# **Understanding the link between health systems and cancer survival: a novel methodological approach using a system-level conceptual model**

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**Abstract**

**Objectives**

Cancer outcomes are determined by a range of health system-, service delivery- and patient-related factors, although their contribution and relative importance will vary across populations and systems, an issue that is not well understood. This study aims to develop and demonstrate potential uses of a conceptual (‘logic’) model that visualises the pathways across the entire patient journey through cancer care services, identifying key factors that might be amenable to system-level interventions to enhance cancer outcomes.

**Methods**

A rapid review of the literature on the relationships between broad health system factors and cancer survival in high-income countries was supplemented with data from a stakeholder survey (n=128) exploring perceptions of how system factors might impact outcomes. Collating this information, we developed a detailed conceptual model depicting causal pathways along which survival might be influenced at different stages of the patient journey, further informed by input from clinicians and researchers regarding its possible uses and development.

**Results**

The model illustrates where aspects of the health system are likely to impact directly or indirectly along the cancer patient pathway. It depicts the complex interactions between structures, information systems, health professionals, processes and outputs: acting in often non-linear and cyclical ways that influence outcomes. Potential ‘breakpoints’ along the journey are highlighted, where, without effective co-ordination, patients risk falling through the cracks with adverse impacts on outcomes.

**Conclusions**

The model provides a novel way to extend existing descriptions of cancer survival variation, and to convene stakeholders to identify key points where health services could be adapted to improve outcomes.

Key words: health systems, macro-level, meso-level, cancer, cancer survival, cancer outcomes, conceptual model, breakpoints

**Introduction**

Cancer survival varies globally, with especially pronounced differences between high and low income economies [1], but also between countries with seemingly similar health systems [2]. There has been a long-standing interest among policymakers and researchers in identifying the key factors associated with international differences in survival, including the role of health services and systems [3, 4]. However, the evidence that has linked health system ‘factors’ with cancer outcomes has remained inconclusive. Thus, some studies find associations between higher health spending and cancer outcomes [5-7], and others do not [8]. This is not particularly surprising, as outcomes reflect the complex interplay of a range of factors related to the patient, the service, and the system more broadly [9].

Much recent work has focused on the early stages of the cancer patient journey to explain international differences in survival. Particular attention has been given to attitudes, beliefs and awareness of symptoms [10-15] and the role of primary care [16-18], reflecting wider concerns about timely diagnosis as a key determinant of outcomes. A growing emphasis on moving what is now hospital care into the community can impact the levels of aftercare and monitoring available for patients just completing or having completed treatment [19]. Yet, to understand fully how health systems influence cancer outcomes, it will be important to consider the entire cancer patient journey using a systems approach to understand the interrelationships between primary prevention and screening (where applicable), diagnosis, specialist care and treatment, survivorship, palliation and end-of-life care.

This systems perspective differs from traditional approaches, which frequently examine individual health system factors or inputs, such as regulation and financing [8], levels of care [16], availability of specialists [20-22], and cancer drugs [23-25] in isolation. It remains difficult, however, to attribute observations from mostly ecological studies to specific system features, given the varying financial, regulatory and organisational contexts within which cancer care systems are embedded [26]. There is little systematic work exploring factors at various health system tiers and along the cancer patient journey that uses a theoretical framework to help explain observed variations in outcomes.

This paper contributes to closing this gap. It uses a systematic approach to guide analysis of the complex and multi-layered relationships that act at the different tiers of the cancer care system and the wider health and societal systems within which it sits. We build on work carried out within the International Cancer Benchmarking Partnership (ICBP, Box 1) [27, 28]. The ICBP brings together a network of policymakers, academics and clinicians researching cancer survival in a range of relatively homogeneous high-income countries with high-quality population-based cancer registries, universal health care using taxation as the principal funding mechanism and comparable health spending as a proportion of national income.

