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Morris, Melanie; Seguin, Maureen; Landon, Susan; McKee, Martin; Nolte, Ellen; (2021) Exploring the Role of Leadership in Facilitating Change to Improve Cancer Survival: An Analysis of Experiences in Seven High Income Countries in the International Cancer Benchmarking Partnership (ICBP). *International Journal of Health Policy and Management*. ISSN 2322-5939 DOI: <https://doi.org/10.34172/ijhpm.2021.84> (In Press)

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1 **Type: Original Article**

2 **Exploring the Role of Leadership in Facilitating Change to Improve Cancer**
3 **Survival: An Analysis of Experiences in Seven High Income Countries in the**
4 **International Cancer Benchmarking Partnership (ICBP)**

5 **Abstract**

6 **Background:** The differences in cancer survival across countries and over time are
7 well recognised, with progress varying even among high-income countries with
8 comparable health systems. Previous research has examined several possible
9 explanations, but the role of leadership in systems providing cancer care has attracted
10 little attention. As part of the International Cancer Benchmarking Partnership, this
11 study looked at diverse aspects of leadership to identify drivers of change and
12 opportunities for improvement across seven high-income countries.

13 **Methods:** Key informants in 13 jurisdictions were interviewed: Australia (2 states),
14 Canada (3 provinces), Denmark, Ireland, New Zealand, Norway and United Kingdom
15 (4 countries). Participants represented a range of stakeholders at different tiers of the
16 system. They were recruited through a combination of purposive and ‘snowball’
17 strategies and participated in semi-structured telephone interviews. Interview
18 transcripts were analysed thematically drawing on the WHO health systems framework
19 and previous work analysing national cancer control programmes.

20 **Results:** Several facets of leadership were perceived as important for improving
21 outcomes. These included political leadership to initiate and maintain progress,
22 intellectual leadership to support those engaged in local implementation of national
23 policies and drive change, and a coherent vision from leaders at different levels of the
24 system. Clinical leadership was also viewed as vital for translating policy into action.

25 **Conclusion:** Certain aspects of cancer care leadership emerged as underpinning and
26 sustaining improvements, such as appointing a central agency, involving clinicians at
27 every stage, ensuring strong leadership of cancer care with a consistent political
28 mandate. Improving cancer outcomes is challenging and complex, but it is unlikely to
29 be achieved without effective leadership, both political and clinical.

30

31

1 **Keywords:** Cancer Outcomes, Health Systems, Leadership, Governance, Driving
2 Change

3

4 **Key Messages:**

5 **1. Implications for Policy Makers**

- 6 • To narrow the gaps in cancer outcomes between high-income countries,
7 attention must be focused on the leadership structures in place for making and
8 implementing change.
- 9 • Central bodies or agencies can be pivotal for providing long-term follow
10 through of cancer plans and strategies, and can wield funding levers to ensure
11 implementation.
- 12 • Clinicians and leaders at every tier of the cancer care system should be involved
13 at every stage of strategy development and implementation so that policies are
14 relevant and likely to be implemented.
- 15 • Political will is vital to provide a strong mandate for those leading cancer care
16 and the changes needed.

17

18 **2. Implications for Public**

19 There are persistent differences in the cancer outcomes of high-income countries which
20 might be expected to have similar access to healthcare and technologies. Some of this
21 difference might be due to how cancer care is organised in each country and how the
22 cancer care system is led. We found that some features of more successful countries
23 were: central cancer agencies, the involvement of clinicians and all levels of cancer care
24 leadership in planning and implementing the cancer plans, and strong political will to
25 follow through on cancer plans with funding. We believe these things could help to
26 improve cancer outcomes in countries that may have some resource restrictions, but are
27 generally able to provide good healthcare for their whole population. Cancer care could
28 be more seamlessly delivered, treatments could be more equally distributed and long-
29 term plans (for example for equipment or infrastructure updates) could be followed
30 through more reliably.

