



## How might healthcare systems influence speed of cancer diagnosis: A narrative review



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### ABSTRACT

Striking differences exist in outcomes for cancer between developed countries with comparable healthcare systems. We compare the healthcare systems of 3 countries (Denmark, Norway, Sweden), 3 UK jurisdictions (England, Wales and Northern Ireland), 3 Canadian provinces (British Columbia, Manitoba, Ontario) and 2 Australian states (New South Wales, Victoria) using a framework which assesses the possible contribution of primary care systems to a range of health outcomes, drawing on key characteristics influencing population health.

For many of the characteristics we investigated there are no significant differences between those countries with poorer cancer outcomes (England and Denmark) and the rest. In particular, regulation, financing, the existence of patient lists, the GP gatekeeping role, direct access to secondary care, the degree of comprehensiveness of primary care services, the level of cost sharing and the type of primary care providers within healthcare systems were not specifically and consistently associated with differences between countries. Factors that could have an influence on patient and professional behaviour, and consequently contribute to delays in cancer diagnosis and poorer cancer outcomes in some countries, include centralisation of services, free movement of patients between primary care providers, access to secondary care, and the existence of patient list systems.

It was not possible to establish a causal correlation between healthcare system characteristics and cancer outcomes. Further studies should explore in greater depth the associations between single health system factors and cancer outcomes, recognising that in complex systems where context is all-important, it will be difficult to establish causal relationships. Better understanding of the interaction between healthcare system variables and patient and professional behaviour may generate new hypotheses for further research.

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## 1. Introduction

Striking differences in outcomes for cancer between developed countries with comparable healthcare systems have been evident since the first Eurocare study in 1995 (Berrino et al., 1995). Detailed analyses of more recent Eurocare studies have allowed estimates of avoidable premature mortality in Britain compared to the rest of Europe (Abdel-Rahman et al., 2009), and have informed an English policy objective of saving 5000 lives annually by 2014 (Department of Health, 2011). Underpinning efforts to achieve this objective has

been a National Awareness and Early Diagnosis Initiative (Department of Health, 2007) to drive service improvement and research. To better understand the reasons why apparently comparable countries differ in their cancer outcomes, an International Cancer Benchmarking Partnership was established by the Department of Health in 2010. Comprising 12 jurisdictions in six countries on three continents, all with comparable wealth, universal access to healthcare and high quality cancer registration, it addresses differences in epidemiology and population awareness and beliefs through to primary care behaviours and systems, and includes exploration of root causes of diagnostic and treatment delay (Cancer Research UK, 2010; Butler et al., 2013).

Individual, clinical and system factors are related to differences in cancer survival. Although much is known about patient and

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practitioner influences on the diagnostic process for cancer, literature is lacking on health system factors that could help explain variation in outcomes. Given comparable clinical competencies, the interaction between different healthcare systems and practitioners may result in different outcomes. For patients with symptoms that could indicate cancer, this may impact on the way that they access healthcare in the first instance and their progress thereafter to the point of diagnosis (which in turn is related to survival and mortality (Torrington, 2011; Vedsted and Olesen, 2011)). The aim of the study reported here was to compare the characteristics of healthcare systems in ICBP jurisdictions, as they relate to cancer diagnosis, to identify characteristics that would plausibly modify the diagnostic pathway, and thereby outcomes, for patients with suspected cancer.

## 2. Background

Achieving good cancer outcomes is an important goal for healthcare systems. Despite increasing scientific, clinical and biological knowledge on prevention and treatment, cancer remains one of the leading causes of death and its incidence is increasing in many countries partly as a result of demographic changes and increased survival from, for example, cardiovascular diseases (Coleman et al., 2011; Jemal et al., 2011; Bray et al., 2012; Murray et al., 2013).

A considerable body of literature exists, demonstrating differences in survival between countries, even those with apparently similar healthcare systems (Coleman et al., 2008). In particular, findings from the EURO CARE studies suggest that Denmark and the United Kingdom have poorer 1- and 5-year survival rates across a range of cancer types than other Western European countries (Sant et al., 2001; Karim-Kos et al., 2008; Berrino et al., 2009; Verdecchia et al., 2009; Coleman, 2011).