**Box 1. The International Cancer Benchmarking Partnership**

The International Cancer Benchmarking Partnership (ICBP) is an international multidisciplinary collaboration of clinicians, academics, data experts and policymakers which aims to quantify international differences in cancer survival and to identify factors that might influence observed variations. The work uses a range of approaches including epidemiology, and health systems and policy research. Eight cancers are studied: colon, liver, lung, oesophagus, ovary, pancreas, rectum and stomach. Some of these are common and contribute a larger burden of disease (lung, colon and rectum) while others are less common but involve more complex diagnostic pathways and have high mortality (liver, ovary, pancreas, stomach and oesophagus).

ICBP explores variations in survival from these cancers across seven countries (Australia, Canada, Denmark, Ireland, New Zealand, Norway and the UK) and twenty-one jurisdictions within these. Within Australia and Canada, a number of the jurisdictions are explored separately, and all four countries in the UK are separate participants. In Phase 1, Sweden was a participant, and Ireland and New Zealand joined in Phase 2.

These countries all have high quality population-based cancer registration, and primary care led universal access to health care. They are broadly comparable in wealth and have similar healthcare expenditure.

ICBP aims to unpick the reasons that cancer survival variation exists across similar countries.

Adapted from ICBP [27]

We present the process of developing, and potential uses of, a conceptual (‘logic’) model that visualises the range of possible interrelationships and causal pathways linking health system factors and cancer survival. It builds on the principles of logic models, traditionally used in programme planning and evaluation research, to make explicit the underlying assumptions of (hypothesised) routes for achieving desired results from a given intervention [29, 30]. Logic models have been promoted as ways to apply systems thinking to evaluation of complex programmes and policies [31-33]. In this study, we build on this notion by visualising a series of hypothesised causal pathways (‘intervention logic’) [34] that link health system factors and cancer outcomes, in particular survival (which is the focus of the ICBP), delineating *health system inputs* (i.e. material resources such as facilities, capital, equipment, drugs; intellectual resources such as guidelines, technology assessment; and human resources, that is the workforce); *processes* (patient-related, organisational); *outputs* (e.g. waiting times, access); and *outcome*s (e.g. recurrence, survivorship, death). The conceptual model provides a first step in the identification of key factors that might be amenable to system-level interventions to enhance cancer outcomes internationally [27].

**Methods**

The development of the model followed a two-pronged approach. First, we outlined a simplified cancer patient pathway, from suspicion of cancer through diagnosis to treatment and beyond. This was informed, initially, by clinical pathways for cancer as developed by the National Institute for Health and Care Excellence (NICE) in the UK [35]. We also drew on cancer patient journeys that were developed in the literature on routes to diagnosis and the management of cancer in England [36, 37] Thus identified, pathways and cancer patient journeys provided a starting point to which we added further elements from cancer patient pathways or journeys developed in other countries, where appropriate (e.g. Australia). We mapped the relevant points along the journey, such as entry to the pathway via screening, consultation with a general practitioner (GP) with subsequent referral, or emergency presentation, and then diagnostic processes, treatment and beyond, producing a simplified cancer patient pathway (Figure 1).

**Figure 1. Simplified cancer patient pathway**

We then undertook a review of literature, using an iterative approach. We considered studies that used conceptual or logic models in other settings [29-33, 38-40], and that explored links between broad health system factors and cancer survival, drawing on the extant academic and grey literature in high-income countries [13, 26, 41-44]. Using the four core health system functions described in the 2000 World Health Report framework (governance, financing, resource generation, service delivery) [45], we identified the macro- and meso-level health system factors that were of potential relevance to the cancer patient journey [13, 26, 41-44, 46, 47].

We supplemented the literature with data from an unpublished 2015 ICBP survey of researchers, clinicians, service providers, patients and NGOs (n=126) (Table 1), which explored respondent’s perceptions of how system factors might impact cancer survival and sought to identify measures that might improve cancer survival. Its focus was on the countries that, at that time, participated in the ICBP (Australia, Canada, Denmark, Norway, Sweden, and the United Kingdom) but also considered broader issues that were not specific to a particular health system.