31

32

1 **Background**

2 Cancer survival has improved substantially in recent decades but continues to vary
3 widely internationally,¹ even among countries with seemingly similar health systems.^{2,3}
4 Existing research has explored reasons for these differences, focusing on the continuum
5 of care from awareness of symptoms⁴⁻⁹ and timely diagnosis¹⁰ to cancer treatment,
6 aftercare and monitoring of patients.¹¹ The role of health services and systems in
7 determining outcomes is widely acknowledged, with attention to issues such as
8 regulation and financing,¹² primary care¹³ or availability of and access to timely
9 diagnosis and treatment.^{3,14-21} However, a precise determination of how characteristics
10 of health systems contribute to cancer outcomes has been difficult,^{12,22-24} likely in part
11 due to the complex interconnections between patients, health service organisations, and
12 health systems.^{25,26}

13 We previously argued for a systems approach to understand how aspects of health
14 systems impact cancer outcomes.²⁶ Leadership, and governance, now seen as a key
15 building blocks of a health system, are crucial for achieving high performance.²⁷
16 Conceptions of leadership vary widely, with one widely cited definition describing it
17 as “the process of influencing others to understand and agree about what needs to be
18 done and how to do it, and the process of facilitating individual and collective efforts
19 to accomplish shared objectives” (p.23,²⁸). Leadership can be assumed by different
20 actors within the health system. Although overall leadership is a government’s
21 responsibility²⁹ and necessitates a political mandate, some leadership functions in
22 service organisation and delivery, including in cancer care, tend to be delegated to
23 subordinate bodies such as health authorities, non-governmental agencies, or
24 professional associations. These might be national, regional and/or local, often
25 reflecting the constitutional arrangements in a given country, whether it is a unitary
26 state or federation, and the distribution of responsibilities for health policy within it.³⁰
27 Within complex health systems, leadership is by consent, creating the conditions for
28 success, the incentives for those who must deliver services, and holding them to
29 account.^{29,31} Leadership should be assessed by its ability to identify where change is
30 needed, design appropriate responses, implement them, and ensure that objectives are
31 achieved. In the context of cancer care, experience in many countries points to the
32 importance of having a cancer strategy setting a clear vision of what is needed and how
33 it will be achieved, and which delivers a high level of ownership among those who must

1 make it work.^{30,32} Political leadership is equally important, as is the intellectual and
2 technical leadership from individuals, reflecting the complex and complicated nature
3 of healthcare. In addition, it is essential to have clinical leadership, assembling,
4 managing, inspiring, and evaluating the multidisciplinary teams that are necessary to
5 deliver modern health services. All of these manifestations of leadership are
6 interdependent. Success is unlikely if any of them are missing. Moreover, they must
7 operate at all levels of the entire system (in primary, secondary and tertiary care) based
8 on effective communication along the whole pathway followed by the patient on their
9 journey from initial diagnosis through treatment to cure or palliation. There is growing
10 evidence linking the style and quality of leadership at different tiers of a health system
11 to health outcomes^{33,34} but in particular at the level of the hospital.^{35,36} However, little
12 research has systematically studied the role of leadership in relation to cancer care and
13 how this may be linked to cancer outcomes such as survival.

14 This study seeks to fill this gap by exploring the role of leadership in cancer care
15 delivery in seven high-income countries, reflecting on experiences of stakeholders
16 within the system. It is part of the work of the second phase of the International Cancer
17 Benchmarking Partnership (ICBP-2)^{37,38} which has brought together a wide network of
18 policymakers, academics, and clinicians researching cancer outcomes in a set of
19 comparable high-income countries (Australia (3 states), Canada (10 provinces),
20 Denmark, Ireland, New Zealand, Norway, UK (4 nations)), all of which have high-
21 quality population-based cancer registries, universal access to healthcare funded from
22 general taxation, and spending comparable shares of their national income on health.
23 The approach taken in this paper was guided by a conceptual model depicting
24 interrelationships and causal pathways linking elements of health systems and cancer
25 survival along the patient journey. Leadership is conceptualised as a key element all
26 along this pathway.²⁶ We explore themes identified by stakeholders in relation to the
27 different loci of leadership within the system.

