter, R., Martone, M., Porteous, D., et al (2007) Data Integration in eHealth: A Domain/Disease Specific Roadmap.	[**Chapter**] In *HealthGrid 2007: From Genes to Personalized HealthCare: Grid Solutions for the Life Sciences*. Vol. 126:144-153, Studies in Health Technology& Informatics. IOS Press. ISBN:1-59593-298-4 http://geneva2007.healthgrid.org/fileadmin/presentations/session_8/4_ure.pdf

ELEARNING 2002-2004		
CP 1	Ure, J., Malins, J., and Cullan, L. (2002) Studiospace: a virtual learning environment for teaching and learning in art and design.	[**Report]** Final Report to Scottish Higher Education Funding Council. *Robert Gordon University Press*. ISBN 1901 085 66X
EBUSINESS 2005-2011		
CP 2	Ure, J. and Jaegersberg, G. (2005) Invisible Architecture: The Benefits of Aligning People, Process and Technology: Case Studies for System Designers and Managers.	[**Book**] British Computer Society. ISBN: 9781902505596 http://www.bcs.org/server.php?show=nav.5917
CP 3	Jaegersberg, G. and Ure, J. (2011) Barriers to Knowledge Sharing and Stakeholder Alignment in Solar Energy Clusters: Learning from Other Sectors and Regions. (Joint co-authorship)	[**Journal**] *The Journal of Strategic Information Systems*, 20 (4):343-354. Elsevier. ISSN: 0963-8687 http://www.sciencedirect.com/science/article/pii/S0963868711000187

1.5 CONTRIBUTION TO THE FIELD

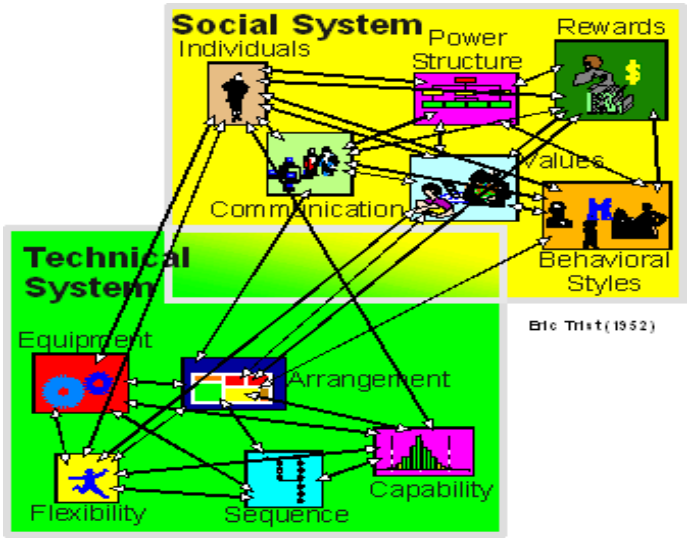

Fig. 1.5. An early conceptualisation of sociotechnical systems. (Trist, 1950)

Extending the application of sociotechnical theory across domains

The thesis extends the application of sociotechnical theory and method to the design of digital infrastructure across three domains, and links cognate strands of the discourse across work by authors in each of these contexts. This bridges the work of theorists in ICT assisted systems in education, business and health, and highlights some of the generic socio-technical issues which are currently not addressed in professional development, as recent failures of flagship systems attest (Peltu & Eason 2008).This in part reflects the gap in theory, and practice with regard to the successful design and implementation of such systems at scale – where there are opportunities to learn from other projects and other regions.

Each section of the thesis (eLearning, eBusiness, eHealth) also provides an extensive review of the domain specific literature, highlighting the different discourses, and the contribution of the research in those contexts. The publications take sociotechnical

systems theory (STS) as one possible overarching umbrella for looking at how technical and human systems can be aligned to advantage, and how misalignment can create cost and risk.

What is sociotechnical systems theory?

Sociotechnical systems theory is derived from the early work of Mumford (1983, 2003, and 2006), Trist (1950, 1974, 1976, and 1981), Emery (1959, 1960, 1964, 1983) Pasmore (1988; 1995) and Cherns (1976; 1987). It grew out of research on the impact of introducing new engineering technology on work practices in coal-mining, where the prevailing vision of standardised technology failed to deliver the promised cost-efficiencies - in large part because of misalignment of technical systems with local work practices. Figure one highlights the emphasis on how very different systems come together as a hybrid whole in this theory.

Then as now, technology afforded new opportunities for aligning people, processes and technologies, and reconfiguring roles and rights in enacting and managing them. The competing views of how this new technically assisted society should be constituted, by whom, and how, resonates with similar debates in today's emerging digital territories, and is one of the cross-cutting themes.

> "From the beginning the sociotechnical concept has developed in terms of systems, since it is concerned with interdependencies. It has also developed in terms of open systems theory, since it is concerned with the environment in which an organisation has actively to maintain a steady state. Von Bertalanffy's paper (1950) on 'Open Systems in Physics and Biology' became available at the time that the sociotechnical concept was being formulated."
>
> Trist, 1981

The early sociotechnical systems theorists thus provided the first theoretical framework for understanding technology-assisted work in terms of the alignment (or misalignment) of 'coupled' social and

technical systems. In this they anticipate the issues in the emergence of large scale ICT-assisted systems.

> "The technical and social systems are independent of each other in the sense that the former follows the laws of the natural sciences, while the latter follows the laws of the human sciences and it is a purposive system. Yet they are correlative in that one requires the other from the transformation of an input into an output, which comprises the functional task of a work system. Their relationship represents a coupling of dissimilar which can only be jointly optimised. Attempts to optimise for either the technical or the social system alone will result in the sub-optimisation of the sociotechnical whole."
>
> Emery, 1959

Developing cross-cutting themes/identifying recurring issues

Technology, and technological paradigms often embody assumptions about social and technical arrangements, (Agre, 1997, Dourish, 2001; 2011), and the thesis follows this strand of thinking across three domains, looking at how each has iteratively reinvented this wheel in the move from the 'vision' of seamless data sharing at scale to more nuanced combinations of scalable and local, and ultimately to the more user centric view of infrastructure at scale. The papers bridge the work of relevant theorists in each domain in this regard, from the social shaping agenda of social studies of science and technology (Williams, 1996) to collaborative computer assisted working (CSCW) in the work of Paul Dourish (1992), Actor Network Theory (Callon, 2006) and the various flavours of constructivism (Giddens 1984) such as enactment theory (Orlikowski, 1992) and the leverage of users and communities in social network media outlined by Tapscott and Williams, 2006 in particular. (These are reviewed in detail in CP1 and 2.)

This work, through what then became the Tavistock Institute, pre-figured many of the issues in the introduction of more digital

technology on work practices, and is only now being fully acknowledged as a useful theoretical lens. Over fifty years later, in Los Alamos labs in the US, Joslyn and Rocha (2000) still take a sociotechnical systems view of defence systems, where the alignment of technical and human is, like DNA, seen as a 'coupled system' where synergies are possible, and were misalignments are costly and to be avoided. They define these coupled systems as "depending on the interaction of physical systems that are deterministic with human systems which are less so". The thesis tries to draw out the commonalities across domains in aligning the social and the technical, and the recurring issues which arise.

A key motivation for drawing together examples of recurring issues across domains, is to highlight the potential for incorporating these in professional development. The eHealth and eBusiness papers also suggest approaches to sharing the experience of those in other domains and other regions, providing examples of the potential to cut cost and risk by avoiding known risks. This is a principal aim of the research presented.

Mapping Conceptualisations of Sociotechnical Systems

One of the principal contributions of the thesis is to map the evolution of different approaches to aligning these different strands, and reflecting different ways of thinking about the relationship between technical and human systems.

One-size fits all.

First generation eHealth systems (and eBusiness systems) focused on the value of economies of scale, facilitated by the interoperability afforded by standardized formats and protocols. In this initial vision of seamless data, diversity across users was seen as a challenge to standardisation, rather than an asset. The implementation of these early systems across disparate communities quickly highlighted the need to take account of those more user or context

specific factors for such systems to be viable and acceptable in practice.

Core and Local Solutions

The next generation of computer-mediated systems for sharing data and coordinating services at scale were characterized by hybrid systems separating the data which could be standardized, from those more person or context specific local issues, where communities of practice mediated the interpretation of the data, and the actions that corresponded. For example, in telehealth, the standardized sensor data was validated and extended by personal information sought by a nurse, and negotiated with a patient or a carer. Such compromise solutions to representing and managing computer-mediated data are more viable in practice, yet they are unwieldy, costly and time-consuming. They also require separate pipelines, and the additional information is not easily integrated into other records, or into the existing processes.

User –centred infrastructure

This is now familiar in business contexts as Web 2.0, or wikinomics, (Tapscott & Williams 2006) as a means of leveraging users and communities as a resource for generating knowledge and creating value. This is to build the digital data management infrastructure around users and user communities themselves, as for example with what has come to be known as Personal Information Management systems and user –centred platforms (Buchanan et al, 2012).

Looking back, it is also interesting to note that the three successive waves of interest in user involvement, (from the early work of Trist (1950), through to Dearing in eLearning in 1997, and Wanless in eHealth, in 1994), were in a context of financial austerity, requiring ‘more for less’. It has been in these contexts where alternative reconfigurations of people, processes and technologies were considered as a means of creating synergies, and minimising cost and risk.

Exploring collaborative methods across domains

The thesis highlights the development and growing use of participatory /collaborative action research in different domains, as a medium for understanding and managing the way actors themselves are central to the process of re-aligning the social, the technical and the organisational over time. Bowker et al (2010) emphasise the dynamic evolution of these interdependencies.

> "This vision requires adopting a long-term rather than immediate timeframe and thinking about infrastructure not only in terms of human versus technological components but in terms of a set of interrelated social, organizational, and technical components or systems
>
> Bowker G., Baker K., Millerand F. & Ribes D. (2010)

Early sociotechnical systems theorists are associated with collaborative approaches to work process management as a philosophy, and in the research methods they advocated to explore this.

For Trist and others, developing a sociotechnical systems approach to explain the introduction of technology in mines, collaborative action research was as much a philosophy (of co-development, participation, empowerment and change) as a research method (Trist 1976).

It perhaps also reflects the fact that the sociotechnical group included the founder of this research approach, Kurt Lewin, (1946) who was an influential figure in their search for methods, and who also acted as a bridge between UK and US researchers in relation to other philosophical influences from America. This included theoretical ideas such as pragmatism (Peirce 1903; Dewey 1933) that were critical of rigid, top-down applications of technology in the organisation of industrial and also educational systems at the time, and looked at alternative, more locally and community based initiatives that leveraged the knowledge of users as a resource. It

all sounds surprisingly modern. (The NIHR, for example, have promoted a collaborative approach in the co-development of patient pathways as Experience –based Design (Bate and Robert, 2007), and a similar concept is also used in business process re-engineering as a means of collaborative change management.)

Leveraging the local knowledge and agency of stakeholding users

The publications also contribute to an understanding of the value (and the potential disruptiveness) of empowering users through technology. They show the progression of ideas from early work by Schon and Freire in educational contexts through to the potential lf digital technology to empower users in ehealth in the work of Callon (2003) and Callon and Rabeharisoa (1998), where access to personal data and communication channels allowed patient and carer communities greater advocacy in shaping healthcare, and patient pathways. CP1 and the supporting presentation reviewing VLEs trace this progression through different educational discourses.

Vannevar Bush (1945), Hutchins (1995) and Shneiderman (1998) anticipated the move to more generative, user centred approaches in software design. Ben Shneiderman's 'Codex, Memex, Genex' presentation in 1998 provided the trigger for considering evolving generations of eInfrastructure in terms of the social and the technical from (1) standalone systems for data sharing, to (2) collaborative and ultimately (3) generative user centred environments, building directly on the architecture of cognitive and social processes to enhance cost-effectiveness.

Early and ongoing involvement of users is presented as key to minimising unexpected costs and risks, and as central to the renegotiation of roles, risks and resources in the reconfiguration of roles, rights and resources in digitally mediated services.

As developments in eBusiness and social media (such as Facebook) have demonstrated, users are a unique resource that can be leveraged to both individual and commercial advantage. They are knowledgeable about local needs and barriers, and able to act within their own communities in ways which add value to the community, and to the viability and usability of the service as a whole. The research contributes further evidence of the growing perception that this can provide both a better business model, as well as a fairer and more tailored service for users and communities of interest such as patient groups. (Hood 2010; Al Ubaydli 2011).

CHAPTER 2: EXPLORING THE ISSUES (ELEARNING)

2.1 INTRODUCTION

eLearning infrastructure was developed around the challenges of provision for larger, more diverse student cohorts, and a shrinking educational resource. The exhortation of the Dearing Report (1997) to ‘do more for less’ was the catalyst for an emerging vision of ICT as a means of achieving economies of scale through standardization, modularization and virtual reach to wider audiences. Research councils were funding multiple programmes to implement and evaluate to VLEs – looking in particular for evidence of cost: benefits, but often finding unanticipated costs, risks and barriers.

The tension between the vision of technology and the emerging challenges on the ground, is a cross cutting theme. This project was the first opportunity to explore the issues, and this report was therefore the most important for me personally in giving me a theoretical and a practical understanding of the issues. It provided the perspective brought to subsequent projects, such as eHealth, where ICT infrastructure has also been held up as a means of addressing scale and diversity at a time of fiscal restraint. The Wanless report in 2004 signaled a similar process of ICT adoption (as a means of dealing with growing healthcare demands and shrinking resources.) The thesis argues that few of the lessons from eLearning were learned during this new wave of development in eBusiness and in eHealth, or from other national research programmes (Ure 2001).

The report provided the foundation on which all the subsequent papers have built in terms of theory, socio-technical/socio-political issues in system design in the context of eLearning/Intranet environments. In particular, it highlighted the range of ways in which people, processes and technology can come together, and the different technical, social, economic and political implications of

different scenarios. It has been included as a means of tracing the genesis of the themes in a practical and a theoretical context, and raising the questions which informed all the work that followed in other domains.

2.2 CORE PAPER 1

Ure, J., Malins J., and Cullan, L. (2002) Studiospace: a virtual learning environment for teaching and learning in art and design. *Robert Gordon University Press.* ISBN 1901 085 66X.

The Studiospace report was the outcome of a Scottish Higher Education Funding Council (SHEFC) Strategic Change Evaluation Project (Grant No. RG9801), with a focus on

- evaluating the potential to integrate a VLE into learning and teaching within a Design Faculty
- considering the potential to reduce the cost of the staff resource through (i) the development of re-usable online resources, and (ii) the integration of pedagogical and administrative processes.

The audience were from an educational background, (with a focus on the use of ICT to support design research and learning), policy makers seeking to evaluate the potential of virtual environments for cutting cost and/or adding value, and to a less extent, system designers.

I was the main researcher, together with the technical team, involved in identifying requirements and developing educational solutions for online learning.

OVERVIEW

The Studiospace report presents an early overview of the research issues in an emerging field and is therefore included as a foundational publication, rather than a high impact one, as a means of showing how I conceptualised the issues at the start of the research. The publication provides

- a broad literature review of collaborative, visual and practice-based virtual learning environments and suggests a theoretical framework for analysis
- a field study (needs analysis) on and off campus
- research results (an overview of the potential costs and benefits, in educational and in economic terms)
- questions on the most appropriate and cost-effective approaches to designing networked technology at scale, across multiple constituencies.

Methodology

The methodology for the field study was based on an interactive, action research cycle (Chenitz and Swanson 1986; Glaser and Strauss 1967; Guba and Lincoln; Carr and Kemmis 1986), moving from initial formative feedback for and by the internal stakeholders and collaborators, to more summative external feedback against specific criteria that were identified.

This was in three stages, with feedback, modification and re-testing at each to identify stakeholder requirements (technical, organisational, educational and professional) in collaboration with users as a basis for both design and subsequent evaluation of the pilot system.

The participatory and ongoing approach to development - an appropriate method for complex and dynamic contexts - was in contrast to the prevailing 'waterfall' approach[9] to software design (Royce, 1970).

[9] The waterfall approach assumes a fairly linear progression through pre-defined stages, with user engagement and requirements gathering only at the outset.

Evaluating Costs and Benefits

A cost and benefit analysis of the identified stakeholder needs revealed many hidden or unanticipated costs that would offset the potential benefits of providing online access to more students, with the same staff resource.

The potential for staff cost reduction that might be achieved was offset by a range of other costs, such as the need for

- additional hardware,
- new software licenses to be maintained,
- additional IT support staff
- training costs.

The cost of reviewing, re-engineering, integrating and implementing these processes within the existing structures also had wide-ranging implications which were/are not only financial but also motivational, and even territorial.

Here as also in the projects that follow, the pressure to provide research evidence to justify the cost of investment in new technology was further complicated by the difficulty of comparisons with traditional practices. Similar issues arise in the evaluation of health technology (CP 4-9), where new technology actually changes both clinical practice and patient behaviour, making comparisons meaningless.).

By the same token, the research detected opportunities for synergies, which might provide benefits in a system designed around them. There was evidence of immediate benefits in the enhanced support for new online courses in the Faculty, in terms of

- collaborative working in shared spaces from remote locations, with web-based tools that facilitated collaboration between communities of researchers, learners and lecturers
- access to digital resources for research or teaching which could be generated by networked communities

- more transparent and accessible formative and summative assessment, and auditing[10], through web-based support tools, (Ure et al 2001c) such as online personal and professional development profiling (PDP).
- Extended opportunities for collaboration and strategic alliancing (more for less), through jointly recognized courses in university networks of excellence (Ure et al 2001a,b)

The resulting Studiospace environment was designed around the (then innovative) concept of communities of practice (Wenger 1998). This is premised on the idea that knowledge is socially constructed, (Berger & Luckmann 1966; Giddens 1984) and mediated by dialogue with peers. It also drew on the potential of interfaces to allow distributed communities of practice (CoPs) to generate resources for the community as a whole.

Reconfiguring Roles, Risks and Resource Allocation

The migration of services to a digital context was, here and in subsequent projects, a double-edged sword. It reconfigured roles, risks, resources and resource allocations in new ways, and in doing so, impacted on the roles and rights of users.

In some cases for example, technical assistants felt that their role, and even their job security could be undermined by a system that substituted for them in the demonstration of technical procedures. Teaching staff had concerns that they would fall heir to new unpaid roles managing distance students and online resources. This had implications for the acceptance of the system in practice.

This was to be a recurring theme that was somewhat peripheral to the debate on system design at the time, despite the impact on

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[10] A similar digital trail in some of the telemonitoring projects a decade later, has also made the patient pathway more visible in a way that was not previously evident, and not previously auditable (CP7) for retrospective research or quality audit.

implementation in practice, and emerging work in the social science of technology.

Latour (2001) and Callon (1998; 2003) for example raise issues of representation and power in the context of technology use, and this project, like those that followed, highlighted the need for a basis for managing the representation and role of users in these new digital territories. This is again a significant issue in subsequent papers in eHealth. It also relates to the governance of new digital spaces, with new affordances in a number of emerging areas – from the Internet of Things[11] through to patient led research networks, (Wicks 2011) and personal information management infrastructure for user led management of access to data and government or council services.

Technology as a Catalyst for Rethinking Services

There were winners and losers, raising issues of the roles and rights of different actors in the configuration of these new digitally enhanced spaces. There were also, as Laurillard (1993) and Resnick (2002) suggest opportunities to rethink services around needs, and to create new synergies, where different departments could align resources strategically to shared ends – for less. (an idea that is developed significantly in eBusiness and eHealth in other ways.