**Table 1. Location and professional role of respondents to the ICBP’s 2015 survey**

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Country** | **Academic** | **Data specialist** | **Patient representative** | **General practitioner** | **Specialist healthcare professional a** | **NGO** **employee** | **Policy / management** | **Other b** | **Total** |
| **Australia** | 2 |  |  |  | 4 |  | 1 |  | 7 |
| **Canada** | 1 | 1 |  |  | 3 |  |  |  | 5 |
| **Denmark** | 3 |  |  | 1 |  |  |  |  | 4 |
| **Ireland** |  | 2 |  |  | 3 |  | 1 |  | 6 |
| **Norway** | 1 |  |  |  | 3 |  |  |  | 4 |
| **Sweden** | 1 |  |  |  | 1 |  |  |  | 2 |
| **UK** | 17 | 1 | 9 | 12 | 35 | 11 | 9 | 2 | 96 |
| **USA** | 1 |  |  |  |  |  |  |  | 1 |
| **Unspecified** |  |  |  |  |  |  |  | 1 | 1 |
| **Total** | **26** | **4** | **9** | **13** | **48** | **11** | **11** | **3** | **126** |

a including: oncologists, surgeons, clinical nurse specialists and a public health consultant

b including: Director of External Affairs, Pharmaceutical industry professional, Physical Activity Development Officer

Building on these strands of work, we developed a detailed draft conceptual model depicting the likely causal pathways through which the organisation, governance and financing of a health system, at both macro and meso levels, might influence cancer survival at different stages of the patient journey, from primary prevention to palliative and end of life care.

The draft model was reviewed at an ICBP workshop convened by Cancer Research UK in London in February 2018. It brought together senior scientific and policy experts in cancer care (from Australia, Canada, and the UK), and clinicians and researchers participating in the ICBP project (epidemiologists and health services researchers) (Table 2). Working groups facilitated by three authors (MM, EN, SL) discussed the draft model and its applications, and feedback was collated and used to inform its further development. The model was produced using the interactive Lucidchart online software [48].

**Table 2. Attendees at ICBP Researcher workshop**

|  |  |
| --- | --- |
| **Role** |  |
| Specialist clinician/cancer policy expert | 3 |
| Specialist clinician | 5 |
| Cancer policy expert | 3 |
| Cancer epidemiologist | 8 |
| Health services researcher | 8 |
| Total | 27 |

**Results**

**Error! Reference source not found.** illustrates the full model: the hypothesised causal pathways and interrelationships by which health system factors can be expected to impact directly or indirectly on different stages of the cancer patient journey, from recognition of symptoms at pre-diagnostic stages through to survivorship or death.

**Figure 2. Conceptual (or ‘logic’) model incorporating the cancer patient journey and showing its interaction with health system factors**

This shows that the system is extremely complex, involving many interconnected actors and processes. Achievement of the optimal outcome for cancer patients depends on whether they are able to complete a coordinated journey, which in turn rests on the optimal configuration of a series of system factors. Some factors act at the macro level, including resources (financing, infrastructure, education and training), system governance (including leadership and oversight), and organisation of the cancer system. Others act at the meso level but depend on the efficient operation of health system functions at the macro level. These include the availability of products and equipment, information systems and a skilled workforce (e.g. general practitioners, diagnosticians, physicians, oncologists, surgeons, nurses, pharmacists, allied health professionals). Each level interacts with the many processes (e.g. referral from general practitioner to a specialist, diagnostic testing) and intermediate outputs (e.g. waiting times for an appointment). These interactions are often non-linear and cyclical, with discontinuities occurring where macro- and meso-level factors do not align.