28 **Methods**

29 We used a qualitative exploratory design,^{39,40} gaining insights by gathering information
30 from those directly involved in the topic under investigation. We draw on key informant
31 interviews from a subset of the jurisdictions covered by ICBP-2, complemented by a

1 review of cancer policies and strategies from each of the jurisdictions (published 1995-
2 2018) to place interview insights in context.

3 ***Data collection: Document review***

4 Cancer policies and strategies were identified through an iterative process of searching
5 through government websites and through contacts on the ICBP Programme Board.
6 ICBP representatives from each jurisdiction were consulted to ensure completeness of
7 the process.

8 ***Data collection: Key informant interviews***

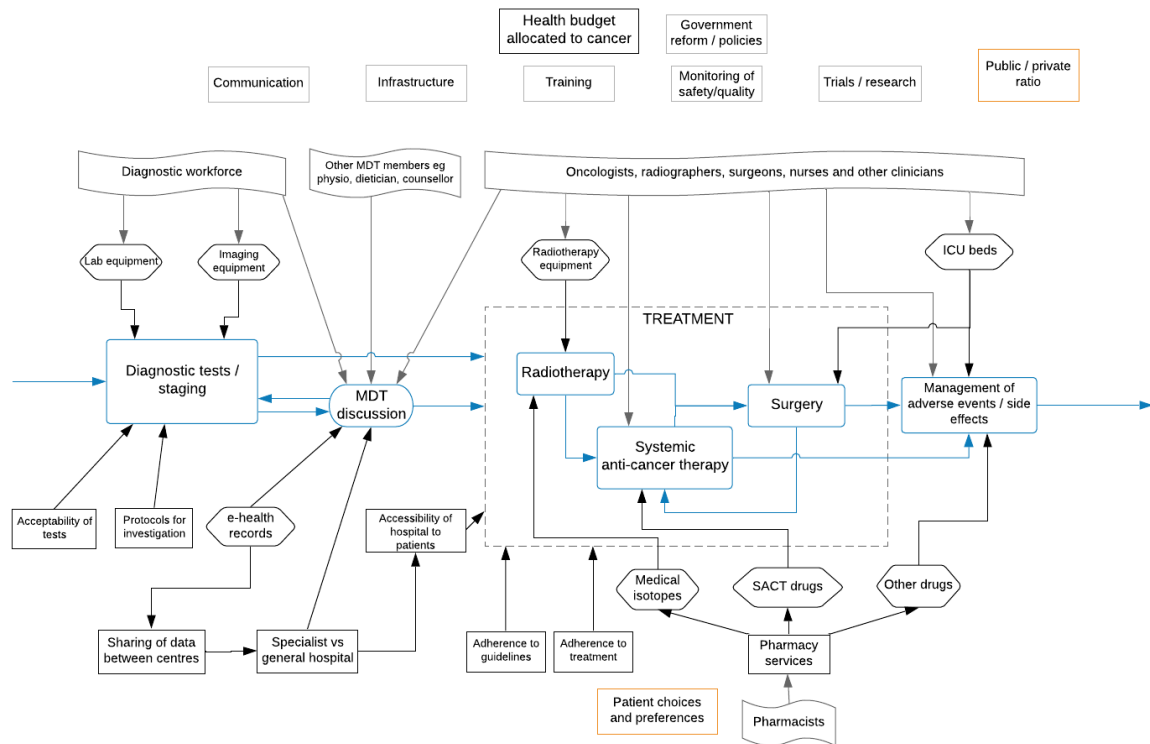
9 Key informant interviews were carried out in 13 jurisdictions between January 2019
10 and March 2020: New South Wales and Western Australia in Australia; Manitoba,
11 Nova Scotia and Ontario in Canada, Denmark, Ireland, Norway, New Zealand, and the
12 four UK nations (England, Northern Ireland, Scotland, Wales). Given the devolved
13 nature of service organisation in Australia, Canada and the UK we also included
14 national stakeholders to provide insights into policies and regulations national levels.
15 The subset of jurisdiction was selected to give a broad representation of different
16 outcomes, as well as a range of population sizes and geographical distributions.