In this paper our baseline comparator is the 1-year survival rate. Among many elements related to cancer survival (quality of care, patient behaviour, treatment availability) data suggest that delay in cancer diagnosis is an important factor related to poor 1-year survival rates (Gatta et al., 2000; Molassiotis, 2007; Olesen et al., 2009; Thomson and Forman, 2009; Holmberg et al., 2010; Coleman et al., 2011; Foot and Harrison, 2011). In many countries initiatives exist to address this aspect of cancer care (Rubin et al., 2011). However, it is important to get a more detailed understanding of what is contributing to diagnostic time intervals. A longer primary care interval can be a result of, for instance, differences in clinical skills, access to investigations or the culture and the system in which the primary care practitioner operates. Simply putting the responsibility on the practitioner will not provide the explanation, nor give an indication of how best to intervene to improve healthcare outcomes.

Explanatory models of the diagnostic process for cancer have been developed (Olesen et al., 2009; Walter et al., 2012). The pre-diagnosis period is now generally accepted to have two key phases: an appraisal/help-seeking interval, influenced by patient behaviour, and a diagnostic interval. The latter is subdivided into primary care, referral and secondary care intervals and during these patient, practitioner (provider) and system factors may cause delay. Patient delay in their appraisal of symptoms is generally accepted to play a significant role (Andersen and Cacioppo, 1995; Macdonald et al., 2004, 2006; Mitchell et al., 2008) and is influenced by behavioural, psychological and socio-demographic factors as well as symptom awareness (Bener et al., 2002; Tromp et al., 2004; Simon et al., 2010). The interaction between the healthcare system and the public may also play an important role in patient delay. Patients may postpone contacting their GP if they have previously

experienced barriers to engaging with the healthcare system (Simon et al., 2010; Andersen et al., 2011).

Although a comparatively short component of overall delay to diagnosis, primary care delay has received much attention from researchers. For example, there is a variation by age, gender and cancer site in the number of GP consultations prior to referral and the length of time that elapses before referral (Lyrtzopoulos et al., 2013). One of the most significant factors associated with diagnostic delay is symptom misattribution or initial misdiagnosis (Mitchell et al., 2008). Other factors include knowledge, clinical skills, beliefs, access to relevant investigations, constraining referral guidelines, or pressure to reduce referrals from general practice.

System factors operate primarily during the interval between initial referral and final diagnosis, though they can also affect investigations in primary care. Examples include waiting times for secondary care, administrative delays, lack of integration between different levels of care, and inadequate access. Several studies show that waiting times for tests and lack of referral guidelines are among the most important issues related to system delay (Bjerager et al., 2006; Davies et al., 2007). Recently increasing attention has been paid to finding system solutions to support earlier diagnosis, including revision and implementation of better referral guidance, improved access to diagnostic tests, cancer screening improvement and fast-track pathways for patients with potential cancer (Molassiotis, 2007; Neal, 2009; Olesen et al., 2009).

Finally, the literature is inconsistent regarding the relationship between cancer outcomes and health expenditure: some studies show that higher healthcare spending is not always associated with better cancer outcome (Kanavos and Schurer, 2010; Sullivan et al., 2011; Aberg et al., 2012). Others suggest that availability of effective diagnosis and treatment modalities depends on macro-economic factors like health investment (Micheli et al., 2003). The question is whether systems allocating significant resources to cancer care also perform better: while many other factors have an impact on cancer outcomes, beyond the level of investment dedicated to cancer or even to the healthcare system as a whole, the investments made may not automatically lead to better results.

Many factors may explain differences in cancer survival rates, including patient behaviour, treatment availability, quality of care, integration of care, stage at diagnosis and treatment and biological factors (Gatta et al., 2000; Sant et al., 2003). These factors should all be seen in the context of healthcare as a complex system whose elements interact in a non-linear way, producing often unexpected results (Plsek and Greenhalgh, 2001; Lipsitz, 2012). For this reason a complex system's properties and characteristics should be taken into account when analyzing or investigating health system issues.