The model highlights the many possible ‘break points’ along the cancer patient journey where patients risk falling between the cracks without effective investment in time, capacity, skills and relationships. The interconnectivity shown emphasises the potential for ‘knock-on’ effects along the pathway, which will affect outcomes, from experiencing poor care quality and adverse events, to reduced quality of life and wellbeing, and, ultimately, lower chances of survival. It illustrates the likely effects of changes in the composition of components on processes, which may or may not be compensated through alternative mechanisms along the journey. For example, a skilled cancer (and non-cancer) workforce is key to a functioning cancer system, with their expertise and interactions with each other, the patient and the system more broadly, operating at different points along the cancer patient journey. Changes in the balance of key skills and competencies will affect those interactions at different levels and stages, influencing whether and how the cancer patient will move along the pathway. Thus, shortages in some skills, say, radiology, will significantly affect the speed and (likely) quality of diagnosis, influencing the planning and initiation of treatment and continued management of the cancer patient. Such a scenario assumes the presence of a functioning support system involving an adequate infrastructure (equipment or consumables, such as radioisotopes) and support staff. It is conceivable that especially prolonged shortages will negatively affect these pre-conditions too, further exacerbating the challenges arising from understaffing [49].

**Discussion**

The conceptual model developed here provides a novel way to move beyond and extend existing descriptions of differences in cancer survival. It will help policymakers, practitioners and researchers seeking to improve cancer outcomes understand and address the complex relationships between elements acting at different levels of health services and systems that are thought to contribute to variation in survival. It is the first step in a process that, ultimately, seeks to enhance the patient journey, ensuring that the care patients receive is optimised at each stage.

The model offers a means to identify both the consequences of failings, where they exist, and their primary causes. It reflects how cancer survival lies at the end of a large set of interconnected elements and processes that operate in complex ways and over time. Some initiatives have focused on one part of the pathway, such as a push for early diagnosis [18, 50, 51], but in reality, each can have a knock-on effect on the other. This was highlighted in a recent study of colon cancer patients in Victoria, Australia, which demonstrated that alignment with various stages of the cancer care pathway was significantly linked to improved survival [52]. It is also important to note that the parts of the pathway, and of the system as a whole, that are more significant will differ depending on the cancer site. For some cancers, earlier diagnosis is feasible and improvements in that part of the pathway, illustrated on the left-hand side of the model, will have a large impact. For others these initiatives will not make a substantial difference to survival; rather the availability of certain treatments and expertise, in the middle and right side of the model, will be more influential on outcome [53]. It shows how important it is, therefore, to look across the whole pathway at what will make the most difference for each disease.

Each of the arrows in the figures represent, to some extent, the timeliness with which each element follows the other, but by necessity, any model represents a simplification of reality, and capturing the elements of time and human behaviour remains a key challenge. Where there are known system constraints in diagnostic capacity, for example, it is conceivable that patients are less likely to be referred for a diagnostic test even when it is indicated. This may reinforce delays above and beyond those caused by the initial capacity shortages, and simply increasing diagnostic capacity is unlikely to sufficiently address the problem because of the complex interactions between this part of the system and others. Conversely, excess capacity is likely to encourage lowering thresholds for referral, which will induce referral behaviour that may be difficult to scale back when necessary [54].

The model also highlights that isolated interventions, for example increasing funding for cancer drugs, are unlikely to lead to sustained improvement in outcomes. For example, the introduction of the Cancer Drugs Fund (CDF) in the English National Health Service (NHS) in 2010 sought to promote access to new cancer drugs under the publicly funded system [55]. This decision followed the publication of a report finding that new cancer drugs in the UK were less readily accessible in routine care compared to other high-income countries [56]. However, assessments of the first phase of the CDF are yet to find empirical evidence that “prioritizing drug expenditure … will improve outcomes for cancer patients over and above greater investment in the whole cancer management pathway (screening, diagnostics, radiotherapy, surgery) and reducing access barriers” (p. 1747) [57].