17 Interviews sought to capture a range of stakeholders directly and indirectly involved in
18 the planning, organisation or delivery of health and/or cancer services (hospital
19 managers, regional authorities and government officials, including of arms' lengths
20 bodies), along with representatives of professional bodies and of patient associations,
21 and other relevant agencies with cancer or health policy expertise. Key informants were
22 identified through a combination of purposive and 'snowball' strategies, working with
23 local ICBP-2 collaborators and searching websites of key organisations involved in
24 policy development or decision-making at local level delivery of cancer services.

25 The range of experts interviewed varied with the population size of the jurisdiction and
26 the way health services are organised and governed. Informed by our previous
27 work,^{41,42} we sought to recruit approximately eight experts in Australia, 20 across
28 Canada, 6-8 each in Denmark, Ireland, New Zealand and Norway, and approximately
29 20-22 across the four countries of the UK.

30 Interviews were conducted by telephone or by videoconference due to geographical
31 distances; this approach to interviewing is considered to be as effective as face-to-face
32 interviews.⁴³ The topic guide for interviews used a semi-structured format;⁴⁴ it was

1 developed iteratively, informed by our conceptual model²⁶ as well as themes that were
2 identified from our review of cancer documents. The guide was piloted among
3 clinicians and other members of the ICBP project board with feedback incorporated.
4 Interviews explored stakeholders' views on cancer policies and services in their
5 jurisdictions; likely explanations for observed improvements and variations in cancer
6 survival; key achievements and (continued) challenges in cancer service organisation
7 and delivery along the patient journey; and perceived effectiveness of policy levers and
8 instruments driving cancer services and policies. The topic guide included survival
9 trends for four illustrative cancer sites in each of the seven countries for the period
10 1995-2014 (oesophagus, rectum, pancreas and ovary; Appendix), reflecting some of the
11 eight cancers which are the focus of ICBP-2. These had different outcomes among and
12 within countries. However, we did not limit discussion to them: health system
13 mechanisms often operate across cancers and so any were considered during the
14 interviews, according to participants' expertise or interests. We also provided an
15 illustration of the diagnostic and treatment elements of the cancer patient journey,
16 abstracted from our conceptual model,²⁶ to facilitate discussions of enablers and
17 barriers in cancer service organisation and delivery in each jurisdiction (Figure 1).
18 Interview participants were provided with a project information sheet, topic guide and
19 consent form in advance to the interview. Three authors [MM, MS, EN] conducted the
20 interviews. The first 20 interviews were conducted by at least two authors to allow for
21 reflective questions from the second interviewer. It also ensured that as 'solo'
22 interviews started to be undertaken, there was a consistent protocol followed by all. At
23 this point, each of the three authors took the lead on a particular jurisdiction to ensure
24 consistency of approach. Interviews were recorded with participants' permission, and
25 transcribed verbatim. Two interviews were not recorded but the content was recorded
26 in contemporaneous notes.