## 3. Methods

We aimed to compare and describe healthcare systems of three countries (Denmark, Norway, Sweden), three UK jurisdictions (England, Wales and Northern Ireland), three Canadian provinces (British Columbia, Manitoba, Ontario) and two Australian states (New South Wales, Victoria) using a conceptual framework based on the work of Starfield and colleagues (Macinko et al., 2003; Starfield et al., 2005). The framework assesses the contribution of primary care systems to a range of health outcomes. It draws on the key characteristics identified and codified by the authors as factors influencing population health, from macro level characteristics including national regulation and financing of healthcare to micro level factors such as access to primary and secondary care and diagnostics. These characteristics were shown by Starfield et al. to be individually associated with good quality primary care. We added a further factor relevant to cancer diagnosis, namely access to secondary care, both for patients, and for primary care physicians

accessing diagnostic investigations, and included a sub-category of speed of access to the category of access to primary care.

Ethical approval was not required as no human subjects were involved in the investigation.

The initial investigation comprised a literature review (carried out in 2013), accessing both peer reviewed and grey literature, which enabled us to build a detailed picture of overarching influences such as how healthcare systems were regulated and financed in each jurisdiction. We took a narrative approach (Mays et al., 2005) which enabled us to synthesise the different types of literature and draw out themes across the data to illuminate our main aim, i.e. to compare different healthcare systems in order to explore possible factors influencing cancer outcomes.

ICBP Board members for each jurisdiction identified key informants within their countries, to whom an initial draft of the review was circulated. These were experts in primary care from both academic and policy backgrounds who provided further details and corrected any anomalies or errors in the review. This information was incorporated into a second iteration which again was circulated to key informants. Through this process, based on consensus development guidelines (Murphy et al., 1998), we were able to build a detailed picture based firstly on published literature, then augmented by the in-depth, key informant local knowledge.

Key features of the healthcare systems we investigated were grouped under the following headings which are based on Macinko et al. (2003), which in turn were derived from secondary datasets, published literature and technical documents, and consultation with international experts:

- Regulation;
- Financing;
- Primary care provider;
- Centralisation;
- Access to primary care;
- Access to secondary care;
- Longitudinality;
- First contact;
- Comprehensiveness;
- Co-ordination.

We discuss our findings below under each of these headings.

## 4. Findings

### 4.1. Regulation

Regulation for the purpose of this study relates to whether national policies exist that regulate the distribution of primary care providers and facilities, and whether health services are available to all.

All six countries aim at universal population coverage, and for the most part, exhibit strong centralisation, certainly in terms of policy-making. In Canada some general standards are set by the Federal Government, mainly through the Canada Health Act (1984), but also by virtue of its taxation and spending power. The provincial governments determine all aspects of healthcare including budgets, resources, and physician and other healthcare worker distribution. Australia also has a federal system, but policies are agreed at national level and the States and Territories have responsibility for delivery.

Inequality in the geographical distribution of GPs has long been a policy concern in the UK, and is a major issue in Canada and Australia, since areas with the fewest GPs tend to have worse health outcomes and greater deprivation. The geographical areas with the greatest problems with GP recruitment and retention tend to be

deprived urban areas (Sibbald, 2005) in the UK, but rural areas in Canada and Australia.

The Nordic countries share a common model of healthcare based on funding through central taxation, universal access, publicly owned hospitals and comprehensive cover. These high level features suggest similar healthcare systems, but in fact there is significant variation in the way that healthcare is delivered (Magnussen et al., 2009). Decision-making is decentralised to regional boards although in recent years there have been moves towards “recentralisation” in Denmark. The municipalities, a local level of administration below the regional boards, have responsibility for a wide range of health and welfare services including public health and preventive services. Sweden has the least centralised decision-making and policy setting of the jurisdictions reviewed, operating a devolved internal market system.