Lack of Transfer Across Regions

The benefits of (and barriers to) the use of VLEs in this way was already being leveraged to extend provision in large scale networks in Canada (Bates,1999) and across in North and South America (Ure 2001), through alliances that combined scale and scope with a

11 The EU-funded project CASAGRAS ('Coordination and support action for global RFID-related activities and standardisation') aims to provide a framework .for defining . .international issues and developments concerning radio frequency identification (RFID), with particular reference to the emerging 'Internet of Things'(IoT)

range of expert content that could not easily be matched by individual universities.

This emerging model, was absent from the debate in the research community in the UK (Ure 2001b). The prevailing vision of scaling IT in the UK at that time was not tempered by the lessons already being documented beyond Europe, and successive investments in VLEs, including the flagship UK eUniversity, arguably failed as a result.

CONTRIBUTION TO THEORY/PRACTICE

In a fragmented field, the literature review contextualised the social, technical and organisational issues in a coherent framework, supported by the literature. The publication contributed to both theory and practice in providing a review and categorization of learning environments across contexts.

Theoretical Framework

It provided a unifying framework for contextualizing different kinds of virtual infrastructure in terms of the way they aligned the technical and the social, and presented the evolution of strategy as three ‘generations’, each premised on different educational paradigms for sharing information, or supporting action.(See Fig.1).

Each of these evolutions aligned the technical and the human in different ways, with different associated strengths and weaknesses, and different underlying assumptions about the way such systems could mediate information and action.

The need to consider the potential alignment or mis-alignment of technical and human infrastructure set in train an interest in networked environments as sociotechnical complexes which would carry on over different projects for the next 10 years. A broad review of the literature showed this was still fragmented across disciplines, terms and tacit assumptions about ways in which

people, processes and technologies can create value. The mapping of examples from business and design contexts suggested these could be mapped in terms of the extent to which they were Open/Closed systems, and whether they were user or technocentric. (CP1, p22)

This provided the basis for considering, and contextualizing the issues in subsequent work in other domains, in eBusiness, and in eHealth, and has been included for this reason.

A presentation by Ben Shneiderman on the evolution of approaches to visualization was an important impetus in this. Codex Memex, Genex (Shneiderman1980) went beyond the rather two dimensional conceptualization of 'human factors' as it then was, and spoke to a more interactive, systemic leverage of the social and the technical in ways that could add value. The work of cognitive (Hutchins 1995) on Research in the Wild, Timo Honkelaa (1998) in Finland, William Clancey in 1997, highlighted the implications of this for more effective means of leveraging the way vision works to enhance the potential for visualizing data, using the same principle. Social networking media were ten years away at this point, but use this underlying principle of both aligning with, and harnessing existing dynamics, whether cognitive or social (Hutchens 1995; Tapscott 2006; Nunez 2008).

This paper highlights the evolving strategies adopted to address the issues of aligning and integrating standardised technical infrastructure with the disparate requirements of multiple user groups. This was further developed to include business infrastructure in Chapter 2, and eHealth in Chapter 3.[12]

[12] A presentation to ALT-C framed the evolution of strategy in those terms, and has been built on since then. Ure et al 2001a

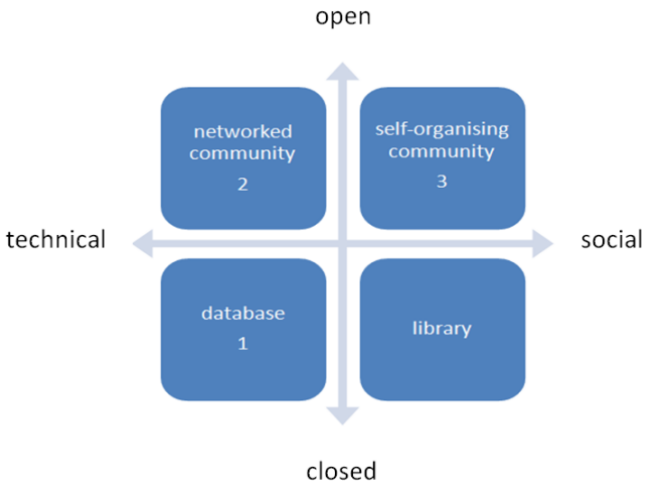

Fig. 2.1. Contextualising Virtual Learning Environments in terms of social/ technical and open/closed dimensions

Generation 1: Information Sharing Environments

The initial emphasis in networked environments was the passive information-sharing element of information and communication technologies (ICTs), associated with the 'banking' model of education as Freire describes it (Freire 1972). In this context the network was simply a vehicle for wider or more flexible access to information. Subject 'gateways' and digital archives such as JSTOR[13] and [14]JORUM are the most familiar examples of these systems in an educational context This was a 'one size fits all' approach, where users need to understand and adapt to the architecture of the system.

Generation 2: Collaborative Community Environments

The second generation of networked environments reviewed emphasised the potential of information and communication technologies to support communication and active collaboration in

13 JSTOR Repository of scanned print journals www.jstor.org

14 JORUM Repository of teaching resources www.jorum.ac.uk

the creation of new and shared learning resources. The mantra here might be that ‘the whole is more than the sum of the parts’.

These environments were associated with the constructivist approach to learning associated in educational contexts at the time most particularly with the work of Jonassen(1996, 1999), of Wenger’s (1998; 2001) concept of communities of practice concept, Castells (1985) Rise of the Network Society and Giddens’ structuration theory .The focus here was on the concept of community building across distributed groups linked by technology in new or more extended ways.

Some of the research approaches emerging at this time concentrate more on the role of actors as change agents in the construction and reconfiguration of social and/or technical networks. Schön D. (1983) was highlighting the role of practitioners as change agents within the community. Lamb & Kling (2003) and Putnam (2000) also highlighted the role of actors brokering the exchange of social and knowledge capital across network hubs, often as a source of organisational advantage (Nahapiet & Ghoshal 2000).

The Computer Supported Collaborative Work CSCW community emphasised the ‘social shaping’ of technology on the ground, (Bijker and Law 1992; Williams and Edge 1996; Procter & Williams1996; Mackenzie 1999;) and the potential of using ethnographic approaches to make some of these relations more visible (Harper 2000; Anderson 1992; Grudin & Grinter 1995).

More dynamic strands of this were emerging however, from enactment theory (Orlikowski 1992; 2000, 2002 and Senge 1990) in the business context, to Mackenzie’s later work on performativity (Mackenzie et al 2008) in financial trading markets, where the architecture of socio-technical interaction over time is more evident. This more systems based focus has increasingly drawn on complex and dynamical systems theory. Plsek & Greenhalgh 2000 and Bar

Yam for example, provide new insights for designers and managers by framing healthcare systems as complex systems.

The potential to align with cognitive and social dynamics is evident at this stage, and a greater cognizance of the problems associated with sharing information without context.[15]

Generation 3: Generative Environments

These environments take this a step further, allowing users to collectively shape or even create new environments in some cases. These included early examples of immersive environments with avatars, and anticipated the development of social networking media much later, in the way they explicitly leverage the user or the user community to create or transform the environment.

The mantra here might be 'the parts re-define the whole', where the strategy is increasingly to harness the knowledge, agency and infrastructure of the community to create value. It anticipates the focus of Web 2.0 strategy as outlined by Tapscott and Williams, (2006) although the term did not exist at this point.

Hutchins (1995) and Honkelaa(1998) were doing this through design that harnesses and extends intuitive cognitive architecture with 'zoomable map'. Technology. Sawhney and Parikh (2001) were also starting to see how eBusiness networks could harness distributed user communities as value creators, using the example of Amazons user profiling / recommendation software.

Giddens' structuration theory (1984) points in this direction, as do the many variants developed for the context of business IT design and use (De Sanctis & Poole 1994; Greenbaum & Kyng 1991; Orlikowski 199; Suchman 1987).

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15 As data, information and knowledge concepts were often conflated, and rarely defined, the role of context in the process of sense-making was often under-estimated. (CP2, Chapter. 6: pp53-62 covers this in more detail, and provides a theoretical framework that draws on Cañas (2001).

Latour's Actor Network Theory (ANT) (Latour 1991; 1993) became an equally influential framework for understanding sociotechnical systems as networks of actors and relationships, including power relationships.

Latour (1973), and more recently Callon (1987, 1991, 2005) , Reddy and Dourish (Reddy et al 2003) highlighted the way these actors co-create meaning and structure in social and medical contexts, as technology opens new possibilities.

Again this links back to many of the same philosophical foundations as the Tavistock group in their rethinking of work practices (Core Paper 2 provides a broad overview of different theoretical approaches that have been used to frame the relations between people, processes and technology).

Emerging work on financial systems (Knorr Cetina 1981; Mackenzie et al, 2008) was beginning to highlight the way in which the whole socio-technical complex (in this case financial markets) can be re-shaped and often distorted by the way in which particular social and technical systems come together.

At the same time, later developments in eHealth Hanseth et al (2004), Berg (1999; 2004), Dourish (2001; 2011), Reddy et al (2003), and Callon (2003) were starting to report on the implications of this kind of redistribution of roles, risks and power hierarchies in the design of health information systems at a more systemic level. The eHealth papers on mobile healthcare and the HealthGrid papers on ontologies redraw the same evolution, in Core papers 5-9.

Mobile and wearable computing were still emergent, but have since provided an ideal opportunity to fully leverage this approach, harnessing both technical and human (cognitive and social) resources to best advantage. The Future Internet (FI) will bring

together the Internet of Things (IoT)[16] (Vermesan 2012) and Internet of Services (IoS)[17] in ways that are increasingly re-conceptualising informatics and system design around the challenges of coordinating interacting sets of technical and human agents at scale over time (Milner 2009; Harel 2011).

The publication also raises a number of cross cutting issues that I build on in subsequent publications. These all relate to the challenges associated with using digital infrastructure to mediate information and services for very disparate and distributed users at scale.

CRITICAL ANALYSIS

The project outlined in the report generated the questions which informed subsequent research. These related primarily to the alignment (or misalignment) of people, processes and technology, at different stages, and would recur in different forms in the subsequent projects.

The report contributed methodologically to the identification of user/stakeholder needs as a basis for the choice and evaluation of educational technology. This was an advance on the prevailing vision in educational technology, of implementing ‘best practice’ in learning and teaching as a gold standard.

One strength of the publication is the breadth of the review, of the literature, and of the environments available in different disciplines. This provided a basis for classification and the development of a framework for conceptualizing how digital and human systems could be aligned, and the implications of different scenarios for costs, risks and benefits.

16 IoT Internet of Things

17 IoS Internet of Services

Looking back at the approach, I would have included a clearer breakdown of the participants of the target research groups, and would have formally coded constructs from interviews, to provide a more transparent evidence of the conclusions we reached. This reflected in part the exploratory nature of the project itself, and the somewhat evolutionary and exploratory approach to methodology, which was developed in response to the perceived limitations of the approach initially adopted by the technical team.

This has evolved over the period, and the subsequent papers have a much more rigorous and transparent methodology section. The more recent mainstreaming of qualitative and collaborative research methods in the design of technology, and the acceptability of both qualitative and sociotechnical approaches to research has meant that there are now more publication opportunities for this kind of work.

Impact

The project can be viewed as exploratory in an emergent and very contested field. For me as a researcher, this was a necessary first stage to share, explore and confirm ideas. It allowed me to both engage with and learn from approaches to digital infrastructure design and use in a wide range of communities, contexts and countries at a formative stage, and the subsequent papers build on this in a more focused and rigorous way. In this regard, it impacted significantly on my thinking, and shaped my subsequent research.

Observation of the strategies adopted in other eLearning communities in the Americas, as part of work with Scottish Enterprise, and Aberdeen University also contributed to this (Ure et al (2000), and led to the development of an eLearning project as part of the World Energy Cities Partnership (WECP)[18] to take

[18] WECP Workd Energy Cities Partnership www.wecp.org

advantage of some of these approaches in developing professional development for managers online.

This theme of knowledge transfer, and the barriers and enablers for it, begs the question of why research infrastructure has not also evolved to meet the more rapidly emerging issues in the field. The supporting paper Virtual University, Real Competition (Ure et al 2001) represented the very real frustration of seeing the cost to a developing digital economy of failing to identify key risk factors, and mitigating strategies already familiar in other countries, and in the research portfolio of other countries (Bates 1997, 1999), and in other domains.

Supporting Papers

The Supporting Papers in Fig. 2.2 are provided simply as context to how the emerging strands were followed up, as they run through subsequent core publications, where they are further developed. They were largely peer reviewed Conference papers where the concept of leveraging social and technical capital was an area of emerging interest.

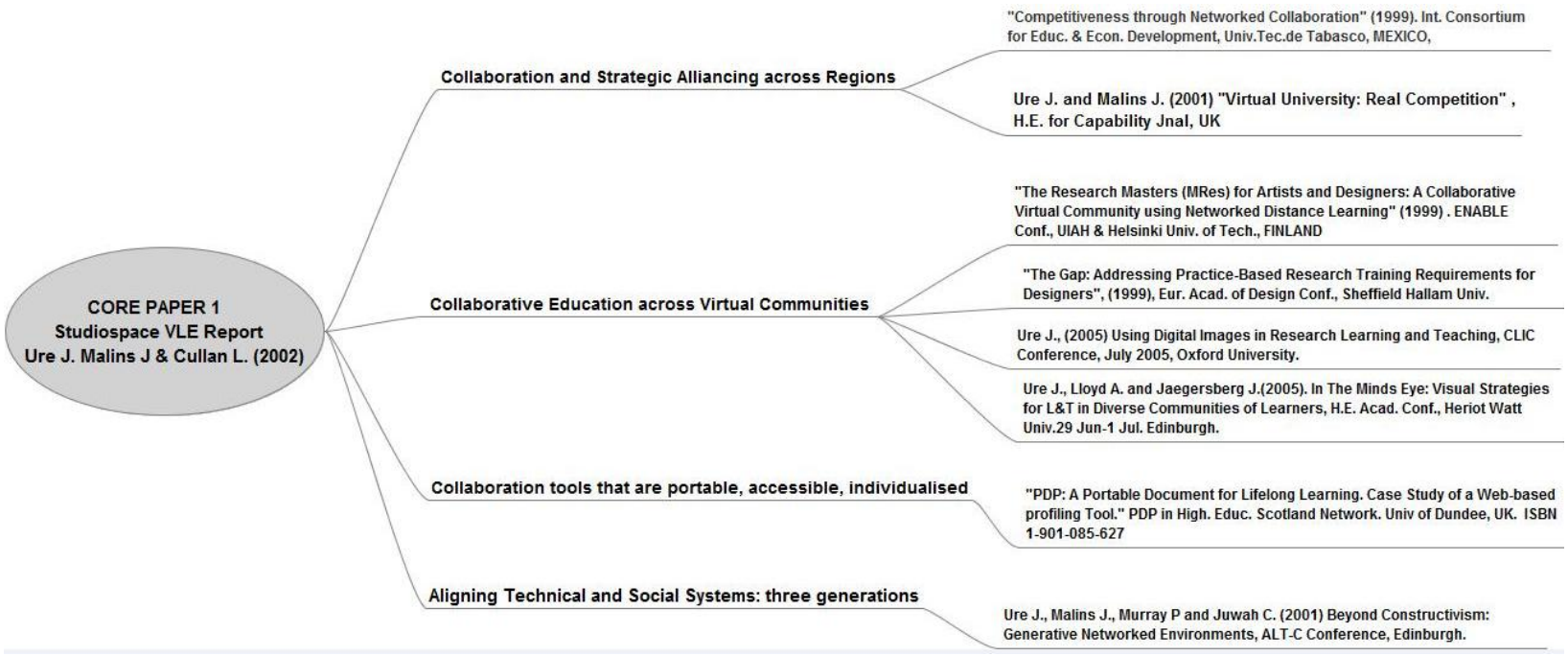

Fig.2.2 Supporting papers developing different strands.

3 eBusiness: BUILDING CONSTITUENCY, DEVELOPING STRATEGY

3.1 Introduction

The eBusiness publications derived from the experience of managers in different industry contexts, at a time when businesses were extending networked systems towards more global information sharing and service provision[19] .

Scaling technology proved easier than scaling community, with recurring issues that reflected the difficulty of implementing the 'one size fits all' approach to interoperability and economies of scale., These difficulties were a catalyst for the evolution of a range of alternative alignments of the social and the technical

CP2 provides a range of case studies of the recurring issues, and the evolution of new strategies, and outlines the implications for policy, practice and professional development.

Core Papers 2 and 3 represent the development of collaborative work in the context of extended enterprise systems such as supply chains, portals and clusters across a range of projects with funding from a range of organisations including Scottish Enterprise in the initial stages, ESRC at Edinburgh with Prof. Ashley Lloyd, and as Research Coordinator for joint projects led by a German partner, Prof. Gudrun Jaegersberg, funded by the Deutsche Akademische Austausch Dienst (DAAD)[20] and the Brazilian research funding organisation CAPES[21].

Sharing our experience of research on the topic from very different bases led to further joint work, a book for managers for the British Computer Society (BCS).

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19 With different implications for design, and with dependence on particular understandings of 'information' and knowledge'. These were rarely defined, but impacted significantly on the approaches adopted.

20 DAAD www.daad.org

21 CAPES http://www.capes.gov.br/

3.2 CORE PAPER 2

Ure, J., and Jaegersberg, G. (2005) Invisible Architecture: *The Benefits of Aligning People, Process and Technology: Case Studies for System Designers and Managers*. [Book] British Computer Society. ISBN: 9781902505596

http://www.bcs.org/server.php?show=nav.5917

OVERVIEW

Standardising safety compliance procedures was actually making it **more** dangerous in some places, not **less**.

CEO, Petrotechnics[22]

JIT (Just in Time procurement software) work s in Germany. Why doesn't it work in Brazil? It's the same technology? What's the difference?

Senior Manager, Volkswagen AG

This book of cases was written in response to the concerns of the many managers of portals, extranets and supply chains with whom I came in contact across very different projects. This was at the time of the transition from mainframe computing, to systems with a global reach. Software to manage processes across global sites (e.g. safety standards compliance software) was being implemented in sites around the world in very different organisational, educational, cultural and geographical contexts. The cases highlight the particular tensions that arose between the vision embodied in the software, (the technical infrastructure) and the reality on the ground (the social, organisational, economic and political one). It draws together outcomes of various studies in the context of the literature.

The intention, highlighted in the guidance given by the British Computer Society was to write an accessible text[23], rather than an overly

22 Design and manage safety compliance systems in oil and gas

academic one, as a means of highlighting recurring issues associated with the cost and risk evident in many large scale projects. They reflect the concerns of managers who spoke consistently of

- unpredicted cost and risk, where apparently standard technical and business systems were not compatible with local ones
- lack of training in handling the soft processes that impact on the competitiveness of extended enterprise systems.
- lack of management tools for mapping and managing these non-technical problems

The Introduction highlights the rationale for the book, as outlined, and in Chapter 1, provides an example of one of the most recurrent problem: solution scenarios - the problem of aligning standardised processes (such as safety compliance) with the local context and the expectations of the local community. The solution he adopts (to separate core and local elements of the software), is one which in principle recurs across the board, but often after a failed first attempt to implement a 'one size fits all' solution to interoperability and economies of scale..

Chapters 2 and 3 provide case studies from different sectors to highlight the extent to which scaling up infrastructure across disparate communities is problematic in ways which are recurrent, and for which there are already a range of possible approaches to mitigating the risks.