1

2 **Figure 1.** The cancer patient journey: a simplified model

3 *Source:* adapted from Morris et al, 2020²⁶

4

5 **Interview analysis**

6 Analysis of interview transcripts employed a thematic approach, progressing through
 7 data familiarisation, coding, and theme refinement. Transcripts were read, cleaned and
 8 re-read by two authors [MM, MS]. The qualitative textual analysis initially followed
 9 nodes generated from the interview topic guide and informed by the WHO health
 10 systems framework^{27,29} and that developed by Atun et al. for the analysis of national
 11 cancer control programmes,⁴⁵ developing a coding scheme.⁴⁴ Transcripts were coded
 12 in NVivo 12 software⁴⁶ by individual researchers, who assigned a tentative theme (or
 13 ‘node’) to each meaningful phrase. Themes were then discussed among the research
 14 team, with nodes grouped together and re-coded into overarching themes.³⁹ In this
 15 paper we focus on the themes that emerged around leadership and governance. The
 16 results included below reflect the situation and progress in each jurisdiction at the time
 17 of the interview. Jurisdictions may have developed new cancer strategies since then,
 18 e.g. an updated Cancer Action plan was released in New Zealand and a new National
 19 Cancer Control Agency established after the interviews.

1 **Ethical Issues/Statement**

2 This is part of a project with ethical approval from LSHTM Ethics Committee (ref
3 15169).

4
5 **Results**

6 We interviewed 79 people representing six categories of organisations across the 13
7 jurisdictions (Table 1). Seventy interviews were conducted (six interviews included
8 more than one participant), lasting an average of 54 minutes (range 35 to 77 minutes).

9
10 **Table 1:** Organisations represented, by interview participants and country

Jurisdiction	Type of organisation (main role)						Total
	National / regional government	Regional / local hospital management	Professional association	Patient organisation	Academia	Other ^a	
Australia ^b	5	2	1	1	1	1	11
Canada ^c	8	7	2	1	1	-	19
Denmark	1	1	1	2	1	1	7
Ireland	2	1	1	-	1	1	6
New Zealand	3	-	1	-	1	2	7
Norway	1	2	-	-	1	1	5
UK ^d	7	6	2	3	1	5	24
Total	27	19	8	7	7	11	79

11 ^a For example cancer societies and charities

12 ^b Including Pan-Australia, Western Australia, New South Wales

13 ^c Including Pan-Canada, Manitoba, Ontario, Nova Scotia

14 ^d Including England, Northern Ireland, Scotland, Wales

15
16 Within the overarching themes of leadership and governance, participants raised issues
17 that fell into four sub-themes, each identified as important potential drivers for change
18 that would ultimately shape cancer survival: 1) political leadership steering the
19 development of cancer services; 2) intellectual leadership by those possessing a set of
20 technical competences and skills that can bring about change (transformational
21 leadership), combined with a dedicated political mandate; 3) the inclusion of clinical

1 leadership in decision-making and implementation, and 4) leadership across the
2 different tiers of the system. We report on these in turn.

3 It is important to emphasise that most participants highlighted the complexity of factors
4 that may have contributed to observed improvements in cancer survival over time in
5 their jurisdictions. This was especially true for leadership, where direct connections
6 were seldom made with improvements in particular outcomes.

7 *Political leadership*

8 Participants reported that political engagement with cancer care often came about in
9 response to public and media reports on their jurisdiction's performance on cancer
10 outcomes with others that were seen to be doing better. Study participants highlighted
11 the role that a series of publications from the 1990s onwards, such as the EURO CARE⁴⁷
12 and CONCORD studies⁴⁸, had played in prompting action, leading to policies that
13 included increased investment in services and infrastructure. In some cases, the policy
14 response led to the creation of new agencies charged with providing leadership of
15 cancer strategies and, in some, placing individuals renowned for their cancer expertise
16 into leadership positions. Taken together, these measures were viewed by many
17 participants as contributing to sustained progress.

18 The English 2000 Cancer Plan⁴⁹ was one strategy that emerged following these early
19 reports, cited by almost all English participants as having played a critical role in
20 subsequent improvements in cancer services. Similarly, in Denmark, international
21 benchmarking was seen to have placed cancer firmly on the national policy agenda,
22 with a national Cancer Steering Group established in 1998 by the Ministry of Health,
23 "based on a public debate about the quality of cancer treatment and results in Denmark
24 compared to the countries around us" (p. 5).⁵⁰ Its members were tasked with drawing
25 up the first national cancer plan (published in 2000), which was accompanied by
26 significant investment in expanded diagnostic and treatment capacity.⁵⁰ Norway
27 published its first national cancer plan in 1997, and again this was seen to have been
28 stimulated by evidence of lack of progress in cancer care compared to other countries,
29 leading to increased investment in diagnostic and treatment capacity.