### 4.2. Financing

All the European countries included in this review have primarily tax-based systems, considered the most progressive and cost-effective in terms of their administrative simplicity.

Denmark has separate national health taxes, with healthcare budgets set annually through negotiation between central government and the regional boards; the state and municipalities set and collect taxes, with the regions, responsible for the healthcare system, paid by the state to do this. In Sweden, about 75% of health funding is raised by local council taxes; the rest comes from central government. In Norway, tax rates are centrally regulated, though raised locally with overall funding being a combination of locally raised taxes and central grant funding.

A key difference between the UK and Nordic jurisdictions is that, unlike the UK, the Nordic countries' health boards are locally elected and can make some of their own decisions about raising finance for healthcare. Decisions on public health spending in England have recently shifted to local authorities.

Australia and Canada both have insurance schemes that are paid for mainly from general taxation. In Australia there is also a small compulsory tax-based health insurance levy (Medicare) that covers the costs of primary and secondary care through a schedule of fees, supplemented with patient co-payment. Additionally, approximately one third of the population carry additional private health insurance; the Australian Government provides a significant tax rebate to off-set the cost of private health insurance. Canada's health insurance programme is also known as “Medicare”. Rather than a single national plan, it is a national programme comprising 13 provincial and territorial health insurance plans which share certain common features and basic standards of coverage. Roles and responsibilities for Canada's healthcare system are shared between the federal and provincial-territorial governments.

Co-payments for primary care are generally considered a barrier to access (Gulliford et al., 2002). In England, Wales, Northern Ireland and Canada there is no cost-sharing for primary medical care visits. This is also true in Denmark, although about 1% of the population opt for cost-sharing in return for more freedom of choice. In Australia some people take out insurance to cover the low level of cost-sharing, even though for the majority of GP consultations there is no co-payment. In Norway there is a low level of cost-sharing. In Sweden, there are user charges but these vary between county councils so there is no national parity. Co-payment for drugs and prescriptions exist in all countries except Wales.

High secondary care co-payments are also considered a barrier to access (Gulliford et al., 2002). In most of the countries in this study, there is no cost-sharing for hospital care through GP referral, or in Australia where the patient is admitted as a Medicare patient. In Sweden and Norway there is limited cost-sharing for some

specialist care; for outpatient specialist care including diagnostic investigations, the majority of practitioners charge co-payments.

We also considered financial incentives for GPs. England, Wales and Northern Ireland have operated a quality incentive scheme, the Quality and Outcomes Framework (QOF), since 2004. QOF provides financial rewards for achieving specified standards in a large number of clinical, organizational and patient experience indicators. The impact of QOF has been widely researched and recent publications show a modest impact on quality improvement and inequalities reduction (Alshamsan et al., 2010; Checkland and Harrison, 2010; Gillam et al., 2012). Only two indicators relate to cancer: maintaining a register of those diagnosed as having cancer, and undertaking a review within 6 months of receiving a diagnosis.

Although implementing “Pay for Performance” (P4P) has been discussed in Canada (Coutts and Thornhill, 2009; Yan et al., 2009) only Ontario has implemented a widespread scheme to date; this includes screening for colorectal and cervical cancers. Other provinces are experimenting with limited incentives for chronic disease management or pilot projects with limited numbers of providers, none of which relate to cancer. In Australia, the Practice Incentives Programme (PIP) is made up of a number of incentives including one on cervical screening.

Sweden's county councils differ in their payment systems to primary care but most include incentives. Since 2006, they have been ranked by measures of efficiency and quality. These are not linked to financial rewards, but the data can support pay-for-performance schemes at the local level. In Denmark, there are no reward schemes explicitly tied to performance, although regions may take action in a case of poor performance.