Chapter 5 provides a range of very generic strategies observed in aligning these extended systems with local requirements, and solutions adopted.

- Using a common platform – designing technology around the more stable and intuitive architecture of cognitive or the social processes
- Bridging the gap – human or technical 'middleware' at interfaces where risk can be mitigated or value added
- Creating new linkages between technical and/or human networks

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23 I was asked not to include references in the text, hence the suggested readings at the end of each chapter

- Aligning systems more strategically to cut costs or add value

These go from core and local solutions, through to the option to build on cognitive or social systems, harnessing the technical and the human resource to advantage, as Hutchins (1999), Honkelaa (1998) and Shneiderman (2004) in some senses do, anticipating what Tapscott (2006) has called wikinomics.

The book says less about the role of research in this, other than to highlight the role of users as a core and under-used resource – it is more concerned with pointing to the regularities across disciplinary boundaries, and the implications for cost and risk mitigation, which are the focus of Chapter 6.

Chapter 6 highlights the fact the individuals and communities can also be conceived of as information systems, from the perspective of system design, as evolutionary biologists do (Segel and Cohen 2001; Varela 1974), in ways that are now relevant in the context of agent-based systems. In relation to this, it points to the lack of clarity in the use of concepts of data information and knowledge often conflated in the context of knowledge management research. It provides a suggested framework for understanding knowledge as the interface between information and action, building on concepts of both learning theory and Bannister's (1986) construct theory.

Chapter 7 looks at the implications for designers and managers or re-invention rather than re-use.

CONTRIBUTION TO THEORY & PRACTICE

The main aim of the book was to address the concerns of managers, and facilitate transfer across organisations and sectors in this regard. It also aimed to raise the profile of a sociotechnical approach, and in this sense, to build constituency around it.

The cases highlight the potential benefit or risk add cost , risk or value, and the evidence that a few very generic issues accounted for many of the problems, and that also, there were a range of strategies which

could be considered or adapted, and for which there was already a range of experience in practice.

The concept of re-use rather than re-invention of these strategies is one that recurs in the eHealth papers in the following section, as is the potential for leveraging that resource to advantage.

The research extends and develops sociotechnical systems theory to new and more extended domains such supply chains and clusters in CP3.

CRITICAL ANALYSIS

The strength of the book is the abstraction of common issues across a range of sectors in the process of ‘going global’ and facing a range of challenges that were not shared, often for reasons of commercial confidentiality, and also because of the barriers to interdisciplinary research and publication.

It foreshadowed the experience of similar issues encountered in researching eHealth systems at scale (Chapter 4) and a number of the issues identified in subsequent analysis of project failure which also

The editors at the British Computing Society specified that this was not to be written as an academic text, hence the theoretical literature was appended after each chapter, and a review of theoretical approaches and the relevant references is included in the final appendix to the book.

The weakness is perhaps in the difficulty of writing a general book for disparate audiences. The demands of ethnographers, requirements analysts and business managers were not always easy to reconcile. In keeping with editorial Diktat, I tried to provide a real and accessible context, and unambiguous language, which did not always succeed.

Impact

The BCS invited lecture series, and dissemination by the organisation itself ensured a level of impact with managers from very different sectors, which allowed me to extend and validate the findings, and

confirm the perception that this was a significant problem for them, with most indicating the spend over 70 to 80% of their time, and felt they were not trained for the more socio-technical and socio-political aspects of the work

3.3 CORE PAPER 3 eBusiness

Jaegersberg, G. and Ure. J. (2011) Barriers to Knowledge Sharing and Stakeholder Alignment in Solar Energy Clusters: Learning from Other Sectors and Regions.[Journal] ***The Journal of Strategic Information Systems, Volume 20, Issue 4, December 2011, Pages 343-354. Elsevier.*****ISSN: 0963-8687.**

INTRODUCTION

Regional and national policy makers have invested heavily in the cluster concept as a means of generating value for regions, particularly through the opportunities for small regional enterprises as vehicles for growth and job creation (Ure 2010; Jaegersberg & Ure 2003)

Economic theorists such as Porter (2009), have shaped many of policies being adopted, from a macro-economic perspective, yet the process by which actors within the group are helped (or hindered) in aligning knowledge, expertise and interests is less well understood.

The implementation and development of clusters is subject to a range of local sociotechnical and socio-political dynamics, which also need to be taken account of if the anticipated benefits such as wealth creation and competitiveness are to be realised. While some of this is already recognised at the level of the enterprise Peters 1982; Senge 1990) this has not been so evident at the level of policy and strategy in clusters.

OVERVIEW

Supply chains and clusters are sociotechnical complexes par excellence, where disparate technical systems mediate the exchange of information and the coordination of services across many players. (in many ways akin to the concept of telemonitoring at scale, discussed in CP 7, 8. This provided a new domain in which to validate the evidence

of recurring issues, and to look for strategies in different clusters, at different stages of development.

Policy (and thus practice) in the development of these huge regional investments, have traditionally been guided by the macro-economic vision implicit in Porter's (2009) work. As in other e infrastructure contexts, the vision of unified economic outcomes from the application of generic policy has been tempered by evidence of implementation in the context of more socio-technical, socio-political and even geographical factors at play in local contexts.

In essence, Porter's theory has been the shaping vision for the design and implementation of infrastructure to support innovation and economic regeneration in the regions. The gap between vision and reality has been a large and expensive one, where research has been slow to track and feedback the rapid developments on the ground, and to relay the experiences of those on the ground who are innovating in practice (von Hippel 2002, 2004) - until, as in the oil and gas sector, the capacity for competitive innovation is lost and policy is slowly revised, post hoc.[24]

This very extended study builds on the findings of earlier papers on oil and gas and automotive supply chains, as sociotechnical complexes,, and provided an opportunity to explore them in another context, in an area of economic importance.

From a theoretical perspective, it also contributes to Porter's macro-economic theory of cluster development, highlighting the value of including insights from stakeholding users on the ground to inform implementation around local needs.

It further develops the methodology used in earlier work, using online tools to facilitate the scale and cost of the qualitative work, and to use

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[24] If clusters are to realize their objective in practice and create wealth for the region, there is a need for a better understanding of the barriers to knowledge sharing and alignment between stakeholders on the ground, particularly in relation to SMEs as the engine of the growth and job creation that clusters aim to generate. They represent 99 per cent of all European enterprises, contribute two thirds of European GDP and provide 75 million jobs in the private sector. Yet they are often poorly represented and integrated in supply chains and clusters (OECD 2008; Jaegersberg & Ure 2011;, Ure 2007d)

emerging themes as the basis for wider validation using online questionnaires.

The use of student internships to extend the research also contributed to two further aims of the project:-

- to support professional development in an area that is under-represented in the traditional curriculum, (Hazzan 2010) and where new inn ovation is emerging in the field (von Hippel 2004)
- to highlight the value created by students, acting as a bridge between regions, and between actors

The paper highlights a view that is further developed in the eHealth section, that investment in ICT-assisted projects at a regional and a national scale is rarely supported by research which illuminates the complexities of practice in the diverse context of application.

Methods

Qualitative research (Denzin et al 1994) was seen as an appropriate methodology to adopt, and can of itself often act as a catalyst for both knowledge transfer and change, between communities in a rapidly evolving and distributed network.. The qualitative issues (independently coded by two and sometimes three researchers,), were used to develop online questionnaires to validate this quickly with a wider range of actors in the network, and achieve both scale and depth, as well as compensating for bias in the sampling. These were carried out using an online survey tool, and stored in a secure database. The data is on a large scale, and in a form that allows for cross analysis for multiple purposes. This paper was the first use of one strand of that data, looking at communication issues for SMEs within clusters.

Research Aims

The research aimed to explore the recurring barriers that SMEs perceive as impacting on their ability to incorporate effectively into the cluster as a whole, and to highlight the implications for policymakers, and other stakeholders in the region and for learning also from other clusters at different stages of evolution who may have addressed some of these issues. This follows the pattern of earlier research and benchmarking work between oil and gas clusters in Western Australia, and in Scotland (Ure et al 2007d).

The research reflects a wide range of outcomes at a unique scale, one strand of which is represented here, and with implications for policy in practice that is not currently available elsewhere.

Table 1
Country cluster × research activities.

Regional clusters	Research activities			
	Cluster mapping	Semi-structured interviews	Questionnaires circulated	Survey return rate (%)
Italy Lombardy, Veneto, Emilio Romagnia	✓	36	256	22
Spain Valencia	✓	15	–	–
Portugal Baijo Alentejo	✓	11	339	16.8
UK Scotland	✓	16	266	15.4
Germany Saxony, Thuringia, Saxony AH	✓	12	297	21.5
South Africa Johannesburg	✓	11	251	21.5
Chile Antofagasta	✓	12	272	15.4
USA California	✓	17	252	23.4
Brazil Rio Grande del Sul, Ceara	✓	2 ongoing	Ongoing	Ongoing
Canada B.Columbia Alberta, Ontario	✓	5 ongoing	Ongoing	Ongoing
N=	✓	137	1933	Av. 19.4

Fig 3.1 Country Cluster x Research Activities

CONTRIBUTION TO THEORY/PRACTICE

Theory

The paper contributes to theory and practice at different levels including a contribution to an economic understanding of the barriers to SMEs which refines current theory and practice.

It also makes a case for researching clusters as sociotechnical(and socio-political) complexes, and provides qualitative and quantitative evidence of the issues, and the possibility for learning from other regions.

Method

It provides one approach to managing qualitative research at scale, and over the course of the evolution of these large infrastructure which Bowker et al (2010) and others identify a need for in infrastructure studies, but which others such as Coeira (2004; 2009) also point to a need for in eHealth infrastructure

The large scale and the originality of the topic are strengths here. These were Cinderella topics at the outset, a decade ago, abut have been completed at a time where the topic and the context (energy) are of particular interest.

It highlights the key barriers for SMEs, and the strategies being adopted to mitigate the risks, including less visible aspects such as the impact of failure in communication technology on the ground, the perception by SMEs that Universities were difficult to work with, and the role of representation and agency of SMEs in policy fora

It also proposes and pilots a methodology of reconfiguring research and training infrastructure so as to better leverage the diversity of knowledge in different regions (leveraging strengths) while offering the potential to compensate for weakness through collaboration. This reflects the origin of the concept in the work done for Scottish Enterprise, in a context where strategic alliancing has been a successful strategy for (a) competitiveness (b) dealing with diversity –

by alignment of communities to achieve a common aim, using technology as a mediator.

It validated generic issues across clusters, and significant differences between others. Transfer cannot be direct, obviously, but an awareness of the most costly and likely pitfalls in bringing people, processes and technology together at scale are central to mitigating cost and risk in the implementation of large scale infrastructure at scale (Anderson 2008; Ure et al 2007d).

CRITICAL ANALYSIS

The strength of this research is the scale, and the use of qualitative and quantitative methodology to

- Provide actionable input to minimise cost and risk at key interfaces in the network
- Provide research with SMEs in the field to inform policy at a macro level
- Demonstrate an integrated approach to combining research and curriculum development across regions, to facilitate the timely feedback of emerging issues that are critical for competitiveness in the digital economy.

Impact

As the field has coalesced, there have been more opportunities to disseminate in management journals such as JSIS, although inter-disciplinary and practice based work is featured less often[25], unless it clearly develops existing theoretical approaches, as for example, Porter's theory of cluster development

[25] This is paradoxical given that IT and business project at are inherently emergent and inter-disciplinary, and unfortunate in a context where speed and currency of information is of the basis for competitiveness

Less formally, the impact has been in the brokerage of links and shared experiences across constituencies

- the involvement of large numbers of organisations and people, in different countries over an extended period, the research itself has promoted exchange and joint working,
- publication in international trade magazines and Conferences for industry audiences
- Special Conference Tracks in International Conferences

From a methodological point of view it extended previous work, and in the use of NVIVO[26], and another database package, allowed for much more rigour, transparency and detailed breakdowns of the samples across thematic areas, and across regions. It also allows for Framework Analysis, which is increasingly used to look at thematic issues across stakeholders, as for example, in one recent study of the issues in the implementation of the NPfIT project and could be adapted to look also at issues across regions. Following up with post-interviews in some of these regions has just started, and this will provide a more developmental insight into how these issues have evolved.

In hindsight, it could also usefully have used software for social network analysis, such as UCINET[27] which would have been of significant value to have an analysis of the gaps and barriers in the social and professional network. This would have given context for interpreting the results of the actants in that network, and added a further dimension to the analysis in that context.

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26 The most widely used qualitative data analysis software which provides evidence of the process through which qualitative research outcomes are derived from raw data. Available from www.qsrinternational.com

27 www.analytictech.com/ucinet/

4. EHEALTH: INFORMING THEORY & PRACTICE

4.1 INTRODUCTION TO HEALTHGRIDS

Most of the recent publications have been qualitative studies with stakeholders as a basis for informing design, or implementation at scale in large scale eHealth infrastructure. Although the wider social implications of embedding technology were beginning to emerge in telehealth, they were still over-shadowed by the emphasis on more formal evaluation of health technology with clinical trials as the gold standard. Qualitative research on these issues was largely absent from the debate in the HealthGrid community at this stage however, with the exception of the recognition of ethical and legal governance issues.

Those papers relating to **HealthGrids (CP 4, 5, 6)** focus on the issues in gathering requirements for designing Grid-enabled data-sharing infrastructure as a basis for research at scale across very disparate and distributed communities of specialists. They reflect on the (often socio-technical) barriers in practice to sharing de-contextualised data at scale, and the approaches adopted to address some of the challenges. Many of which are recognizable from earlier work on data sharing in distributed business systems, and those links are made. They challenge the Grid computing vision of 'seamless data sharing' at scale through distributed computing (Foster et al 1999,2001), and highlight the need to provide ways of better engaging users in shaping a sustainable vision if the investment is to be realised.

Those relating to **Telehealth (CP 7, 8, 9)** focus more on the sharing of wireless telemonitoring data as a basis for service provision in the context of long term conditions. Early detection of changes from normal parameters provides a basis for early intervention and the prevention of costly hospital admissions.

The telehealth papers share a common methodological approach, using qualitative research with stakeholding users to identify the challenges in configuring distributed people, processes and technologies at scale in a more extended network. They reflect on the recurring sociotechnical and socio-political issues, and the implications of different implementation scenarios at this scale.

4.2 THE HEALTHGRID PAPERS (4, 5, 6)

Many of the most challenging problems faced by project teams in designing HealthGrids relate to the difficulty of achieving agreement across communities on adoption of particular terms and classifications, to allow data-sharing across sites, and in particular, across the European Health Area.

Although Core Papers 4, 5, 6 give some background to Grid computing, they assume some specialist familiarity with Grid computing and ontologies. Some context to the concept and it's relation to the theme of sociotechnical systems may be helpful.

The Grid concept (cyber-infrastructure in the US) was developed to provide access to high performance computing resources to multiple dispersed groups, and to do so cost effectively by making better use of underutilized computing resources from any part of the network (Berman et al 2003; Foster and Kesselman 2001[28]) and also underlies the concept of Cloud-based computing.

The vision of 'seamless data sharing' it embodies derives from early work in the classical sciences, where data was based on well established classificatory systems. Classification in the clinical context is not only less clear cut however, it also varies a great deal across communities and over time. The difficulty of aligning this vision of scalable systems for data sharing, with the constructs and requirements of many disparate specialist groups, in an evolving field, has been a fascinating context for exploring sociotechnical issues and their implications.

The literature on Grid computing has had a largely technical focus as the starting point. These publications were intended as a counterbalance. They provide evidence of the need to address barriers to sustainable use which address social and technical barriers as integral and interacting parts of the system as a whole. The work of Lee and Dourish (2006), Ribes and Finholt (2010) and the more recent work

28 They provide a useful glossary of Grid terms on http://www.grid.org.il/?CategoryID=365

from Tim Berners-Lee (2007)[29] have provided rare exceptions to this. (See Fig. 4.1).

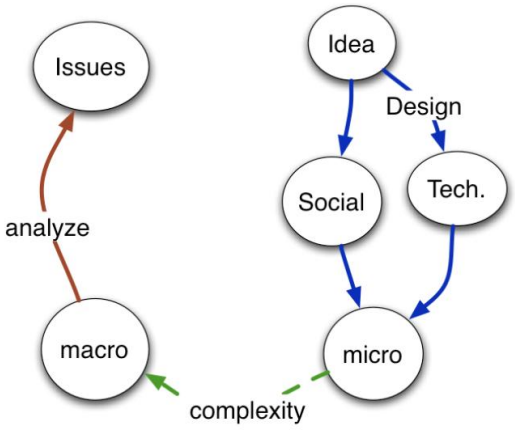

Fig.4.1. Slide from the online version of Tim Berners-Lee's Lovelace Lecture in 2007 h
http://www.w3.org/2007/Talks/0313bcstbl/#%287%29

[29] The lecture highlights the need to consider the social and the technical aspects of software design, and the issues of scaling these from micro to macro.

4.3 CORE PAPER 4

Ure, J., Procter, R., Martone, M., Porteous, D. et al, (2007) Data Integration in eHealth: A Domain/Disease Specific Roadmap. In HealthGrid 2007: From Genes to Personalized HealthCare: Grid Solutions for the Life Sciences. Jacq, N., Muller, H., Blanquer, I., Legre, Y., Breton, V., Hausser, D., Hernandez, V., Solomonides, T. & Hofmann-Apitius, M. (eds.). Vol. 126, pp144-153, *Studies in Health Technology and Informatics*, IOS Press.ISBN:1-59593-
http://geneva2007.healthgrid.org/fileadmin/presentations/Session_8/4_Ure.pdf

This is a double peer reviewed paper published as a chapter in the book of selected papers from the HealthGrid Conferences, which are the primary international conferences for research on HealthGrids. The main focus of this publication is very much in line with the focus of the series as highlighted on the publisher's website. They focus on "technologies, solutions and requirements that interest the grid and the life-science communities to foster the integration of grids into health" and are geared to "grid middleware and grid application developers, biomedical and health informatics users, and security and policy makers with a common focus on the application in the health domain".

The publication differed from the other papers in the volume, in that it referred to the sociotechnical barriers and enablers, rather than the technical ones.

I was the principal author of the paper. The co-authors are the lead investigators of national HealthGrid projects in the UK, France, Spain, Germany, UK, Canada and America brought together by the author for a workshop with support from the UK eScience Centre.

The aim was to roadmap the non-technical issues challenging large scale data sharing in Grids, which were perceived as significant but under-researched, and not well represented in the public debate.

This research was carried out while working for the NeuroGrid project, funded through MRC Grant Ref no: GO600623 ID number 77729 and the Generation Scotland project funded by Scottish Funding Council through Grant No. SRDG03006.

OVERVIEW

The research and the publication arose from my role in requirements analysis for the MRC-funded NeuroGrid[30] project www.neurogrid.ac.uk , and for the CSO-funded Generation Scotland www.generationscotland.org. . Both were developing eHealth infrastructure to facilitate data-sharing in research by distributed groups of psychiatrists, imaging scientists geneticists and informatics researchers. In the case of Neurogrid, this involved sharing brain imaging data (MRI scans) across research sites in Oxford, Nottingham, London and Edinburgh. The aim was to facilitate access to multiple disparate sets of data that were either too big for real time processing on a local computer, (as for example in the case of brain scans), or too diverse and distributed to be accessed and analysed as one dataset.