One other example is standardised cancer patient pathways (CPP) and dedicated pathways, implemented in many countries to fast-track patients with suspected cancer towards early diagnosis and timely treatment, and, ultimately, improve cancer outcomes [47]. Evidence from Denmark suggests that the introduction of CPPs has improved relative survival and lowered mortality among cancer patients with symptoms who were diagnosed through primary care following the introduction of CPPs [18, 58]. Importantly however, while that work finds that CPP implementation has caused at least part of the survival benefit, it is difficult to disentangle the role of CPPs from other improvements that have taken place in the Danish health care system at the same time, including the increase in radiotherapy facilities and revision of clinical guidelines. Thus, by looking systematically at these interrelationships, it could be ascertained that investment in one input may have little impact without corresponding investments in other areas.

The model offers a means for those involved in cancer care as providers and recipients to trace problems they experience back to their root cause. It also provides a framework for gathering data depicting (parts of) the cancer patient pathway to help analyse associations between elements of the pathway, identify patterns that matter more (or less) for the patient journey or describe (likely) consequent effects where components are not aligned. This latter point was illustrated in the aforementioned study of colon cancer patients in Australia, which was able to trace the patient journey from prevention to palliation using service utilisation indices for the different stages (e.g. colonoscopy, CT scan, time to adjuvant chemotherapy). This showed that where the journey deviated from what was described as the optimal cancer care pathway, patients were more likely to have poorer outcomes [52]. With the advent of more sophisticated datasets it may thus be possible to use the model to (routinely) identify where there are departures from and breaks in the pathway that will, directly or indirectly impact survival.

In this way, the model also facilitates the identification of causal pathways and potential feedback loops, both positive and negative. For example, conversely to the situation of excess capacity mentioned above, when awareness of long waiting lists leads to raising the threshold for referral. Or, staff shortages may be a result of inadequacies in training and retention, which can sometimes be addressed by increased funding but, where this is not possible, it will point to a need to explore alternatives, such as task shifting or redesign of working arrangements.

The value of identifying alternative approaches to cancer care is built into the current project, which explores the break points that exist in different health systems internationally, and how they each address these issues. Some ideas cannot simply be transferred from one setting to another one, but a recognition that they have been used successfully elsewhere provides a basis to see whether they can be adapted to local circumstances. Although the model was developed with a focus on high-income countries, we believe that it provides a useful starting point for the description of any cancer care system. Clearly, the model is only a first step in the process of identifying and testing potential areas for improvement in cancer care that should ultimately result in improved outcomes for patients. It was beyond the scope of this study to validate the model by populating it with empirical data. It was designed to provide a ‘road map’ for both policy development and research. As more high-quality data becomes available that enables linking different parts of the pathway empirically, such as from ongoing ICBP work, as well as imaginative use of proxy measures to depict parts of the pathway [52], it may be possible to model the cancer patient pathway and explore the effects of meso-level factors such as workforce or equipment and infrastructure on outcomes, along with scenarios of where small changes can potentially have the largest impacts while not discounting the interconnectedness of the various factors that work along the pathway. The main value of the model as a whole is the ability to see beyond a specific issue to anticipate potential intended and unintended consequences of actions.

**Conclusions**

The utility of a conceptual or ‘logic’ model to describe complex systems has been shown in its clear illustration of the intricate causal pathways that link different elements of the systems that contribute to cancer survival. The model allows for easy tracing of pathways and mechanisms in order to direct further investigation and sequelae can also be taken into account in the model. It is, however, necessary to go beyond the two-dimensional representation of the model conveyed here. The model is dynamic, requiring different inputs to come together in the right place at the right time and it is, in essence, a ‘living’ model subject to ongoing development through the lifetime of a project. Clearly, the model could and should be refined further as we come to better understand the causal relationships between factors, particularly those acting at the macro and meso levels.

The nature of the model is such that it can be adapted to one cancer site and the specific pathways, treatments and workforce involved in care of patients with that particular disease, or viewed at a higher level to encompass the whole cancer care system. It can also be extrapolated to different disease areas to help to understand what might impact the care of patients with those conditions.

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**Data Sharing**

No additional data are available.

**Ethics**

This study is part of a project with approval from the LSHTM Ethics Committee (ref 15169).

**Competing Interests**

We declare that we have no competing interests.

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