#### 4.3. Primary care provider

Primary care can be defined as healthcare provided at the first point of contact with health services (Starfield et al., 2005). Generalists (general practitioners, family doctors) provide most primary care in the six countries in the study, along with nurse practitioners and other primary care nurses. In most of these countries, the GP also acts as a “gatekeeper” to diagnostic tests and secondary care, which effectively ensures that almost all patients have a regular primary care doctor or GP group (Willcox et al., 2011).

There are significant differences between the jurisdictions related to GP contracts. GPs in Australia are mostly private practitioners paid for via fee-for-service from public funds and patient co-payments. In Denmark and Norway GPs are self-employed (though some Norwegian GPs have public employee status). In Sweden, approximately 60% of GPs are public employees, 35–40% employed by private companies and 5–10% self-employed.

In the 3 UK jurisdictions, most GPs are self-employed and contracted to provide general medical services through the NHS. There are some corporatised practices and some GPs are directly employed in settings such as out-of-hours/walk-in centres or to specific sectors of the community, e.g. refugees.

#### 4.4. Centralisation

Central determination of health services in theory is considered to create consistency of care provision between localities although empirical evidence may show marked geographical variations within a single country. Clinical guidelines are also seen as key in ensuring a nationally consistent standard of care. All the countries considered here exhibit a strong degree of central determination but in Sweden, Denmark, Canada and Australia guidance is produced centrally but decision-making and responsibility for provision is devolved to local level.

All jurisdictions have a current national plan or strategy for cancer. The extent to which clinical guidelines for cancer are available and implemented is less consistent. In England, National Institute for Health and Care Excellence (NICE) guidelines are available for 27 cancers, and NICE pathways exist for breast, colorectal, lung and ovarian cancers. In Denmark, Cancer Plan II (2005) implemented guidelines to introduce fast track diagnosis and treatment pathways for 11 specific cancers. Cancer Plan III (2010) introduced a national screening programme for colorectal cancer and a “fast track diagnosis pathway” for patients with nonspecific symptoms of severe illness that might be cancer, supplementing the fast track pathways.

Sweden and Norway have national guidelines for most cancer sites, but in Sweden the emphasis is on secondary care. In Australia, New South Wales has the first state-wide Cancer Institute in the country. There are national guidelines now for most cancers in Australia.

#### 4.5. Access to primary care

Under this heading we consider:

- nurse provision of first contact care;
- alternative locations for primary care provision;
- free patient movement between primary care providers within an episode of care;
- speed of access.

Table 1 shows locations from which primary care is provided, and whether patients can move between providers.

Speed of access to primary care is seen as important for earlier cancer diagnosis, with healthcare providers playing an important role in facilitating or impeding treatment delay (Walter et al., 2012). Therefore, proposals to improve clinical outcomes should include actions directed at patient and primary care delays (Neal, 2009; Algar and Neal, 2005). Swedish law requires that patients have to get a contact the same day they request it, and an appointment within seven days. Sometimes first contact care is handled by a nurse. In the 3 UK jurisdictions, national performance targets have been used to drive improvements in access to general practice. Until the abolition of these targets (for England, but not Wales or Northern Ireland) by the coalition government in 2010, patients were guaranteed access to a primary care professional within 24 hours and to a primary care doctor within 48 hours.

#### 4.6. Access to secondary care

Gatekeeping can serve to control the use of specialist and other expensive services, thereby restricting healthcare costs. In this sense it can also be seen as restricting access to otherwise beneficial healthcare to conserve resources at the expense of the patient. We considered whether patients can access secondary care directly, and in most cases, they cannot (see Table 1).

An alternative to specialist referral is for the PCP to directly access specialist investigations to assess the patient with suspected cancer. We identified investigations that require specialist input but which may be made available in this way – upper and lower gastrointestinal endoscopy, CT/MRI and non-obstetric ultrasound. We did not include chest radiography or simple blood tests (both universally available in the ICBP countries). In Table 2 variation in availability of these investigations is described.