The paper draws particularly on a road-mapping workshop[31] I set up with six other national Grid projects developing ontologies in the same (or related) disease domains. I sought funding from the UK eScience Centre to roadmap the barriers, and explore collaboration between the EU and the US programmes, following on from on an earlier workshop[32] on data integration and usability issues in the context of bio-banking. The event was co-hosted by the UK e-Science Centre and contributed

30 www.neurogrid.ac.uk MRC Grant Ref no: GO600623 ID number 77729

31 UK eScience International Workshop Re-use or Re-invention - a Roadmap for Data Integration (Schizophrenia as a Test Case), UK eScience Centre, Edinburgh, Nov. 29th 2006 http://www.nesc.ac.uk/esi/events/709/

32 UK eScience workshop with Generation Scotland on May 6, 2006. Data Quality/Usability Issues in e-Health: Practice, Process and Policy http://www.nesc.ac.uk/esi/events/684/ www.nesc.ac.uk/action/esi/contribution.cfm?Title=684

to the wider road-mapping process led by the European HealthGrid[33] SHARE project team, who also participated.

Focus

Access to multiple source s of data of different types has the potential to transform research in contexts such as schizophrenia, where datasets are not only at different sites, but also at different scales. The analogy here is Google Earth for the body, and projects such as the Virtual Physiological Human[34] are premised on the potential to integrate such data at scale. The eHealth vision of large-scale, seamless data sharing was deemed to have a key role in enabling the development of the European Research Area in future research, based on data sharing and integration at scale (Breton 2005).

The workshop and the paper contribute to the road-mapping of common issues in developing this vision, particularly in relation to the development of the ontologies which provide the glue that links different data sets. Creating ontologies requires agreement on what data is relevant, and how it can be represented, so that disparate datasets can be analysed as a whole.

While this had been treated largely as a problem of technical interoperability, many of the barriers in practice related to how (or whether) the disparate communities of users were able or willing to come together and agree on shared terms, classifications and work processes.

The paper highlights the difficult interfaces between the unified technical infrastructure for collecting and federating data, and the (very disparate) local processes for using data, often designed for different purposes. It points to sources of error that pose a threat to the rather simplistic vision of data sharing at scale, using technology, and points to

33 http://www.healthgrid.org/ (Accessed Oct. 2012)

34 http://www.europhysiome.org/roadmap/

the value of design that takes account of user communities as a resource in the design and management of such data.

DEVELOPMENT OF THEMES

The paper develops the analogy of a data 'supply chain' underpinning eHealth and translational medicine as a gradual conversion process where many types of error or bias can arise at different stages. This process of 'Chinese whispers', from sampling, collection, coding, aggregation, analysis or use, was famously described by Duguid (2000) as the 'social life of data'.

This challenges the optimistic vision of seamless data sharing, and points to the need to consider the wider context of how data is perceived, classified and used in different communities in design and implementation at scale. The papers point to a role for collaborative research with users as one vehicle for this. The difficulty of aligning the technical and the social was at the heart of the problems that arose – at different stages in the process, and at different scales. (See Fig. 4.2)

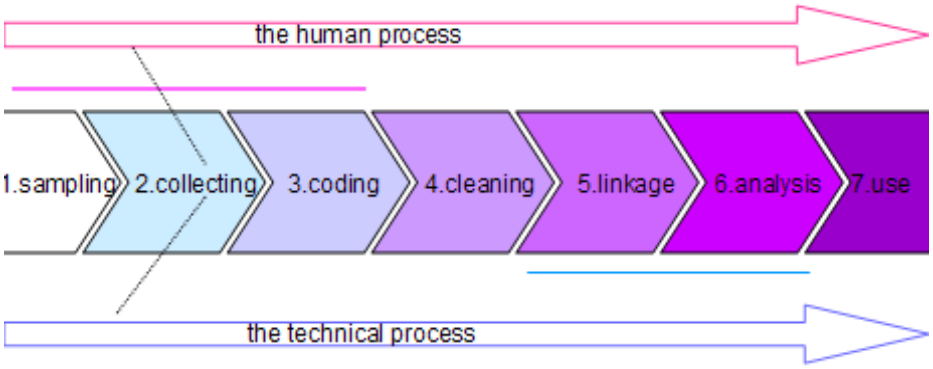

Fig. 4.2. Data sharing issues in HealthGrids.(Ure,2007b,2009a) [35]

35 I found it useful to represent the issues that arose in a stage specific way, in that the problems which arose at each stage were very different. From a practical perspective, it was useful to identify opportune points within the process where people, processes and technologies were often misaligned, and where particular solutions had been used. This 'pathway' approach probably derives from having seen it used to roadmap collaborative engineering processes, (Hammer and Champy, 1993) and is used in the eBusiness papers. It is one that has also been used by the NIHR to re-engineer patient pathways (Bate & Robert, 2008) through roundtable sessions with the different users.

Recurring Sociotechnical Issues

The paper looks at the recurring issues and considers some of the strategies that may apply.

Sampling, Collection (Across Sites)

The practical experience of project managers consistently highlighted the difficulty of ensuring the quality and consistency of collection, coding and collation, all of which were subject to significant rates of human error, misinterpretation or site-specific effects that were not directly evident. Cleaning and error trapping software only captured particular types of error and many anomalies could only be recognized by those with local knowledge of where and how the data was collected. 'Unknown unknowns' presented an invisible source of risk to data quality at scale, and pointed to the value of local monitoring of data.

Data Coding

Within project teams there were difficulties in achieving agreement on how data should be coded, and preferences for particular classification systems. This required agreement on models that met the needs of clinicians, biologists, imaging scientists, IT designers and researchers with very different aims, and working practices.

The 'one size fits all' model of data envisioned as a central reference point for sharing of resources across sites was in conflict with the criteria of diverse professional communities that would define adoption and use. (CP2).

The vision of a unified classificatory model was surprisingly hard to achieve. If such classifications are difficult in hard sciences[36], they are considerably more so in bio-medical domains, where disease concepts

36 The loss of an entire planet (Pluto) as a result of the classification system adopted in AstroGrid, and the subsequent adaptation to the classification system in response to objections is itself a revealing picture of how models of reality are constructed, rather than observed. http://www.skyandtelescope.com/news/home/3707031.html

are often fluid, ambiguous, and evolve within and between professional and national communities of practice (Dupre 2006; Bodenreider 2004)

While there was some acceptance of the fact that concepts of disease would vary, and that compromise was required, there was an underestimation of the extent to which tangible physical structures were differently conceptualized, bounded, or defined in relation to other structures for specific purposes (Bodenreider *et al*. 2004; Bergman et al 2002).

Data Quality in Distributed Networks

In aggregated data, without local information, anomalies were hard to identify. For example, one study cited measures of resting heart rate captured in one site, which were unusually high. Observations on the ground as part of the research project highlighted the fact that participants in this site had had to climb six flights of stairs before the ('resting') heart rate test, because the lift in the hospital was out of order. This would not have been evident from inspection of the data alone.

Other examples were evident in the harmonization of data across sites, with slightly different equipment. This vision of automated data sharing relied heavily on the use of protocols (standardised processes) and harmonisation algorithms (to manage differences in equipment across sites), since differences between datasets may be a function of the testing and analysis process itself. The subsequent discovery that individual hospitals had re-calibrated the scanners provided more evidence of the risk of assumptions about the quality of the data in the absence of local knowledge about local changes in procedure. These observations highlighted both (a) the risks of combining data from multiple sources, and (b) the value of local knowledge (and agency) in shaping the quality of the data.

Data Linkage

HealthGrid projects allow the sharing of patient data across multiple regions, and in doing so, challenge the varying local ethical and legal arrangements for sharing data, which prevent the linkage of data that

might identify patients. This proved to be a source of significant delay (and therefore cost) for projects, given the different ethical governance arrangements in different regions. This constituted a major barrier for the ambitions of HealthGrids as a vehicle for data-sharing at scale (de la Flor, 2007).

In this context, a range of strategies to ensure the security and confidentiality of patient data was evident, from a unified model based on role based access to patient data, through to access to user and community led models. Each configured roles, risks and resources in different ways. This theme is the focus of paper 5, and CP 7, 8, which look at the implications of different configurations from the perspective of patients and nurses in particular.

All the papers to some extent reflect the tension between the vision of the interoperability of data and services as a unified system, and the tensions and trade-offs in aligning this with the very different aims, constructs and working practices of different communities, with different aims and criteria.

IMPLICATIONS FOR DESIGN

A key recommendation from the paper, implemented by the group, is the need to build community infrastructure to co-produce data infrastructure, and drawing on the work of Kling (2000) and the example of the US BIRN group participating in the workshop. This has been developed through the papers, looking at the impact of technology implementation on work practices, and the need to ‘design in’ users as part of the (re-development) process. As argued in the telehealth papers subsequently, collaborative action research can act as vehicle for this process.

Harnessing local knowledge and agency

The paper points to the particular value of leveraging the local knowledge and agency of users on the ground in contexts such as safety systems, and emergency systems, where the currency of

information and the speed of response are at a premium. Early adoption of this approach is most evident in contexts where

- the speed and currency of data is at a premium, such as mobile users in safety and emergency systems, (Comfort, 1999,2000; Johnson, 2009; Johnson and Wetmore 2009)
- there is value in individualizing services around the needs of very disparate users, as for example in marketing contexts such as the Amazon user profiling and recommendation system
- the social network provides a context for collaborative change, as for example in the use of collaboratories to engineer and incentivise the adoption of standards in CP5.

The workshop was a catalyst for subsequent collaboration across the national projects to agree minimal core measures of symptom, as a starting point for alignment of national data models. It took a core: local approach rather than attempting to align the whole disease concepts in the first instance.

The paper also points to the speed with which technical infrastructure has been implemented has outstripped the capacity of social and political infrastructure, and the need for new approaches to managing the reconfiguration of roles, rights and responsibilities in these new digital territories.

CONTRIBUTION TO THEORY AND PRACTICe

The strength of the paper relates to the impact on leading research groups in this field, in the HealthGrid and eScience Conferences that are the main for this, and through the participation of many of the national research teams.

It raised awareness of the sociotechnical issues more systemically, in the context of a theoretical framework, and with practical implications for design. The research also contributed to the EU White Paper road mapping the issues (Breton et al 2005).

Sociotechnical issues, while acknowledged by managers (and subsequently now in the context of NPfIT) to be major factors in project failure, (Hendy et al 2005; BCS 2006; Royal Academy of Engineering 2004; H; Sittig 2010), were not then a real focus of discussion in HealthGrid community, beyond ethical and legal aspects of data linkage and the confidentiality of patient data.

The use of a qualitative approach allowed stakeholding users on the ground to voice their experiences, and engage in discussion of the value of different implementation strategies. This provided insights of value in minimising cost and risk in the design and implementation of scale up research and service development. The potential to minimise cost and risk in clinical trials at scale is one reason the Medical Research Council have now recommended qualitative pilot studies with users(Anderson, 2008). The same principal arguably applies to the implementation of services at scale.

Of all the papers presented, CP4 and 5 are the most cited, and downloaded. This was to some extent pre-determined by the fact that it brought together the main players in the field in Europe and America, and all the participants were included as co-authors. This was then included in the formally disseminated debates in publications and the HealthGrid Conferences which are the main focus for the HealthGrid community, and in the White Paper produced on behalf of the EU HealthGrid community.

This impact was sustained initially by the decision to create a wiki-based site to work as a collaboratory on agreeing core data sets, with the UK eScience Centre (taking our own advice) and thus promoting their use. The workshop was a catalyst for subsequent collaboration across the national projects to agree minimal core measures of symptom as a starting point for alignment of national data models.

Much of the evidence of impact however comes through personal communication as to the value of highlighting the sociotechnical and the socio-political barriers, and invitations to contribute on courses, and on

committees such as the Advisory Committee for NeuroLog[37], the national Grid project for sharing brain images in France.

Evolution of Strategy

In all the eHealth papers, including the telehealth papers which follow, the design of the system or its implementation evolved in practice in response to the tension between the vision of the interoperability of data and services as a unified system, and the tensions and trade-offs in aligning this with the very different aims, constructs and working practices of different communities.

This was also an issue that arose in all the eHealth projects, and all the business projects (CP2) in one form or another, with a range of strategies in squaring this circle, from a unified model based on role based access, through to user and community led models. This theme is the focus of paper 5, and CP 7, 8, which look at the implications of different configurations from the perspective of patients and nurses in particular.

CRITICAL ANALYSIS

This was one of the more cited papers, because it was the outcome of collaborative work with many of the principal international groups in this field, and because it presented research on an under-represented set of barriers to the implementation of HealthGrids with clear implications for design and implementation. The Powerpoints from each of the speaker/participants are still available on the eScience Institute website however, and give a flavour of the discussion themes[38].

37 Neurolog http://neurolog.polytech.unice.fr

38 UK eScience workshop with Generation Scotland on May 6, 2006. Data Quality/ Usability Issues in e-Health: Practice, Process and Policy http://www.nesc.ac.uk/esi/events/684/ and www.nesc.ac.uk/action/esi/contribution.cfm?Title=684 http://www.nesc.ac.uk/esi/events/709

A weakness of the research is the lack of a full video transcript of the event. The videoing of the second event, which would have provided a basis for closer subsequent analysis, was not possible on the day, as a result of a second Conference, and some of the workshops were not recorded. This would have allowed for more rigorous coding and analysis of discussion. As it stands it is a position paper/ report of the outcomes of the workshop, rather than a piece of formal research.

4.4 CORE PAPER 5

Ure, J., Rakebrandt F., Lloyd, S., Khanban, A., Procte,r R., Anderson, S., Hanley, J., Hartswood, M., Pagliari, C., McKinstry, B., Tarling, A., Kidd, G., Corscadden, P. (2009) Giving Them Something to Hate: Using Prototypes as a Vehicle for Early Engagement in Virtual Organizations. *Social Science Computer Review*, 27 (Nov. Issue) pp. 569 – 582. ISSN: 0894-4393. Sage.
http://ssc.sagepub.com/content/27/4/569.abstract

OVERVIEW

This was an invited paper, double peer-reviewed, for an interdisciplinary journal that had the particular advantage of covering social science research applications of computing, as well as societal impacts of information technology. It has a mixed audience of informatics and social science specialists, and a particular focus on sociotechnical infrastructure.

I was the principal author of the paper, and the principal qualitative researcher on user requirements. S.L., F.R. and A.K. contributed to the concept and to editing of one of the cases (Case 1) in the paper.

It draws on work from two different portal development projects: Neurogrid funded by MRC Grant Ref no: GO600623. ID number 77729 and the TeleScot Pilot project on COPD funded by Intel through an unrestricted academic grant to Edinburgh University Centre for Population Health Studies (2007-8).

The paper was written for an audience with a focus on the social science of technology design and use. It focuses on draws on the difficulties of designing a HealthGrid portal (a) for very different audiences, (b) with an unfamiliar technology that (c) will impact on their normal work processes in ways that are not evident at the outset. In this regard, it deals with a generic problem in the design of multi-site

systems, many of which are developed as pilots, but are not usable in practice.

These are recognized problems in the course of requirements analysis highlighted in the eBusiness section, where 'wicked problems' (Richey 2011) are a familiar challenge for system designers. Typically, this means that the pilot version of a new service is greeted with a flood of new requirements not in the original specification, and significant changes in the existing specifications. This then requires significant redesign, with all the attendant, costs, delays and recriminations familiar with large scale IT projects. , as also documented in the eBusiness section, and in Reports by the BCS[39] (2006) and the Royal Academy of Engineers (2004)[40].on complex IT projects) in relation to the NPfIT programme.

Content

The paper provides examples of the use of early prototypes as a more tangible sandbox for supporting engagement, shared understanding, and opportunities for creativity and conflict resolution. As one system designer pointed out, 'You have to give them something to hate' at the outset, as users find it hard to frame or discuss meaningful requirements without a tangible context as a point of shared reference. Internet-based conferencing and recording provided an innovative means of piloting this approach with one of the Case Study groups.

Methods

The data from Case Study 1 was derived from ethnographic observations and recorded interviews of stakeholders in a HealthGrid portal project, and in Case Study 2, this is a secondary analysis of semi-structured interviews coded by independent researchers using grounded theory (Glaser and Strauss,1967).

39 www.bcs.org/upload/pdf/BCS-HIF-report.pdf

40 www.raeng.org.uk/news/publications/list/reports/Complex_IT_Projects.pdf

Qualitative research, particularly where it is iterative and participatory, has a particular application where the introduction of new technology is the catalyst for rethinking roles and relationships.

This approach, using Internet –based Conferencing (VOIP: Skype[41]) and other tools, was (then) original as a research approach, and provided useful affordances, in that users (including the designer) could collaborate in real time while 'walking through' the portal, and this process could be recorded. 'Making work visible' is an aid to design that is effective in practice (Suchman, 1995) and this approach allowed the group to 'see' the same landscape as they traversed it and discussed the obstacles. Requirements and suggestions evolved naturally and quickly in this more intuitive space, in a way that had been impossible in previous interviews.

Projects on the scale of Health Grids have to take account of the difficulty of identifying needs and requirements for a system that will in many respects disrupt the existing work processes on which requirements would traditionally be based, and will evolve over time in collaboration with users. The challenge of re-negotiating roles and resources among stakeholders is a challenge that has not yet been fully addressed (Catwell and Sheikh 2009).

DEVELOPMENT OF THEMES

The paper was written as a light-hearted piece of feedback to the Grid community on the approaches that could be used to address a core problem underpinning the failure of many systems at scale.

- the near impossibility of bringing together busy specialists (clinicians, imaging scientists, system designers and others) to agree on requirements in real time.

[41] Internet telephony that is cost free to users

- the difficulty of obtaining requirements in relation to a new and unfamiliar system with unpredictable implications for work practices
- the potential for better understanding of the issues when jointly ‘walking through’ a shared space with tangible interfaces that provide a common landscape for discussion
- the value of separating invariant and variable/context specific elements in design for multiple communities of practice
- the value of collaboratively exploring and configuring this with users as a catalyst for engagement, and a means of minimising cost and risk at an early stage in the proceedings.

IMPLICATIONS FOR DESIGN

The transcribed sessions highlight more specifically the value of the prototype as a vehicle for engagement in practice- as a sandbox for exploring emerging opportunities, and as a common landscape for negotiating the reconfiguration of roles and resources. Hutchins (1995) and Dourish (2001) point to the value of artifacts as a means of ‘grounding’ and supporting distributed or virtual collaboration. Later papers in the context of tele-health also develop this theme, but using the collaborative action research process itself as the vehicle. (CP 7, 8, 9).

This approach is supported by the availability of new, freely available web-based tools for sharing and for recording collaborative sessions such as Skype VOIP and shared desktop applications. These are now commonplace in such contexts, but were innovative at this point.

This application highlights the value of using technology to facilitate engagement with disparate communities in a shared sandpit, where the problems are self evident, and users themselves are challenged to cycle through scenarios and agree on options. Harnessing the natural ability of communities to engage collaboratively in co-producing viable solutions in context is presented as a way of addressing otherwise

intractable issues. It resonates with approaches currently used by the NIHR as experience based design, which brings patients, nurses, designers and others around the care pathway to collectively redesign it (Bate & Robert, 2007), much as happens in business process reengineering.(Hammer and Champy, 1993) (See Section 2.2) and is also used by McGilchrist et al (2007) in the design of different scenarios for security and confidentiality of patient health data in multi-site systems..

CONTRIBUTION TO THEORY/PRACTICE

This paper develops key research themes in (i) exemplifying a core problem addressed by designers of all multi-site systems, (ii) highlighting a practical and transferable strategy for addressing it, by better use of technology to leverage the human resource, (iii) exemplifying one approach to alignment, in scaling up core requirements, while allowing for separate pipelines for community specific requirements that are very different.

It also highlights the potential to design technical information and communication systems around those of social systems, a theme which covered in greater depth in the Discussion Section.

Contribution to Method

The paper also contributed to methodology in adapting newly emerging web-based tools for collaborative research and development in ways that were innovative at that point.

These provided a shared virtual space to ground this process, and work with a prototype to bring out real requirements more naturally – as for example on p 574 – “assumptions were quickly revised, refined or abandoned in the course of the implementation of the system, the initial concept evolved significantly”.

The perception of co-production by with and for users is one that has emerged in recent years, from the early waterfall model (Royce 1970)

where design ‘happened’ at a fixed point after initial requirements gathering, to more recent approaches where design is collaborative, iterative and ongoing.

CRITICAL ANALYSIS

Strengths and weaknesses

Conceptually, the paper frames a familiar problem in a useful (socio-technical) context, and highlights an approach to mitigating the difficulties inherent in such projects. In this it draws appropriately on theory, and reflecting the more sociological tone of this journal and an audience with a focus on those aspects of infrastructure design.

In terms of originality, the use of (then) new media as a vehicle for research at scale was seen as innovative, and cost –effective, and adopted by others on similar projects. The evidence of impact was largely through enquiries and adoption of this approach by others addressing the same problem.

Methodologically, this was interesting, but weak. Had this been anything other than a thought piece, mid project, one might have expected a broader set of examples, from Case 1, with more interviews, and a clearer coding framework. The telehealth papers the follow on demonstrate a more structured approach to documenting sampling strategy, sample breakdown, and ensuring that coding frameworks are appended with associated materials used.

The value for me personally was the opportunity to further develop an understanding of approaches which build on, or harness, the natural resources inherent in communities to construct shared understandings and develop strategy in grounded contexts.

Impact

The paper was well circulated among the Grid community, and the social science and technology community to whom the journal is

directed, and is the most frequently cited of the papers, although arguably one of the least well written.

The methodology generated interest and enquiries within the Grid community, not only as a means of addressing a recalcitrant issue in requirements gathering, but also because it uses technology in an innovative way to facilitate collaborative research with virtual teams, where time and travel costs are often a factor. In fact this approach was adopted and extended in subsequent research reported in CP 2.

It was not a high impact paper out with the community, but was significant in its impact on my own development in this context, as reflected in subsequent papers. It was associated with a number of other presentations within the grid community, as for example in the national Grid Conferences in Nottingham (2007a)and in Oxford (b) , and in the US equivalent in Michigan University (Ure, 2007c), as well as other international workshops (Ure 2008). These are all peer reviewed papers presented to the eHealth or the eSocial Science Community and published in proceedings.

Supporting Papers

Ure J., Procter R., Lin Y., Hartswood M., Ho K. (2007) Aligning Technical and Human Infrastructures in the Semantic Web: a sociotechnical perspective. *US: UK eSocial Science Conference (eSS2007*), Oct 7-9, Ann Arbor, Michigan, US

Ure J, Procter R., Liewald D and Pagliari C. (2007) Combining and Enhancing Data in eHealth. Nirvana or Pandora's Box, *Agenda-setting Workshop Event: Combining and Enhancing Data*, Nat. Centre for eSocial Science, (NceSS) Jan 22, 2007, Manchester. (Published as a long abstract)

Ure J., Procter R., Lin Y. (2007) A SociotechnicalPerspective on Ontology Development in HealthGrids, *Proceedings of UK eScience All Hands Meeting*, 10 -13 Sept, Nottingham.

Ure J., Lloyd S., Rakebrandt F., Khanban A. (2008) Usability, the Tri-wizard Challenge –Recurring Scenarios in the Design of a HealthGrid Portal *HIS08, Human Systems Interaction*, Krakow, Poland.

4.5 CORE PAPER 6

Ure, J., Procter, R., Lin, Y., Hartswood, M., Anderson, S., Lloyd, S., Wardlaw, J., Gonzalez-Velez, H., and Ho, K. (2009) The Development of Data Infrastructures in eHealth: A Sociotechnical Perspective. *Journal of the Association for Information Systems (JAIS)*, 10 (5) Art. 3. ISSN: 1536-9323

http://aisel.aisnet.org/jais/vol10/iss5/3

I was the principal author, drawing on work carried out as the qualitative researcher for two projects on data integration in eHealth, and an international workshop which I organised in collaboration with two HealthGrid projects, and the UK eScience Centre. RP and YL contributed to editing and revision of the draft.

The project which provided the backdrop for much of the research, NeuroGrid, was funded by the MRC Grant Ref no: GO600623. ID number 77729, and the international workshop (re-use of reinvention) on which it also draws, was funded by the UK eScience Centre. Participating neuroscience Grid projects included UK: NeuroGrid [42], PsyGrid[43], CARMEN[44], P3G[45], Generation Scotland[46]; EU: HealthGrid Share[47], HealthAgents[48]; US.Bio-Informatics Research Network[49], EADHB Brain Atlas[50] and the French NeuroLog Healthgrid project[51] .

42 http://www.neurogrid.ac.uk

43 http://www.psygrid.org

44 http://www.carmen.org.uk

45 http://www.p3gconsortium.org

46 www.generationscotland.org

47 http://initiative.healthgrid.org/the-initiative/share-project.html

48 http://www.healthagents.net

49 http://www.nbirn.net

50 http://www.ncl.ac.uk/igm/EADHB/

51 http://neurolog.i3s.unice.fr/neurolog

This was an invited paper for a Special Issue on Sociotechnical Infrastructure, edited by four leaders in the field, and triple reviewed. The JAIS is a high impact journal for information systems specialists, and one of the lead journals in the field of information systems. The Guest Editors are specialists in the design of sociotechnical infrastructure, and this was an invited paper, based on contributions to the eSocial Science Conference in the Univ. of Michigan, Ann Arbor, Michigan. It is therefore written for a mixed audience with a common interest in addressing the challenges of sharing data at a global scale using ontologies.

OVERVIEW

System design is a high cost, high-risk undertaking, requiring effective collaboration and knowledge sharing across very diverse and distributed communities. As the scale and scope of systems for sharing data (in this case medical data) has grown, so have the tensions between the requirements for global and local data models.

The paper draws on unique access to ontologists and project managers addressing this challenge in a range HealthGrids in the same disease domain mentioned in the previous paper, and from an extensive review of the recent literature on HealthGrids and ontologies in the bio-medical domain.

Content and Focus

It provides a high level overview of how ontology designers have tried to square the circle of interoperability and local usability from a review of the literature, and by drawing examples from a series of international workshops.

Ontologies represent a crucial layer in a sociotechnical complex, mediating and thus aligning technical systems that are deterministic with human systems which are less so (Joslyn & Rocha, 2000). The tension in this vision, however, is the difficulty of squaring the need for a

unified set of classifications and relations between data sets, with the many disparate and evolving classifications and relations that are embedded in the working practices of very different (and often highly specialized) user communities.

The paper looks specifically at how designers have addressed this central tension in the way they have designed ontologies, and the way the paradigm has moved – from expecting users to conform to a standardised model, through various compromise core + local models, and more recently, to the concept of engaging users themselves in building the technology around the evolving needs of the user community.

A Sociotechnical Perspective

The paper frames Grids and other complex, distributed infrastructure as co-evolving sociotechnical systems (Joslyn & Rocha, 1999a,b; 2000; Molina 1995), where a key design challenge is the alignment of coupled technical and human information systems to create useful synergies, and traces the evolution of strategy in this regard, contextualising this in the literature, and in practice. It also highlights the potential to learn from the design of business systems, which face comparable challenges, and have already cycled through a range of comparable solutions in practice, discussed in Core Papers 2, 3.

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and more recently, to the concept of engaging users themselves in building the technology around the evolving needs of the user community.

DEVELOPMENT OF THEMES

The paper moves from consideration of the recurring sociotechnical issues, to highlighting the evolution of strategy in the way the technical and the human infrastructure has been aligned, and the pros and cons of different arrangements.

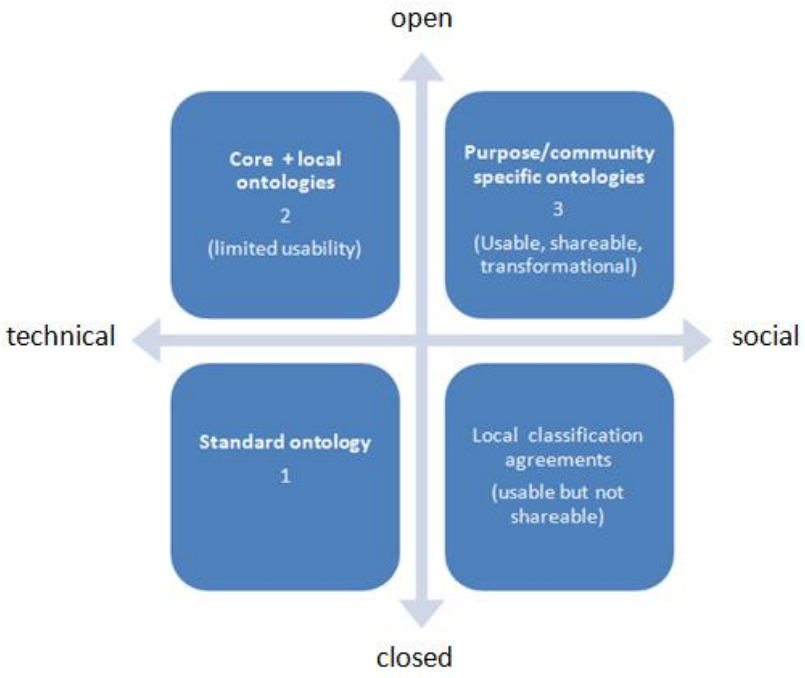

Fig. 4.2 Aligning technical & human information systems: evolving strategy.

One size fits all

The concept of the single ontology can be seen as running counter to the concept of knowledge in research as a fluid, negotiated entity. The experience of ontologists in all the projects grappled with the development of shared classification systems, given the very different ways in which differing communities construed and used it in their own contexts. The interoperability of a unified model was in tension with

usability in practice. The lack of adoption of HealthGrids reflects the difficulty of fitting users around a pre-defined model, after communities have developed their own norms and work practices.

Core and Local Strategies

One common strategy is the separation of a fairly stable core from those elements that are likely to differ among domains and user communities, or are likely to evolve and change over time. A number of Grid projects have adopted a compromise approach of this kind, and this has also been true of other large scale initiatives such as the implementation of electronic healthrecords (Pagliari 2007).

The Policy Grid project [Edwards 2006] provides an example of an eSocial Science Grid which deals with the tension between global and local factors by combining a fairly invariant core, with local variations based on the use of local folksonomies. This has parallels with similar debates in requirements engineering. Shantenu Jha {2007] provides examples from Cactus Grid of the core: local approach, balancing the need for local purpose specific extensibility with a stable core. CP 5, which precedes this, is a good example of how this works in practice in the context of eBusiness systems.

Bridging Strategies

One bridging solution included ontology mediators mapping between existing ontologies, although many reported significant problems in practice.

User and community centred strategies

Socially mediated approaches

Incentives to communities to co-create, or align themselves around shared terms, however, proved an effective strategy at scale. Berners-Lee (2007) highlights the potential value of strategies adopted which leverage the community resource to actively create value from data, using open Source tools. Recent publications of patient led health research in well established journals (Wicks, 2012) using such tools highlights the speed of this evolution in strategy.

This resonates with the evolution of business systems in this regard (CP2) in the generation of value from the leverage of local knowledge and innovation, and the localization of services [Sawhney and Parikh 2001]. Social networking media are based on this precept; although it was not until the commercial success of these that the concept was more evident in research and publication.

Business models (CP2, 3) increasingly cite such approaches as a means of adding value, and enhancing usability (Sawhney and Parikh 2001). Designers of systems dependent on speed, cost or quality (e.g. safety systems, P2P applications and those geared to transient e-business opportunities) have been early adopters of such strategies.

The US Biomedical Informatics Research Network (BIRN) was able to provide the incentives for disparate communities to come together in adopting shared standards, as a collaboratory, using open Source tools and shared resources. The use of shared tools and shared lexicons as free resources is increasingly a strategy, and also provided a process for achieving critical mass, for de facto implementation of a standard and for leveraging distributed knowledge in w3ays that cut cost and risk, and added value for users.

Motta (2007) describes a shift from developing ‘a centrally designed, monolithic ontology towards an automatic integration of ontology fragments, sourced from the semantic web…..relevant to the current user need….and performing both ontology mapping and co-reference resolution on the fly’, which has been termed faceted ontologies (Suominen 2007).

Technically –mediated approaches

While the collaboratory approach uses technology to build on social dynamics, ontologists have also used user tagging to provide a technical solution to the need for purpose specific ontologies for use by a particular community, at a particular time.

Motta (2007) describes a shift from developing ‘a centrally designed, monolithic ontology towards an automatic integration of ontology fragments, sourced from the semantic web…..relevant to the current

user need….and performing both ontology mapping and co-reference resolution on the fly', which has been termed faceted ontologies (Suominen 2007).

CONTRIBUTION TO THEORY & PRACTICE

The paper develops the issues in CP 4, that highlighted the gap between the vision of scalable data sharing, and the reality of practice and perception in different communities, and looks at the evolution of strategy in this regard.

Building technology around the social process

It was clear from the experience of other Grid projects in the NeSC eHealth workshop that ontology development involves the building of an ontology development community and this was a significant outcome of this UK eScience ontology building workshop a recognition of the need to support the development of stable sociotechnical constituencies – an ensemble of technical components (hardware, software, etc.) and stakeholders (people, interest groups, visions, values).

Re-framing the Issues in a Theoretical and a Practical Context

This was intended as a useful contribution to an understanding of why it has been so difficult to realise the vision of seamless data sharing in practice, and how solutions to this underlying tension have evolved.

The field of ontology development has been largely the preserve of specialists, given the difficulty for non-specialists to go beyond the semantics, and identify the elements in play, their relationships, and the potential to draw on other contexts addressing similar issues. The separation of communities in terms of where they publish, and the form in which it must thus be presented constrains exchange and transfer between domains which arguably address similar issues.

In framing this in sociotechnical terms, it highlights the potential to draw on evolving strategy in other fields where similar tensions exist, as for example in eBusiness. Here system design has benefitted from better

leverage of and engagement with the user community. The gap between communities is increasingly seen as a barrier to research (and the publication of research) in this cross-disciplinary field (Hā̄kkinen, 2012).

Contexts where speed, accuracy and human agency are at a premium have been at the forefront of the design of systems that build on the underlying knowledge and agency of local user communities. This is most evident in safety systems for example (Comfort 2002), and in the very dynamic and distributed environments of online business systems (Tapscott and Williams 2006). Recent developments such as Microsoft Health Vault provide infrastructure for patients to access, edit, and link their health records and already provide a sandpit for exploring a radically different paradigm (Vascellaro 2008, Mandl and Kohane 2008; Wicks 2012;) where infrastructure is shaped by and for users. The range of other organisations now providing mobile and Open Source tools to support this approach is discussed in the Telehealth Section in greater depth (CP7,8,9, - following).

Road-mapping and Recommending

This contributed to the EU Share White Paper road-mapping issues facing HealthGrids in achieving the aim of seamless data sharing across the EU Health Area. This brought together UK, EU and American HealthGrids in the same domain (neuroscience) to contribute to a European White Paper on challenges and solutions, and to develop a collaborative group building on core categories for describing brain imaging data.[52].[53]

52 http://www.nesc.ac.uk/esi/events/709/

53 http://www.ncess.ac.uk/events/item/?item=169
http://ncess.web.mcc.ac.uk/events/ASW/ontologies/
http://www.nesc.ac.uk/action/esi/contribution.cfm?Title=700

Re-use or Re-invention

For me personally, the most striking feature of the HealthGrid projects was the paradox between a vision of interoperability across the EU Health Arena in neuroscience, without a mechanism for feedback and exchange between projects building data models of the same diseases, in the same domain.

This was also the most striking feature of the work on Virtual Learning Environments in Section 1 (CP1) where many of the pitfalls already documented in practice and in papers in other regions (Canada and the US in particular) were not reflected in the research and policy at the time.

Similarly, in eBusiness (CP 2,3) There were striking examples of design and implementation issues in very extended enterprise systems, which again were not shared, and not part of the research, training or policy agenda until more recently, in the wake of evaluations of a series of high level project failures.

The HealthGrid papers all echo the point made in CP3 regarding the lack of mechanisms for closing the feedback loop between emerging practice, the curriculum and policy. Ina digital economy, with rapidly emerging issues here, and in the developing world, there is an increasing premium on the speed with which organisations can adapt and compete. All of the papers point in some way to how these gaps can be bridged.

CRITICAL ANALYSIS

The paper addresses a central problem in this field in an original and potentially useful way. It is appropriately contextualised in an extensive review of the literature, and based on a roadmap of the shared experiences of the leaders in this field.

The paper was not (in my view) well written and would have benefited from a further round of editing before submission, This is disappointing

in that this was an opportunity to provide a vehicle for making the core issues more visible and accessible to a wider audience. This is , however, a difficult topic to present out of the computational and ontological context in which it is normally discussed, and attempts to render it for a sociological audience have either been to superficial or too over-burdened with technical explanation.

In the event, and despite being cited and read more than most of my other papers, on reflection and re-reading, it does not quite bridge the gap. In part this reflects the articulation of the idea, and the unsophisticated graphics, but it also reflects the degree of background knowledge of the field which are required to see ontology building from a technical and a sociological perspective

In framing ontologies more generally, and less technically, as the mediating layer in the alignment of technical and human information systems, I hoped to make some of this more accessible to wider audience. In this, the poor quality of the writing does not I feel do this adequately, however a glance at any paper on ontologies to understand the translation and reframing that was required to move it in this direction.

Impact

The paper has been cited more frequently than many of the more general papers presented here, despite the narrowness of the specialist audience. The same principles of design have been presented in different domains, and for me personally, one of the motivating factors in this kind of research is the emergence of cross cutting underpinning strands in the wider enterprise of designing systems that incorporate disparate and distributed people, processes and technologies.

The content of the paper was also disseminated in other forms, (See CP4) in the Healthgrid Conferences and the All Hands conferences which re the core international and national events for this community, respectively. Through these they also informed the EU HealthGrid

SHARE project recommendations for policy and funding for HealthGrids in Europe.

Draws particularly on a series of international Conferences on data re-use in eHealth organised by the author with the UK eScience Centre and HealthGrids in US and Europe which themselves had an impact, and the outcomes were also presented at other national and international Conferences. (See Supporting papers following)...

Supporting Papers

Ure J. Design Principles for Distributed Sociotechnical Infrastructure in eScience, *All Hands Meeting*, Dec. 2009, Oxford

Ure J., Lloyd S., Rakebrandt F., Khanban A. (2008) Usability, the Tri-wizard Challenge -Recurring Scenarios in the Design of a HealthGrid Portal *HIS08, Human Systems Interaction*, Krakow, Poland.