In countries where payment is not required to access secondary healthcare waiting time can be a barrier to access. The UK and Denmark have initiated specific processes to reduce waiting times and enable fast referral especially for diagnostics. GPs refer patients

who they suspect might have cancer to secondary care but this varies by country. In the UK jurisdictions, most patients are referred to a hospital outpatient department, rather than a named specialist. In Denmark, GPs refer to specialists. In Sweden, referrals can be direct to an Oncological Centre. In Australia, referrals are generally to an individual specialist, directly to diagnostic services. A significant percentage of cancers are still diagnosed after presentation to the emergency department. In Sweden, patients can bypass the GP and go direct to hospital or private specialists.

#### 4.7. Longitudinality

Patient lists are considered the optimal way to track patients over time, and patient registration is associated with better continuity of care, not least because clinical records are more likely to be continuous and comprehensive. Most countries have registration systems, with the exception of Australia. In Sweden, GPs keep patients' medical records, but not all patients are registered with a family doctor.

#### 4.8. First contact

First contact refers to the gatekeeping role of GPs, and whether patients are routinely registered with a GP. In Canada 85% of the population is registered with a GP, the rate-limiting problem being availability of GPs. In Denmark it is 99% of the population, and in other jurisdictions it is close to 100% (99% in Norway and the UK). Australia does not have a registration system.

#### 4.9. Comprehensiveness

In the four European countries, primary care provides a mix of services including treatment, minor operations, cervical smears, family planning, and psychosocial care, although in Sweden there is a lower level of provision of family planning in primary care than in the other three countries. Health education/promotion is also carried out at primary care level.

A broader range of services tends to be carried out in primary care in Canada and Australia than in the European countries we studied. Most Family Practitioners (FPs) in Canada carry out a full range of primary care services, and FPs in rural Canada provide a wider range of services than those in urban areas because of the comparative lack of access to specialist care. In Australia, mental healthcare and family planning are both by community services, as well by GPs. GPs provide general medical care, minor operations, preventive care such as immunisations, and, as with the other countries, make referrals for radiology, pathology, and other investigations. As in Canada, the more rural Australian GPs tend to offer a broader range of services than urban GPs, in some cases carrying out more complex surgical procedures such as appendectomies.

#### 4.10. Co-ordination

Co-ordination relates to the existence of guidelines for the transfer of information between primary care and other levels, as it is considered that data transfer is essential for coordinating care between levels. The existence of electronic records is much more widespread in Europe than in Canada and Australia. In Denmark, all GPs use electronic records and can communicate electronically with hospitals and specialists; referral and discharge letters and lab results are transferred electronically. In England and Wales, electronic records are extensively used by GPs. Systems for transfer of radiology and laboratory results are widespread but there is no single common system.

## 5. Discussion

A reasonable degree of similarity might be expected between the healthcare systems of the jurisdictions included in this analysis given the criteria of the ICBP. This comparison, however, has revealed some subtle, though possibly significant, differences. We consider the findings from four perspectives.

### 5.1. The macro-level view of healthcare systems

All six countries seek to provide universal coverage, most with a strong degree of centralised policy direction but varying degrees of devolved decision-making in respect of service delivery. The number of GPs per 1000 population is remarkably comparable between European countries but varies widely in Canada and Australia between urban and rural settings. These differentials could be expected to exacerbate inequalities in care and in access to care. Several countries have sought to actively manage the provision of primary care, in an effort to achieve more equitable distribution of primary healthcare providers.

There are notable differences in the prominence of primary care within healthcare systems. Those in Norway and Sweden exemplify systems in which secondary care has dominated. Many of the jurisdictions have recent initiatives intended to achieve greater vertical integration of care, an example being Medicare Locals in Australia, though the current emphasis on integration in England and Northern Ireland is on horizontal integration between primary care and social care.

Universal coverage, with tax-based funding, is a feature of all jurisdictions. In some, notably in Scandinavia, taxes are raised through a combination of national and local levies. Furthermore, in some jurisdictions there is a transactional element to healthcare at the level of the individual patient or GP. This may have the effect of making the costs of healthcare more evident to patients and doctors, influencing their expectations of the service.

In respect of cancer policy, all jurisdictions have developed a cancer plan or strategy, and in all cases these are supported by guidance for clinicians, though they vary widely by stage of development, comprehensiveness and the time they have been in place.

### 5.2. The GP's relationship with the healthcare system

Here we consider the way in which the services provided by GPs are directed by, or reflect, the policies of their respective healthcare systems. In all countries other than Sweden, GPs are on the whole self-employed and contract to provide primary healthcare services. The nature and quality of the services provided is therefore managed through a contracting process. In Sweden, where GPs have been public employees, the recent introduction of private providers of primary care can be seen as becoming more aligned with primary care elsewhere, while the element of competition to provide services distinguishes that country and Australia from the other jurisdictions.

One means by which quality of care can be managed is through payment for performance which has been introduced in almost all jurisdictions. Incentive schemes are widely seen as a means of improving quality, but they do this selectively only for the aspects of clinical practice for which incentives exist. For cancer care, incentives are limited to engagement with screening programmes, though some organisational and patient experience criteria may indirectly impact on cancer care.

GPs are key to demand management within many healthcare systems. This gatekeeper role is seen as a means to optimise the efficiency of use of specialised services. However, there is ecological

evidence that gatekeeping may be associated with worse outcomes for cancer. Among the ICBP jurisdictions, specific referral pathways for suspected cancer are a feature in Denmark, England, Wales, Northern Ireland and New South Wales. In Ontario and British Columbia Diagnostic Assessment Programmes (DAP) are being established. England is unique in recently reinforcing the gatekeeping process through the introduction of triage and referral management systems. These apply external scrutiny, often by other GPs, to the appropriateness of a referral request. Conversely, some jurisdictions are freeing up access to specialists, with direct access in Sweden, rapid access clinics in Denmark and the possibility of self-referral to a DAP in Ontario, while in New South Wales referral is largely an on-demand process.

### 5.3. The patient's relationship with the healthcare system

There are significant differences in the nature of the patient's relationship with their primary care provider. In the UK, Denmark and Norway there are strong list systems with all citizens required to be registered with a GP. These are underpinned by comprehensive medical records for each individual being held by their registered GP. Sweden and Canada have embraced the principles of patient registration but it is not a comparably comprehensive process, while in Australia no registration system exists.

Primary care may also be provided in other settings, usually as an acute service. In particular use of the emergency department is notable in Manitoba and NSW, while walk-in clinics, typically intended for minor illness, are a feature of healthcare in England, Australia and Ontario. There are several considerations with these alternative providers. First, they do not have access to the comprehensive medical record; second, for emergency departments they may expedite specialist assessment; third, for walk-in clinics they may delay referral, since most patients needing further assessment are referred back to their GP.

A level of co-payment for primary care services, either directly or through additional insurance, is a feature of all jurisdictions other than Canada and the UK. For secondary care it only features in Australia, Sweden and Norway. Co-payment may bring with it a stronger sense in the patient of being a 'consumer' with attendant rights and expectations of the healthcare system. Alternatively, for some patients, the need to pay may deter or even prevent them from being able to seek help when they first need it.

The strong bond between patient and primary healthcare provider resulting from registration has recognised benefits, in continuity of care and access to care. In the absence of comprehensive patient-held records, it enables the creation and maintenance of a comprehensive health record. Its weakness may be in suppressing the ability of patients to switch between providers, thus reducing competition between providers, which might otherwise drive up quality of care.

### 5.4. The Patient's relationship with the GP

The services provided by GPs in the ICBP jurisdictions are broadly comparable. First contact care may be provided by a nurse, reflecting the multidisciplinary nature of primary care teams. Evidence on the practical experience of appointment systems will come from the GP survey but we found few data on the ease with which patients could speak to or see a GP, other than for the UK.

Patients in Australia and, to a lesser extent, Sweden and Canada are relatively free to move between healthcare providers. This mobility seems to be associated with an absence of less rigid registration systems and with more market-driven financial models. Whilst it is possible for patients in the UK and Danish

jurisdictions to move, practical and geographical restrictions make this less common.