Ure J., Procter R., Lin Y., Hartswood M., Ho K. (2007) Aligning Technical and Human Infrastructures in the Semantic Web: a sociotechnical perspective. *US: UK eSocial Science Conference (eSS2007*), Oct 7-9, Ann Arbor, Michigan, US

Ure J., Procter R., Liewald D. and Pagliari C. (2007) Combining and Enhancing Data in eHealth. Nirvana or Pandora's Box, *Agenda-setting Workshop Event: Combining and Enhancing Data*, Nat. Centre for eSocial Science, (NCeSS) Jan 22, 2007, Manchester. (Published as a long abstract)

Ure J., Procter R., Lin Y. (2007) A Sociotechnical Perspective on Ontology Development in HealthGrids, *Proceedings of UK eScience All Hands Meeting*, 10 -13 Sept, Nottingham.

4.6 INTRODUCTION TO TELEHEALTH

Research as a Laboratory for (Reconfiguring) Strategy

The availability of new ways of monitoring, by both patients and doctors, also invokes new models of care, requiring changes in the roles of those involved. Pilots such as these provide an arena for exploring the evolution of different kinds of collaboration and alignments of people, processes and technologies. The papers here are selected from publications written while I was a qualitative researcher on pilot studies of telemonitoring in chronic obstructive pulmonary disease (COPD) and hypertension with the TeleScot project. http://www.telescot.org/about-us.html The projects here were largely jointly managed by Edinburgh and Edinburgh Napier University.

As indicated earlier, the telehealth papers emphasis data sharing to support service provision rather than research. Core Papers 7 and 8 are reviewed together, (to avoid duplication of content) as both relate to the same project, sharing of data across multiple sites involved in the telemonitoring of older patients at home, although written for different audiences. They provide an insight into their experience of using the pilot system, and identify issues in design, implementation or use that could inform subsequent use at scale.

Paper 9 is more focused on the implications for data management in this context, and looks at the views of telehealth research teams on the storage and re-use of this data, in the context of a framework developed by the UK Data Curation Centre (DCC).

4.7 CORE PAPERS 7, 8

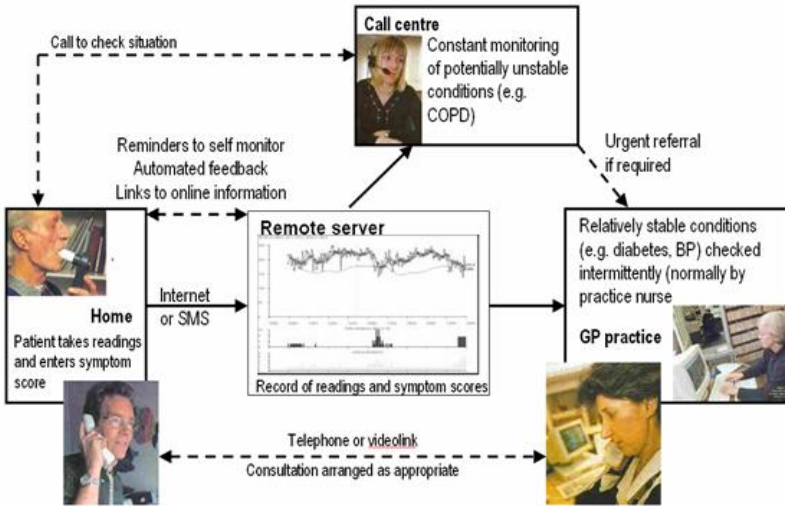

Fig.4.3. Coordinating data, information services across an extended network.

CP7: **Ure, J., Kydd, G., Tarling, A., McKinstry, B., et al, (2009) Disease with Home Monitoring: A Qualitative Study Report on Telemetry Supported Care for COPD Patients in Lothian Region. *Report to Intel UK, the Scottish Centre for Telehealth and Edinburgh University Centre for Population Health Sciences*. Edinburgh Research Archive**

http://hdl.handle.net/1842/5828

www.telescot.org/uploads/4/5/9/4/4594120/telescot-copd-pilot-report.pdf [54]

CP8: **Ure, J., Hanley, J., Pinnock, H., Pagliari, C., and McKinstry, B., et al, (2012) Piloting telemonitoring in Chronic Obstructive Pulmonary Disease: a mixed methods exploration of issues in design and implementation. *Primary Care Respiratory Journal (PCRJ)* 21(1):57-64. ISSN 1759 58X**

www.thepcrj.org/journ/vol21/21_1_57_64.pdf

[54] An ISSN number has also been requested for the series including others by the author in the process of publication

The telemonitoring pilot project which was the focus of the research was funded by an unrestricted academic grant from INTEL and support from the Scottish Council for Telehealth and NHS Lothian. I was the principle qualitative researcher and responsible for designing, carrying out and reporting the qualitative report.

In CP7 I worked jointly with GK in the pre-pilot phase, and with input from AT in the early evaluation of the patient experience. The project report in CP7 provided the framework for more audience specific papers as in CP 8. This is a short overview of the same findings of the report adapted for a largely clinical audience. JH, who is a clinical specialist in that area, helped focus, condense and revise the material. The journal is the primary journal for research on respiratory conditions such as COPD, which was the condition being monitored, and this was an invited paper.

OVERVIEW

Context

The need for telecare solutions has been driven by the anticipated challenges of providing care for an increasingly aging population in the UK where 17.5 million adults in the UK have chronic illnesses set to rise to 35 million by 2030 (Dept. of Health, 2004). The Scottish Government's Care Development Board strategy document (Donnelly, 2008) sets out a vision for the use of telecare technology to support long term goals in this context, including the aspiration that 'remote long-term condition monitoring undertaken from home will be the norm' by 2015. The research reflects the renewed interest in the potential (and implications) of using assistive technology to enhance home-based care of long-term conditions and minimise hospital admissions, building on different visions of digitally mediated healthcare, from the extension of existing clinical services through to the reconfiguring of the disparate clinical, social and community care services. The research is concurrent with a range of other initiatives to assess the value and

impact of such a strategy, as for example in the Whole System Demonstrator Action Network (Davies and Newman, 2009).

Aims

The pilot aimed to gather qualitative evidence of the experience of patients and care professionals in order to inform the planning of a wider randomised controlled trial across Lothian region (McKinstry et al, 2009; Pinnock et al 2009), focusing on the views of the primary users of the system. This was in line with the newly revised MRC guidance framework[55] for complex interventions (Anderson, 2008). In particular, the intention was to understand the contextual and person-specific factors likely to affect the successful implementation of the system, the perceptions and experiences of patients and care professionals using it and to identify issues in recruitment, installation and training as well as ethical issues that would have implications for scaling up the trial, and with implications for future service implementation.

Research methods

We adopted a grounded theory-based approach (Glaser et al, 1999), using semi-structured interviews to obtain insights into the range of different perspectives of interviewees on given issues. The richness of insights from users is useful in ensuring that more objective and representative surveys of a wider population cover the full range of factors that may be at work in a situation. Focus groups were audio-recorded, transcribed verbatim.

55 www.mrc.ac.uk/complexinterventinsguidance

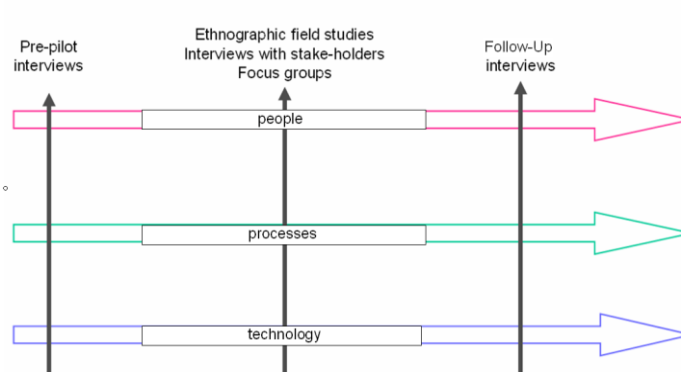

Fig.4.4 The research process

Interviews were then transcribed and independently coded by two researchers, and discussed with the project team. We used focus groups because they have the advantage of using group dynamics to stimulate discussion, yield insights and generate ideas to pursue a topic in depth (Strauss et al 1998) and are particularly suited to subjects with whom participants are familiar and likely to hold diverse views.

Coding of all interviews was carried out and iteratively refined using paired analysis of transcripts by two researchers and in collaboration with the wider group to generate a table of themes and sub-themes, with the associated text segments. Data generation continued until saturation occurred (Corbin J. Basics of qualitative research. 2nd ed. 1998). Deviant cases and possible conflicting interpretations were actively sought. These issues, together with the outcomes of recorded observation studies provided a basis for feedback to the wider team, and in the context of the workshop, to stimulate discussion in order to refine the emerging issues

Complex healthcare interventions impact on clinical, organisational and care processes in ways that cannot always be adequately explored using quantitative methods alone (Levin et al 2009; Plsek and Greenhalgh 2001). Nested qualitative work that brings users together around emerging issues, as for example in collaborative action research /participatory research (Kemmis 2000) or grounded theory (Glaser et al 1967) or in realistic evaluation (Pawson 2001), can refine or raise new research questions as well as illuminating barriers of an operational,

technical, clinical, ethical, organisational, contextual or patient specific issues.

They also provide a vehicle for engaging users in the process of change management (Nicolini 2009) and renegotiation of care pathways using approaches that are already evident in other digitally re-engineered contexts (Prahalad 2008).

The barriers and opportunities evident from the perspectives of patients, nurses, and GPs highlighted a range of issues that would not otherwise have been evident, and which materially shaped the planning for the wider trial.

Patient Perspectives

The overwhelmingly positive perception of patients in relation to telemonitoring services outlined in the report, through a literature review, reflected the reduction of anxiety associated with knowing 'the system' would act as a proxy ensure they would be able to get an appointment on time, in addition to providing evidence to justify 'bothering the doctor'. Shipman (2009) cites strikingly similar findings.

This approach highlighted the perceived causes of delay and anxiety, from a patient perspective, and the contribution of telemonitoring to mitigating this, at each stage of the pathway from initial recognition of symptoms, through to seeking help, and ultimately obtaining medication or intervention. The coded interviews with patients uncovered a range of technical, organisational and clinical issues which

- had clear implications for minimising the cost and risks of scaling
- would not have been evident from the quantitative data alone
- would not all have been anticipated by the investigators. (See Figure 4.5 for an overview.)

This seems to add weight to the argument for involving more of the stakeholders, and particularly users, in the early stages of design and development for large scale implementations of health technology (Anderson 2008).

Nurse and GP Perspectives

Nurses, physiotherapists and GPs on the frontline were also very positive, citing improvement s in the quality of care, positive feedback from patients, but highlighted very different concerns.

Their perception of nurses and other allied health professionals such as physiotherapists reflected their more holistic training, and the familiarity with the problems associated with collaborative care work[56].

Nurse managers particularly highlighted the importance of effective communication and coordination across this more distributed system, such as 'getting the right information, to 'the right person, at the right time' for services to be effective.

"But that's the thing with information - if it's not passed on to somebody then it's NOT a good idea, so there have to be good procedures in place for making sure that the information goes to whoever needs it….without that you can have all the technology you like but it's not going to be useful."

Allied Health Practitioner Manager

The report highlights the value of this approach to triage very different perspectives of the same landscape, and to act as a catalyst for stakeholders to engage in the process of reconfiguring that.

This follows on from the conclusions in earlier papers (CP4,5) about the need for a vehicle for users to come together to renegotiate roles, rights, risks and resource if the technical infrastructure is to align with the social, professional, and organisational one after implementation. Research, in this context, provides a laboratory for strategy with users.

Nurse managers also expressed concerns about the risks of home-monitoring if non specialists and patients underestimated the severity of the condition, and the speed with which intervention (such as oxygen therapy) could be required if severe cases of COPD were increasingly monitored at home by non-specialist community care staff.

[56] CP5; pp 40-45

This raises issues for training for new roles for community health practitioners, as well as for the planning of integration and coordination of services between specialists hospital based teams, physiotherapists, community health practitioners and others in managing new provision, and managing new risks. The research process acted as a catalyst in this regard in engaging stakeholders around these issues to share ideas and engage with issues.

Other studies done in tandem, but not yet published, find similar effects in the monitoring of hypertension (Hanley J., Ure J., McKinstry B. et al), where new data streams are a catalyst for rethinking both diagnostic practice and treatment guidelines, and moving on the basis of better evidence, from a gold standard to a more collaboratively agreed individual benchmark.

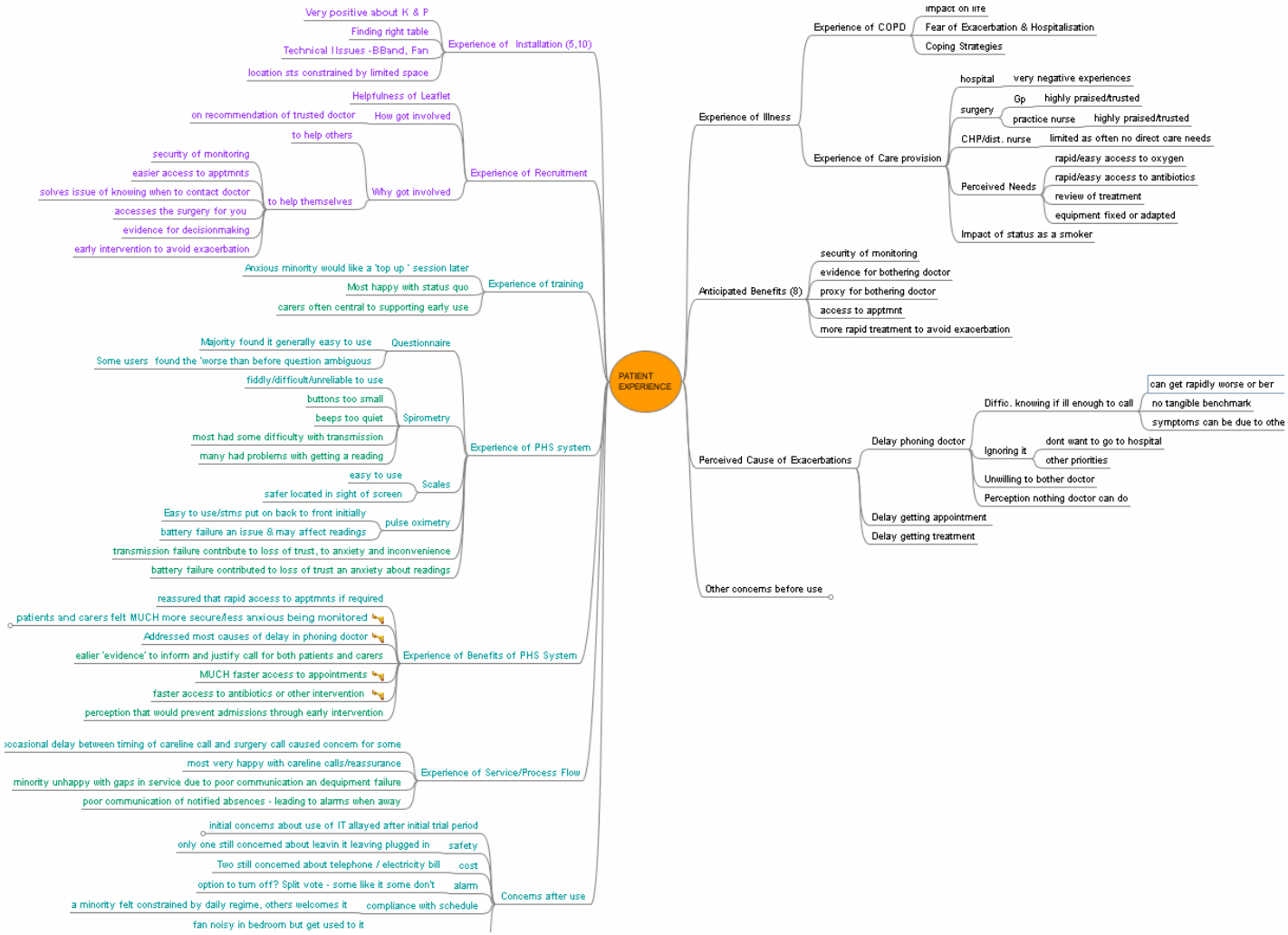

Fig. 4.5 Overview of themes from coded patient interviews. (Extract from CP8)

DEVELOPMENT OF RESEARCH THEMES

Papers 7 and 8 particularly highlight the recurring theme of socio-technical alignment, and misalignment, where the introduction of new technical infrastructure for communicating patient data, and coordinating care services requires a rethinking and a renegotiation of how people, processes and technology come together.

Rethinking practice and Protocols

The role of contextual factors and variation between patients highlighted the limitations of standard benchmarks in this context, and pointed to the need for more reliable early indicators of the difference between an incipient exacerbation and a bad day.

This again resonates with the literature on decision support, and the limitations of decision support algorithms as a proxy for the fuzzier and more collaborative process of diagnosis in context in other distributed eHealth applications based on triage or data linkage (Ure 2009).

Hurst and Wedzicha (2009) also point to the heterogeneity of factors involved, where there can be no 'one size fits all' approach to COPD exacerbation management and prevention' and successful reduction in hospital admission may be reliant on taking account of individual factors (Hurst et al, 2010). From a service provision perspective, this chimes with the growing emphasis on viewing health care systems as complex systems, (Bar Yam (2006) where there is a need to consider where generic strategies are cost-effective (Bar Yam gives the example of vaccinations) and those which require tailoring around individual needs (Here he gives the example of an individual with a rare condition, or a complex combination of conditions)

Rethinking Self Care

Patients' access to their own readings also provided them with a better basis for making decision about accessing care, or evaluating the impact of changes in either their own management of care, or of medication or intervention offered by a care practitioner. A core

question for the wider trial should be the perceptions of/ potential for addressing the self care agenda more directly, in the way Schermer (2009) suggests.

Physiotherapists and practice nurses expressed particular interest in the potential of using the system to provide tailored information and resources to support patients in this.

Rethinking Research

The research approach facilitated the exploration gaps, barriers and opportunities that would not otherwise have been available in the planning of a wider trial and service development. In feeding back the different perspectives and experiences of stakeholders, it provided a vehicle for engaging with the issues in a way that was necessary for the next stage in creating an effective communication infrastructure, and agreeing appropriate approaches to service coordination and delivery that will be cost-effective and acceptable to both users and care providers in an emergent process of exploration and engagement in service development Pilots such as these have useful implications for minimising cost and risk, and providing a sandpit for exploring different scenarios for the coordination of data triage and interventions scenarios.

Collaborative Change Management.

In this process of reconfiguring roles, risks and resources, (Finch et al (2003), Nicolini (2009), Ure et al 2009b) the care compact is essentially redesigned, by default. There are issues of representation in the process of redesigning if it is to be usable and acceptable in practice (Robertson et al 2010; Ure 2011c).

Studies from other distributed digitally mediated domains also address similar challenges with lessons for eHealth. The experience in designing and implementing distributed eBusiness systems in the next Chapter, suggest that rapidly evolving systems require early and ongoing engagement with users be cost-effective (Prahalad 2004; Ure 2009; Tapscott 2008, Sawhney et al 2001; Buchanan et al 2012).

New technical infrastructure, in other words, will require new support structures for renegotiating how people, process and technology are to come together in these new digital territories.

What are the risks of re-allocating risks from hospital care teams to distributed community-based ones? How will resources be allocated for care in a community setting? What are the ethical and legal implications of sharing data across distributed care teams? What are the risks of dependency on digital infrastructure in the case of an emergency?

Questions such as these, and others which will emerge during implementation, have outstripped the capacity of existing legal and governance frameworks, and suggest the need for more responsive and democratic processes of collaborative research and design.

Vehicles for Change

From a methodological perspective, the pilot highlights the potential of collaborative qualitative methodologies such as action research, and experience based design (Bate, 2006) as vehicles for representing as well as engaging stakeholders in this reconfiguration process (Eisenberg 2006; Levin et al 2009; Anderson 2008;Geels 2001). This is increasingly relevant in a context where the traditional mechanisms in law have been overtaken by the new affordances of networked technology which often change power relations (Callon 1998, 2003) in the reconfiguration of roles, rights, risks and resource allocation.

The aim to ‘reconfigure the care mountain’ as one social work director put it, is arguably also reconstituting society, or perhaps less dramatically, the care compact as it stands.

This raises questions which are not within the remit of the system designers, and only emerge in the area of policymakers after the fact – how, where and when are patients, nurses, carers and others to engage in the evolution of these complex juggernauts?

From a more critical point of view, telemonitoring work is typically nurse led, yet the paper, and the field as a whole, has been less inclusive of their perspectives on the ground Two papers geared to a nursing

audience are in process in respond to this perception, and will be submitted to nursing Journals. The more holistic and patient centred training and practices of nurses, as evidenced in their interviews is more in harmony with the model of collaborative and patient centred care than that of GPs and clinicians- the separation of these two communities in terms of the journals to which they contribute, and which they read arguably reinforces a divide that implies a loss in the process of collectively understanding and reconfiguring 'connected' care.

Again this resonates with the conclusions of other papers that the research and the dissemination process is itself often a barrier to the successful design and implementation of digital infrastructure. Recent reports on the design of large scale infrastructure in health informatics from the BCS (2006) and earlier, from the Royal Academy of Engineering (2004) underline a growing perception that training for designing and implementing ICT at scale has not been responsive to changes in a field that cannot be meaningfully understood without engaging with different actors and different domains more systematically.

The many software applications which leverage user knowledge and agency to commercial advantage are testament to this. Amazon profiling/recommender systems, for example, harness the local knowledge of users to target marketing. Others take advantage of the agency of users to act to minimise risk in safety systems, or, as in von Ahn's 'Captcha' technology (2003), harness users' online activity to translate texts at speed and at scale.

CRITICAL ANALYSIS

The research elucidates some of the reasons for these effects in the patients' own words. The findings are also consistent with the wider literature, particularly in relation to perceptions of quality of care, and reduction in anxiety for patients and carers (Barlow 2009; Gaikwad 2009; Lamothe 2006, Whitten et al 2002).

As Koff (2009), Casas (2006) and Wilkinson (2004) suggest telecare studies can in themselves also prompt useful reviews of integrated care of COPD by healthcare teams, as appeared to be the case in this pilot, including the sharing of good practice, such as providing antibiotics at home, to prevent delays in starting treatment.

The paper contributes to theory and practice, in a rapidly emerging area, using qualitative methods that complement the quantitative methods used to establish the impact of adopting telemonitoring at home. The qualitative approach made it possible to tease out possible reasons for some of the findings in more quantitative studies.

Evidence of Impact

Some evidence of impact of the approach comes from the Journal Editorial. This praises the' methodological approach, and its contribution to the field in the journal editorial provided by three senior Canadian specialists in eHealth management, innovation and policy.[57]

> "The report by Ure et al illustrates the value of mixed methods during the evaluation of telemonitoring interventions for people living with chronic conditions. In this case by conducting a preparatory qualitative study, the authors were able to detect and address, in advance, key human and technological issues that could threaten the validity of their RCT.
>
> The study also reveals technological nuances that are rarely considered or reported by RCTs that could have a major impact on their validity. These include the need to reduce uncertainty around data transmission, to simplify self-assessment of symptoms by debilitated patients, and to overcome concerns about increased workloads by improving clinician user interfaces.
>
> The study by Ure et al is a welcome addition to a growing body of literature that invites health researchers to expand their horizons beyond the confines of single methods, and to embrace the richness of insights offered by the combination of qualitative and quantitative tools, particularly when tackling complex areas such as the evaluation of telemonitoring during the management of chronic diseases.

57 Cafazzo JA, Seto E, Jadad AR. Qualitative studies enrich telemonitoring research, practice, and technology design. *Prim Care Respir J* 2012;21(1):10-11. DOI: http://dx.doi.org/10.4104/pcrj.2012.00023

> By abandoning the methodological zealotry of the past which has forced researchers to pledge exclusive allegiance to qualitative or quantitative approaches, we might begin to assemble a holistic view of the myriad pieces that make telemonitoring whole and that can only become apparent when sought through multiple lenses and perspectives. Otherwise, we will be condemned to continue reporting a litany of unsophisticated implementation efforts which have gone awry."
>
> Editorial: Prim Care Respiratory Journal 2012; 21(1):10-11

The wider report has been influential within the telehealth community in Scotland in highlighting the perspectives of patients and nurses in particular, and was the basis of many invited Conference and workshop presentations to nurses and trainee nurses.

It has also been shared with telehealth project managers and researchers in the emerging telemedicine network in Latin America, and part of joint work with the Director of the Venezuelan telemedicine network, and the Economic Commission for Latin America and the Caribbean (ECLAC) who are currently developing shared standards in telemedicine across the region. The issues arising from these two strands led to the development of joint proposals and a joint workshop which are ongoing, and contributed to guest lectures given to ICT4Development courses in Edinburgh and London, as well as national and international Conference presentations.

From a personal perspective, the project has a significant impact on my perspective on the value of user (and particularly patient, carers, nurses) as critical to the mitigating of cost and risk at scale, (Ure 2011) and the need for new research and development vehicles that can leverage knowledge and agency in re-designing systems and care pathways.

Collaborative action research provides an initial catalyst for this, and the NIHR have adapted process re-engineering methods very usefully in the redesign of care pathways in this way as 'experience based design (Bate 2008).This also sits happily with the perception that reconfiguring technology also reconfigures roles and rights with in the care compact in ways which require formal vehicles for renegotiating these.

4.8 CORE PAPER 9

Ure, J., Irshad, T., Hanley, J., Whyte, A. Pagliari C., Pinnock, H., McKinstry, B. (2011) Curating Complex, Dynamic and Distributed Data: Telehealth as a Laboratory for Strategy, *International Journal of Digital Curation* 6 (2).ISSN 1746-8256
www.ijdc.net/index.php/ijdc/article/view/187/267

This was a double blind peer reviewed paper for the specialist journal for data curation in the UK, drawing conclusions from a Case Study[58] carried out for the UK Data Curation Centre (DCC), with funding from the Joint Information Systems Committee funding. I was the primary author, with minor editing and revision from TI and AW.

OVERVIEW

Telehealth monitoring data is now being collected across large populations of patients with chronic diseases such as stroke, hypertension, COPD and dementia. These large, complex and heterogeneous datasets, including distributed sensor and mobile datasets, present real opportunities for knowledge discovery and re-use, however they also generate new challenges for curation. As with the other papers, it is yet another context where there is a tension between the pressure to use a generic framework for managing data, and the very individual approaches acceptable to different professional communities.

The paper summarised a qualitative Case Study with a telehealth team to evaluate their data management and curation practices, in

58 Clinical Data from Home to Health Centre: the Telehealth Curation Lifecycle: http://www.dcc.ac.uk/webfm_send/106

the light of the potential value of the datasets for research, the sensitivity of consent for access and re-use, their unusual size, and the lack of established practice in the management of monitoring data of this kind. The original case study and the report were joint work with Tasneem Irshad. The journal paper seeks to re-contextualise the findings as an argument for more user-centred models of curation.

This paper draws again on qualitative research with stakeholders in the case study, (as earlier) and on the outcomes of two nationally-funded telehealth projects. These were typical of telemonitoring projects generating large scale data from patients with long term conditions, and highlighted some of the issues associated with the management of this kind of data from the perspective of data curators – i.e. in terms of data preservation and possible re-use. It draws on an earlier case study that was tasked with commenting on the potential for adopting or adapting the model devised by the Data Curation Centre. In contrast, this paper rather explores the different scenarios available, and the potential value of giving more consideration to user-led models.

Conclusions include that centralized data curation as framed in the current data curation vision, may need to take account of the increasing trend towards /value of community held data sets, where communities can curate and share their data themselves as is the case in all the previous studies, moreover it makes the point that this can be a means of enhancing quality, ethical issue of confidentiality and access.

DEVELOPMENT OF THEMES

The paper highlights the lifecycle of such data as it passes through many hands, and many transformations, and the concomitant opportunities for loss of data quality or integrity, often without this being visible to those at the end of the chain. So-called ‘unknown unknowns’ (errors in de-encryption, annotation, transmission - In

all of these, the paper points to the potential value of users themselves as data curators if the system allows for this.

A new theme arising here is the need to design in incentives for changing organisational or team behaviour, since the collection of metadata can be a costly, time-consuming and specialized task which brings little benefit to the team involved (Atkins 2003). In a research context where time and costs are at a premium, the allocation of a significant role to data curation though the project is clearly unrealistic unless provision is made at the outset as a required element, and with the requisite funding.

It points also to the experience in eBusiness (CP2,3) in HealthGrids (CP 4,5) and in tele monitoring (CP 7,8) and in the context of safety monitoring, that users can not only bring knowledge of barriers on the ground, they can also act locally to enhance the quality of data – particularly where this is integral to the design. In disparate and dynamic contexts, this is increasingly at a premium, and user led design has been most evident in such contexts as emergency and disaster management.

CONTRIBUTION TO THEORY/PRACTICE

Extending theory

The DCC vision statement states that: “the scientific community has data characterised by structure, volatility and scale. Mobile telemonitoring data offers a view of the kinds of data curation issues raised by highly dynamic and distributed systems in practice. These arguably require us to extend our notions of curation.” The paper extends those notions of curation to include users as potential data curators, and points to the emergence of user and community led infrastructure[59] as a means of managing quality,

59 Mydex www.mydex.org
Cloud4Health www.cloud4health.com
PatientsKnowBest www.patientsknowbest.com

confidentiality and curation more cost-effectively, and increasingly using open Source toolkits to leverage the knowledge and agency of patient group in published research (Wicks, 2012).

Drawing on Theory and Practice in other Domains

The paper contextualises the points it makes in an extensive review of the literature, as well as models and reports It also considered research and development in other contexts where similar challenges arise in the eScience community (Edwards et al., 2007a), the eHealth community (Breton, 2005; Ure et al., 2007) and the digital economy (Sawhney & Parikh, 2001; Tapscott et al., 2006). It also points to innovations in the developing world, where mobile telehealth networks are increasingly the norm, often using Open Source software. This is currently generating a whole ecosystem of models of moderated use and re-use that is arguably under-represented in the literature, given the novelty and speed of adoption, yet which represents mobile patient and community data management on a vast scale. The Harvard-based Sanamobile project,[60] providing Open Source software on a mobile phone for use in remote and rural areas in the developing world provides a good example of how this is reshaping every aspect of eHealth. Infrastructure (Ure J. 2011c; Walsham & Sahay 2006).

Recommendations for practice.

Much of the challenge for curation now derives from the need for organisations such as the DCC to provide opportunities and incentives for these communities to engage in the process of renegotiating roles, and rights of access in the context of use and re-use on which data curation will depend. Some of this can be incorporated into the existing infrastructure that supports applications for funding, for ethics, for clinical trials management, and as part of publication agreements in reputable journals.

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[60] Sanamobile www.sanamobile.org

However, for many aspects of curation, particularly in relation to data quality and data re-use, the current approach is constrained by a lack of resources and incentives. This undermines the huge investment in generating telemonitoring data as a unique new research data resource for machine learning to model trends and individualise treatment.

CRITICAL ANALYSIS

The paper challenged the prevailing approach, as suggested alternatives, both at the Conference, and in the Journal. As the main journal for this community, and one which is closely allied to the equivalent American organisation, it raised awareness of the need to be open to emerging ideas from other disciplines, and other tradition in other countries in what is a very fast moving field. The key points were also presented in the national Conference for Data Curation in London,[61] to the core community for work in this area.

The Digital Curation Centre (DCC) brings together the tradition of data from a computing context, and information from the context of library preservation. While both disciplined acknowledge the need for contextualizing data, and providing provenance, the metaphors are all redolent of classification and storage in a stable environment.

The strength of the paper is the ability to draw on other domains to highlight generic issues, and opportunities to see how these issues have been dealt with in other contexts.

The paper competes with itself in having different narratives, reflecting its origin for a different purpose (a case study review of theory and practice, in relation to a pre-defined model of data

61 Ure J. et al 'Curating Complex Dynamic Data in Telehealth', DCC Conference, London. Dec. 20

curation) and an argument for user centred practice. The different narratives, and styles, sit uncomfortably together, and would perhaps have benefited from being written as two separate papers.

Methodology was somewhat superficially treated, and reflected, as indicated a paper that was constructed from different elements, rather than organically developed as part of a long term project. In retrospect I would have separated the two sections as two papers, and given a better analysis of the target group, breakdown, thematic coding. As it stands, the conclusions do not all flow clearly from the evidence. That apart, this was an opportunity to make a point about the role of users in a community which has often been data –centred, in its approach to the management of data, and of data as a source of innovation.

Supporting Papers

Ure, J. (2011c) Minimising Risk and Maximising Value: Informing Research and Service Development in Collaboration with Users in eHealth and eBusiness. *BCS Health Information Systems Conference*, Edinburgh.

Ure, J. Procter, R. and Lin, Y. (2007b). A Sociotechnical Perspective on Ontology Development. In HealthGrids, *All Hands Meeting,* Manchester. (All Hands is the National Conference for HealthGrid research in the UK, held at the UKeScience centres in Oxford, London, Manchester and Edinburgh).

5 DISCUSSION & REFLECTION

5.1 Introduction

If the social and the technical are inseparable, the design of systems needs to change. We should no longer accept designs that are restricted to technological systems alone, but broaden the scope of the design to include social structures

Coeira E.2004. BMJ

The failure of many high profile ICT-supported systems and services has raised awareness of the challenges in aligning technical social and organisational infrastructure at scale. The associated problems, and the strategies adopted to address them, are the focus of the core papers, contextualized in terms of the literature. The publications present a series of recurring sociotechnical challenges to the design and implementation of sociotechnical infrastructure at scale, and map the evolution of strategy through three sectors over a decade.

Technical interoperability requires stable configuration of requirements and common standards. Local usability requires design that is responsive to (dynamic) local requirements and context of use. Most of the recurring issues reflected the difficulty of squaring this circle.

What is perhaps striking, from an overview of the research, is the serial re-invention, rather than re-use of knowledge of recurrent sociotechnical challenges that impact on cost and effectiveness in large scale digital infrastructure.

The papers also show that migrating to a digital platform reconfigures roles, risks and resource allocations in ways that (a) can be informed by feedback from stakeholding users, and (b) requires a means of engaging with stakeholding users as part of the research and the development process.

5.2 Contribution to Theory and Practice

The publications and their analysis point to a gap in theory and practice, and has gone some way to both building cross-disciplinary constituency, suggesting theoretical and practical frameworks for understanding and addressing these.[62]

The papers trace a development from (1) initial exploration of the field in eLearning, to (2) engagement with a wide range of practice-based professional communities in eBusiness system development and (3) to a more in depth analysis of these issues in the context of eHealth at scale. It suggests that many of the issues that were problematic in current eHealth applications were equally problematic in eBusiness[63] and in eLearning applications, and relate to the nature of alignment (or more frequently mis-alignment) of people, processes and technologies.

5.21 Contribution to Knowledge and Practice

The approach adopted has provided a useful sociotechnical lens for looking at infrastructure in terms of the alignment or misalignment of social and technical infrastructure, and the approaches that have evolved in different contexts.

Are there recurring sociotechnical issues?

A range of recurring problem scenarios was very evident, across sectors. This was particularly evident at scale, where the interdependence of social and technical knowledge became more apparent, and the tension between local and global requirements became more critical. A range of approaches were also evident. Figure 5.1 highlights some of these, taken from eHealth (CP7) but just as evident in eBusiness (CP2).

62 In the BCS book, CP2, this is in the Appendix

63 Some are implicit in Peter Senge's description of archetypes in 1990.

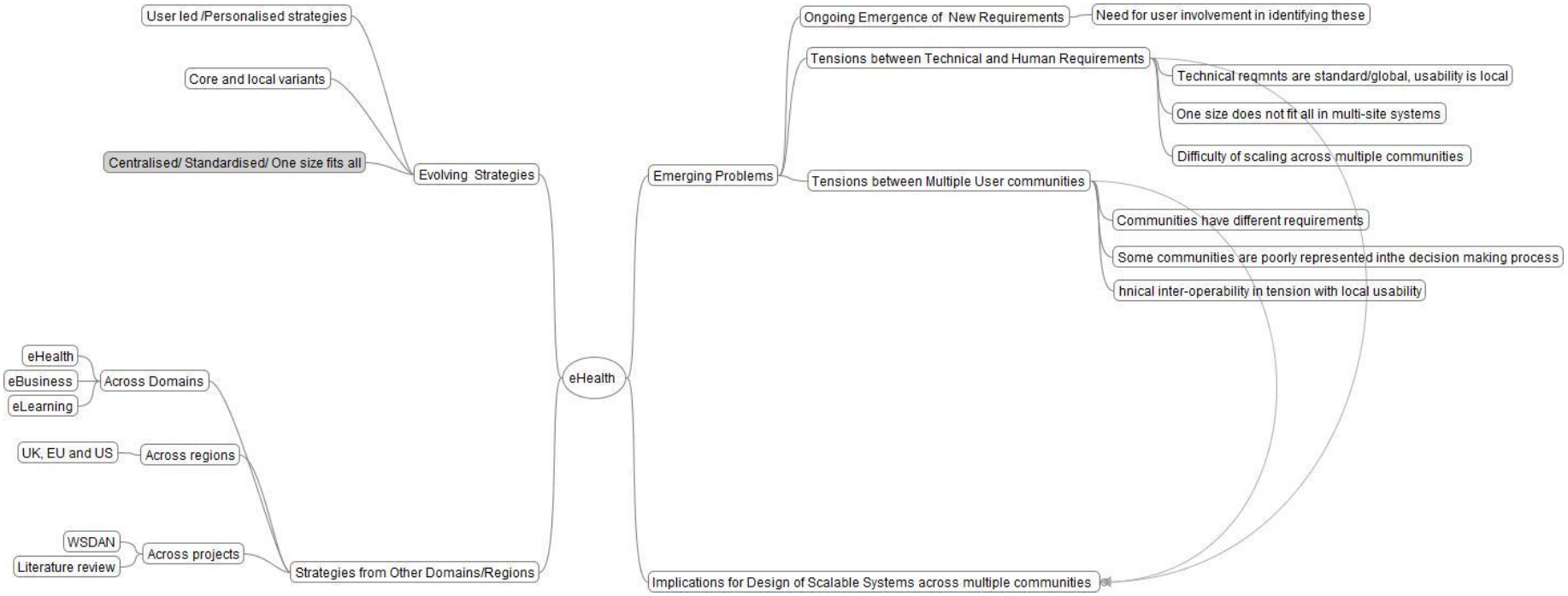

Fig. 5.1 Overarching Themes in eHealth (CP7)

How do designers and managers address these challenges?

The papers drew on a range of nationally-funded system design projects in e-Business, e-Science and e-Health which identified recurring problem: solution scenarios with implications for the design of scalable, interoperable, yet locally usable infrastructure.