Systems of reimbursement (as in Australia) or co-payment may introduce expectations on the part of the patient and perceived obligations on the part of the GP. The latter may mean that patient demand over-rides clinical judgement. In countries where the transactional relationship is not as explicit, the scope is greater for clinical judgement to dominate. In most circumstances need should prevail over demand, but for conditions such as cancer where clinical assessment is necessarily imprecise, patients may not have specialist assessment as quickly as might otherwise occur.

## 6. Strengths and limitations

Differences in 1- and 5-year survival rates for cancer despite comparable wealth and universal access to healthcare underpinned participation in the ICBP and therefore inclusion in this comparative study. These are both imperfect measures of speed and timeliness of diagnosis, though the best that is widely available. Five year survival is also affected by differences in treatment, while one year survival is modified by time taken by patients to seek healthcare. Furthermore, the analyses that demonstrated these differences were based on data to 1999 (Abdel Rahman et al., 2009) and do not reflect more recent changes in healthcare provision. However, a recent analysis of data to 2007 has confirmed that these differences in outcome largely persist (De Angelis et al., 2013).

Key informants were selected by the ICBP Board member for their jurisdiction. The principal requirement was an expert overview of the organisation and delivery of healthcare in their country, with particular reference to primary care and cancer care. They were used largely to validate information gathered by the research team, but also added detail where it was missing. There was no formal measure of this expertise, however, and it is possible that by using a maximum of three in any single jurisdiction, we failed to gather relevant information that a wider group of informants could have provided.

## 7. Conclusions

This paper is a first attempt to investigate if, and at what level, health system factors could contribute to differences in cancer outcomes. Our findings show that for many of the characteristics we investigated there are no systematic and significant differences between those countries with poorer cancer outcomes (England and Denmark) and the rest. In particular, regulation, financing, the gatekeeping role of GPs, direct access to secondary care, the degree of comprehensiveness of primary care services provided, the level of cost sharing, and the type of primary care providers within healthcare systems are not particularly aligned with the differences in cancer outcome. There are, however, some factors that could have an influence on patient and professional behaviour and consequently contribute to differences in cancer outcomes.

### • Centralisation

Despite all the jurisdictions having a degree of central determination of cancer policies, in some, decision-making is devolved to the local level. The debate about the effects on patient outcomes of either centralising or decentralising the key levers in health systems has thus far proved inconclusive (Saltman et al., 2007). It is therefore uncertain whether the degree of centralisation has a significant influence on cancer outcomes, although this factor – particularly in regard to local interpretation and implementation of cancer guidelines – merits further research.

- Free movement of patients between primary care providers

This issue also presents some differences between countries: opportunities for patients to move more freely between different providers could help to improve early cancer diagnosis by providing a competitive incentive for the PCP to ensure optimal care or by enabling patients to seek second opinions.

- Access to secondary care

Most jurisdictions do not have secondary care co-payments. In some their absence could create waiting lists that could have a detrimental impact on early cancer diagnosis. Alternatively, co-payments could deter patients from seeking help at an earlier stage, when treatments could be provided that are simpler, and possibly at less cost.

- List system

There are differences between countries in the comprehensiveness of coverage and the provision of a 'medical home' that comes with registration.

These issues need deeper analysis because at this stage of the research it is not possible to establish a direct causal inference between health system issues and cancer outcomes. Further studies should aim at deepening this analysis by exploring associations between healthcare system characteristics and cancer outcomes (Cohn et al., 2013). In particular, the complex relationship between co-payment and patient behaviour needs further exploration. It seems likely that in jurisdictions with co-payments, patient behaviour will differ depending on whether or not the patient can afford the payment or regards it as a barrier to seeking treatment. Better understanding of the interaction between health system variables and patient and professional behaviour may result in improved outcomes.

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## Appendix A. Supplementary data

Supplementary data related to this article can be found at <http://dx.doi.org/10.1016/j.socscimed.2014.06.030>.

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