These suggest a range of potentially cross cutting principles for design based on the alignment of social and technical infrastructure to achieve synergies, and avoid unpredicted cost and risk through alignment. Core Paper two was written specifically to address the concerns of managers in this regard, and the report from the BCS (2004) subsequent to recent IT project failures points to many of these issues, and specifically to the lack of transfer of these issues to professional development.

Evolving Strategy

A range of approaches have evolved to address these and are exemplified in different domains.

1. One size fits all – provides for interoperability at the cost of usability.
2. Core and local pipelines or standards – separate design of core requirements from more variable or specialized local ones
3. Technical (or human) middleware to map across domains
4. Build on the cognitive and social infrastructure of user communities [64]

The first of these was a viable approach in the more homogenous and local contexts of early software design, but was increasingly less effective for the heterogeneity of multi-site web-based contexts.

[64] e.g. 'wikinomics', social network media, crowd-sourcing, recommender systems, augmentation, embedded computing,

Separating scalable aspects, from context specific ones was a compromise strategy, as was seeking to harmonise these with technical or human mediation. The most recent strategy, building on the existing cognitive and social infrastructure of user communities has been the most radical of these, adopted most rapidly in the context of eBusiness, where t cost reduction and currency of information has driven change[65]

Leveraging the technical & the human resource to advantage

In designing e-Infrastructure for contexts such as mobile networking, or safety and emergency systems, there is already growing adoption of design strategies that leverage distributed human resources more effectively to mitigate cost and risk through knowledge of local requirements, and agency in local communities.

Human agents in the field are increasingly seen as a fundamental part of enhancing the quality and cost-effectiveness of data and services provided. The design of structures to anticipate or reduce fire risks and facilitate rapid intervention is a case in point, based on the assumption that an engineered building, with its occupants, constitutes a sociotechnical system.

It seems likely that the same value model will drive the evolution of e-Infrastructures in eHealth in future. Recent developments providing infrastructure for patients to access, edit and link their health records have already provided a sandpit for exploring user and community led approaches to health information management for example.[66]

Until the evident business value of Web 2.0 applications was established (Tapscott & Williams 2007) the potential role of distributed communities themselves as dynamic and adaptive information systems was generally under-represented in design abstractions, despite the body of work in ethnography and CSCW.

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65 A much more streamlined feedback loop from practice and outcome back to policy and design!

66 Cloud4Health www.Cloud4Health.com and Mydex www.mydex.org are examples

A key finding from the HealthGrid workshop was the extent to which (a) the identification and the elimination of significant errors in the system dependent on local knowledge and agency was a function of social interactions, and (b) there was increasing interest in sharing strategies for managing the tension between core and local knowledge more effectively.

User-led and Open Source

If costs and risk is to be minimised, and value optimised in emerging telehealth infrastructure, there is an opportunity for service developers in telehealth to consider how, when and where users will be represented in the process of reconfiguring roles, risks and resource allocation in these emerging digital territories.

Putting users at the heart of infrastructure design can allow for more responsive and sustainable design at scale, as part of a long term process[67] of co-development (Ribes 2009, 2010, Pollock 2010, Bowker et al 2000; 2010; Berners-Lee 2007) - not only because it is fairer, but also because it is more cost-effective.

Users and user communities are able to lever local knowledge and agency, and are often central to emerging change and innovation on the ground (von Hippel 2002, 2004; Sawhney & Parikh 2001).

The PhD thesis has given me the opportunity to reflect on the cross cutting sociotechnical issues emerging from these projects, the strategies that have evolved to address them. It has also raised questions as to why there has been so little transfer across sectors and regions.

[67] Ribes speaks of 'the long now' of infrastructure development as an evolutionary process, rather than a one off design issue.

5.22. Implications for Research & Training

An overview of the research points to serial re-invention, rather than re-use of knowledge of critical sociotechnical scenarios that impact on cost and effectiveness in large scale digital infrastructure.

The awareness of these deficits by managers at the coalface, suggests that professional development bodies have been slow to recommend the inclusion of such training in the curriculum, and to ensure that emerging issues in the field are captured and incorporated quickly.

The failure of many flagship projects arguably reflects a need to raise the profile of sociotechnical issues in design and implementation of digital infrastructure at scale, and recent reports have underlined the implications of this for professional development in the context of eHealth (BCS HIF Strategic Panel Report 2006; Royal Acad. Of Engineering Report 2004; Eason 2007).

Research and professional development infrastructure

Competitive advantage in a digital economy is premised on the speed and currency of information and innovation, mediated by digital infrastructures that are inter-disciplinary, practice based, emergent, high risk and high cost.

In relation to practice based research such as this, there would seem to be an argument for rethinking this major artery feeding policy and practice in society to ensure this was faster, and more representative of emerging evidence from a dynamic field, where most of the innovation is practice based, and currently invisible

The work with supervised student researchers, themselves making use of free VOIP technology, suggests students themselves can be deployed to bridge the widening gap between research and practice in the field as part of training. They can also act as bridges between

regions, and between academic and business organisations, in ways which add value to the curriculum, and to the economy.

On reflection, I was surprised at the extent to which I had ignored this aspect of the whole, given its role in determining the relationship and the interaction between the other moving parts in

Collaborative action research as a catalyst for change

The papers highlight the value of qualitative research with stakeholders as a means of informing the design of infrastructure at scale, and starting the process of stakeholder engagement in reconfiguring work processes in new digital territories.

The eBusiness publications also suggest that qualitative research of this kind is an important element of competition in an increasingly digital economy and society, where the feedback loop that should inform change in policy, practice and training in a dynamically changing market is currently fragmented, constrained and slow.

Methodological development.

As the papers progress, there is a developing awareness of how to ensure that the methods and the conclusions are more transparently used and presented (comparing the use of qualitative interviews in CP1 for example, at the outset, and the more rigorous presentation of how these were achieved and analysed in CPs, 7, 8 on telehealth, and CP 3 on clusters at the end. The later eHealth and eBusiness papers also build on the methodology, extending qualitative methods, and using this as a basis for both adapting quantitative follow ups. There is also greater incorporation of digital tools that can extend the scale and scope of qualitative research approaches without additional cost.

5.23 Contribution to Theory

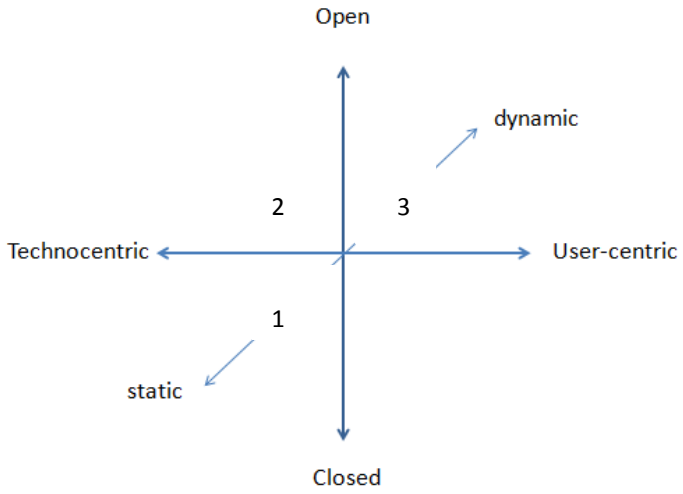

Fig.5.2. (Ure et al 2001) Adapted from a presentation to ALT-C in Edinburgh

Codex, Memex, Genex[68]:Three Generations of eInfrastructure

The papers point to the evolution of different visions of eInfrastructure that have shaped design and implementation from the early eLearning work through to eHealth, each with different implications for how people, processes and technologies are configured, and expected to interact. The move is from a more technocentric, organizationally centred 'one size fits all' approach in Quadrant 1, through to more collaborative, but still technically constrained approaches in Quadrant 2, and ultimately to more generative user-centred approaches which reshape the environment itself in Quadrant 3.

The later papers show the evolution of design abstractions from system-centric to user-centric models of alignment, driven by the benefits of leveraging local expertise and agency. In this regard I

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68 Shneiderman, B. (1998) Codex Memex Genex: the pursuit of transformational technologies. *Proceedings of the ACM Conference on Human Factors in Computing Systems (CHI 98).*

hope to have contributed a framework for contextualising some of the design issues in relation to the sociotechnical whole, and to have demonstrated the value of at least some methodologies and some strategies consistent with this view more systematically.

Vannevar Bush (1945), Hutchins (1995) and Shneiderman (1998) anticipated the move to more generative, user centred approaches in software design. Ben Shneiderman's 'Codex, Memex, Genex' presentation in 1998 provided the trigger for considering evolving generations of eInfrastructure in terms of the social and the technical from (1) standalone systems for data sharing, to (2) collaborative and ultimately (3) generative user centred environments, building directly on the architecture of cognitive and social processes to enhance cost-effectiveness.

Although the third quadrant has expanded significantly over ten years, (with the development of Web 2.0 systems where technology harnesses what users know and can do), the original concept as it was when first developed and presented in 2001 as a framework for understanding the different approaches to the design of eLearning environments (Ure 2001).

Looking back, it is also interesting to note that the three successive waves of interest in user involvement, (from the early work of Trist (1950), through to Dearing in eLearning in 1997, and Wanless in eHealth, in 1994), were in a context of financial austerity, requiring 'more for less'. It has been in these contexts where alternative reconfigurations of people, processes and technologies were considered as a means of creating synergies, and minimising cost and risk.

Towards User-centred infrastructure

Designing scalable and standardised software systems for diverse and distributed user groups has forced consideration of a range of alternative strategies.

Early and ongoing involvement of users is presented as key to minimising unexpected costs and risks, and as central to the renegotiation of roles, risks and resources in the reconfiguration of roles, rights and resources in digitally mediated services. We argue that it can be viewed as a model that is not only more cost-effective for service providers and funders, but is also better tailored to the needs of stakeholding users in context.

It is arguably important to highlight the potential of collaborative action research in this respect, as a vehicle to inform both research and viable service development, uncovering the often unexpected barriers to adoption and use, avoiding potential costs and risks that might otherwise be overlooked, and engaging users in early scenario planning. The NIHR have promoted a similar approach in the co-development of patient pathways as Experience –based Design (Bate and Robert, 2007), and a similar concept is also used in business process re-engineering as a means of collaborative change management.

Qualitative and collaborative research studies with users have been instrumental in identifying barriers to service development in the wild, and tempered initial flagship visions of seamless data sharing with feedback from patients, carers, nurses and doctors on the local and contextual issues that must be addressed if this is to be viable.

As developments in eBusiness and social media (such as Facebook) have demonstrated, users are a unique resource that can be leveraged to both individual and commercial advantage. Users are knowledgeable about local needs and barriers, and able to act within their own communities in ways which add

value to the community, and to the viability and usability of the service as a whole. Pilot services on personal/user based information service infrastructure in London boroughs with social enterprises such as Mydex[69] reflect the growing perception that this can provide both a better business model, as well as a fairer and more tailored service for users, and that viable future services will be developed with, by and for users and communities of interest such as patient groups. (Hood 2010; Al Ubaydli 2011).

5.23 Impact.

Although the impact of research is not always directly measurable, a range of measures has been included, as suggested by Duryea et al (2007).

Citations and Editorial Endorsement

Google Scholar[70] provides one computer generated approximation of journal and book citations, although it is not clear how accurate this is likely to be. With the exception of educational research in the 1990s, most of these relate to eHealth and eBusiness publications in the last six years. See Figure 1. (An alternative, ReaderMeter[71] provides other metrics such as downloads and bookmarks for authors).

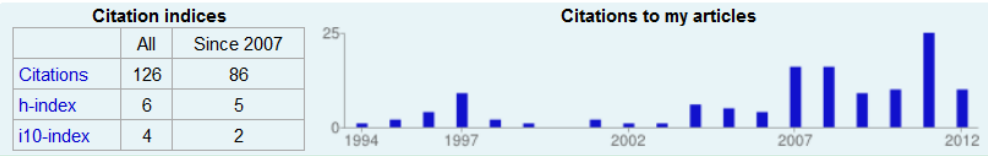

Fig.5.4 Citations. (Source Google Scholar).

69 http://mydex.org/prototype/

70 Google Scholar Link http://scholar.google.com/citations?user=8vk6j4AAAAJ&hl=en

71 ReaderMeter Link http://readermeter.org/Ure.Jenny/papers

Publication is the most straightforward evidence of impact, although Rafols et al (2011) reviews quantitative evidence on the extent to which the use of journal rankings can disadvantage interdisciplinary research in research evaluations and exhibit a systematic bias in favour of mono-disciplinary research. Willmott, (2011), and Martin and Whitley (2010) have found similar results, and point to the impact of 'a monoculture with consequences that can be damaging to funding as well as to research culture' and 'on the visibility of issues arising from inter-disciplinary work'.

The citations highlight greater opportunities for submission in the last three years, in the wake of growing concern at the failure of so many large scale flagship IT projects, where sociotechnical issues have become a more mainstream topic.

Invited Public Lectures

The CV in Appendix 1 lists some of these, including a series of BCS public lectures in London, Swindon, Newcastle, Dundee and Nottingham/Derby[72] , as well as guest lectures as part of post graduate courses on engineering, genomics, telehealth, ICT4D, and on undergraduate courses on the patient experience of telehealth, for nursing undergraduates.

International Workshops and International Conference tracks

Much of the impact derived from organising international workshops, and Conference Tracks to build constituency across communities addressing sociotechnical issues in different sectors or in different projects in

- eHealth and telehealth.[73] [74]

[72] http://nottmderby.bcs.org/event.php?e_id=30

[73] http://wiki.esi.ac.uk/Re-use_or_Re-invention_-_a_Roadmap_for_Data_Integration

[74] www.nesc.ac.uk/esi/events/709/programme.cfm

- engineering and business communities in the supply chain such as the International Society for Product Engineering Conference on Concurrent Engineering.[75]

For me personally, the opportunity to work across sectors has been more influential than abstracting from the literature, despite having done this extensively in all three sectors. In every case the input of users and practitioners on the ground has been the most exciting (and the most reliable) index of the moving points in move to more digital territories.

5.3 Conclusion and Recommendations

Designing for the Digital Economy – What if?

The next wave of investment in technology is the aptly named Internet of Things (IoT) and the Internet of Services (IoS) and will have a range of applications in eHealth in particular. The funding vision and the roadmap is in place (Vermesan 2010).

Fig.5.3 The Internet of Things (Source: Vermesan (2010)

[75] Sociotechnical Systems Track for the Conference on Concurrent Engineering (ISPE CE 2003), July 26-30, 2003, Madeira, Portugal. These were all triple reviewed papers, published as book chapters in the proceeding www.informatik.uni-trier.de/~ley/db/conf/ispe/ispe2003.html

The strategy roadmap, (Vermesan 2010; Ovidio et al 2009), reflects the focus of a predominantly technical community, and concerns with interoperability and shared standards, but says little of the alignment with the wider social, organisational, ethical or legal and political matrix. [76] Yet it is evident that such technologies will radically reshape the potential for new costs, risks, roles and opportunities for different actors, particularly in contexts such as eHealth[77]

Viewing, designing and managing this as a multinational technical project offers the possibility of repeating the same cycle of re-invention that has characterised the first three waves of digital infrastructure, but at an even greater scale.

What if there is no transfer of the lessons that could have been learned from other sectors? What has changed in the relation between actors that would allow those lessons to be learned?

Writing this thesis has made me reflect again on the serial failure of research to proactively inform policy and practice in the design and implementation of the very high cost, high risk infrastructure that characterizes an increasingly digital economy.

In particular, it has highlighted the need to see infrastructure building as primarily about reconstituting the social, and requiring the involvement of stakeholding users in formal spaces to engage in that, as it emerges from attempts to map and prototype services.

The need for new vehicles for reconfiguring roles and rights in these new digital territories is arguably not only about preserving the social contract (Rousseau 1762), or leveraging knowledge to minimise cost and risk, but about ensuring the coordination and competitiveness of societies and economies. The competitive

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[76] In this it provides opportunities to build even more directly on cognitive, social and physiological systems to create new and enhanced affordances, but conversely, offers scope for cost and risk through misalignment at many more interfaces.

[77] Fisher (2008) points to the social dimensions of introducing RFID systems in hospitals, with implications for the wider concept of an IoT at scale

advantage of the Greek economy is now seen as deriving from the development of an open social and a political infrastructure that leveraged the power of local knowledge and agency at scale, through a range of political, legal and social vehicles. Ober (2008) makes the observation that “a time travelling Athenian democrat would condemn contemporary practice, on the grounds that it willfully ignores popular sources of useful knowledge”.

On reflection, it is evident that users and managers on the ground know what is working, what is not, why, and what the options are for changing it. Too often they are-not asked, or the feedback loop is missing, or slow in reaching the public domain.

As a new service, telehealth has the opportunity to rethink research, learning and service provision in ways that are hard to institute in the more contested territory of traditional provision. Emerging economies took that opportunity a number of years ago, and have started to develop new business models and new organisational agreements between regions, using mobile and open source infrastructure (Ure et al 2011c). There is an opportunity here to engage with other countries that are already shaping standards and generating resource for research, diagnosis and provision in radical ways.

Future eHealth Infrastructure.

Increasingly there is now recognition that information technology cannot be properly understood, designed or implemented independently of social and systemic contexts and actors, or of the wider socio-political ecosystem itself (Brown et al 2008).

The design and implementation strategies have been serially re-invented in different domains, with little transfer, particularly in relation to strategies that build on the local knowledge and agency of stakeholding users in the ground.

The next generation of infrastructure for ICT-assisted living at scale, such as DALLAS[78], provides an opportunity to facilitate the means to make better use of what users know and can do – not only because it is fairer, but crucially, because

- it cuts cost and risk in the design and implementation of new eInfrastructure at scale
- it provides opportunities to engage and align the interests of stakeholders in the reconfiguration of the roles, risks and resources

Creating new vehicles for collaboration between users, designers, managers and policy makers will therefore be an essential factor in the cost-effectiveness of eInfrastructure in a competitive digital economy.

The design and implementation of eHealth infrastructure will also require research and disseminations strategies that can provide more rapid feedback and dissemination from the field if policy and professional development are to be well matched to the emerging challenges of disruptive technology.

Future eHealth infrastructures will also increasingly appropriate the availability of online information and tools to shape research and service provision themselves, as many patient groups are now doing (Wicks, 2012), taking advantage of open source infrastructure for both research and service delivery, such as Mydex for example, and Cloud4Health.

78 DALLAS https://connect.innovateuk.org/web/dallas/overview

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Cloud4Health www.cloud4health.com

EADHB Brain Atlas www.ncl.ac.uk/igm/EADHB/

epSOS www.espsos.eu

EU: HealthGrid Share http://initiative.healthgrid.org/the-initiative/share-project.html

e-Infrastructure Reflection Group (e-IRG) www.eirg.org/roadmap/eIRG-roadmap.pdf

Generation Scotland www.generationscotland.org

HealthAgents www.healthagents.net

IOT-A www.iot-a.eu/

Microsoft Health www.microsoft.com/en-gb/healthvault/default.aspx

Mydex www.mydex.org

Online Actor Network Resource (University of Lancaster)
www.lancs.ac.uk/fass/centres/css/ant/ant-a.htm

PatientsKnowBest www.patientsknowbest.com /

PatientsLikeMe www.patientslikeme.com/

Patient Information Online www.pifonline.org.uk/themes/pif-publications/guide-to-records-access/

P3G Consortium www.p3gconsortium.org

PsyGrid Project www.psygrid.org

TeraGrid Grid computing initiative www.teragrid.org

Virtual Physiological Human Available at www.europhysiome.org/roadmap

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