30 In Ireland, the political commitment that arose from international benchmarking was
31 seen to have contributed to a debate that led to the establishment of the 2006 National
32 Cancer Control Programme (NCCP):

1 *“I think that the whole transformation of cancer services was certainly led.*
2 *They looked at other countries to see what the best model for care was or*
3 *are and they followed up their decisions with funding so I think politicians*
4 *across all political parties accept that this was a good decision made at the*
5 *time and has yield[ed] the benefits so I don’t think there’s any question in*
6 *the political arena at those policy decisions...and the strategy that came*
7 *out in 2006 and 2017.” R24_Ireland*

8 More recently, the experience of rapid diagnostic clinics in Denmark was seen to have
9 prompted senior clinicians to persuade policy makers to make changes:

10 *“I think [that] was the moment where some of our leading clinicians who*
11 *have been chomping at the bit to say ‘we need to be so much better, we need*
12 *to have senior leadership buy in for this, it isn’t just about cancer clinicians,*
13 *this is about Chief Executives and Executives owning this agenda”*
14 *R46_Wales*

15 Political leadership, even if only due to outside pressure, may have led to several
16 initiatives, including the development of Cancer Care Ontario and the appointment of
17 the first National Cancer Director in England (1999), which we will return to later, but
18 this push from political leaders was more difficult to sustain. In England we heard
19 scepticism about whether the earlier commitment had been maintained. For example,
20 one participant said:

21 *“the government will focus on the politics and push organisations as to*
22 *what to do, and that gets in the public eye, but it doesn’t necessarily mean*
23 *they’ll open up funding coffers.” R65_England*

24 Reflecting on austerity measures following the global financial crisis, participants from
25 several jurisdictions suggested that commitment to investment in preserving cancer
26 services appeared to have continued and, in the UK and Ireland, cancer services had
27 fared better than others.

28 One tentative lesson from these examples is that political leadership is important, but
29 political engagement is difficult to sustain. Sustained success appeared to be more likely
30 where a body existed to develop and take forward a strategy. The absence of a strategy

1 and an implementing body in Northern Ireland was cited as a reason why it was difficult
2 to ensure sustainable services:

3 *“The longer-term approach to investing in cancer services, we I think have*
4 *been found on the back foot with some of our services, because of a lack of*
5 *attention over a number of years and then we have struggled to catch up.*
6 *And I think a strategy might have afforded us a map, you know, that we*
7 *could have worked over a number of years to achieve something albeit in*
8 *the longer term.” R35_Northern Ireland*

9 Similarly, participants from New Zealand reported how early progress following their
10 first cancer plan had not continued at the previous pace, with little sustained political
11 or financial commitment, with adverse consequences for quality of care.

12 ***Intellectual leadership***

13 Interview participants in Ireland and England highlighted the key leadership role that
14 identified senior officials had played, both in terms of the mandate given and their
15 individual effectiveness. Examples cited by informants include the appointment of a
16 National Cancer Director (‘cancer tsar’) in England who served from 1999 to 2013. The
17 leadership of the individual was seen as being important to driving change, as was the
18 political mandate that came with the role:

19 *“...he was able to galvanise clinicians, both doctors and the nurses and*
20 *other health professionals who all are involved in cancer, but also manage*
21 *upwards towards the ministers as well.” R64_England*

22 *“Tony Blair, when he did make his commitments to appointing a ‘national*
23 *cancer tsar’ as it was called [...] [showed that cancer] was a national*
24 *priority.” R64_England*

25 However, successful leadership requires protected time to effect change, which was
26 noted to have reduced over time (“and I think that is part of the overall squeeze on the
27 NHS” (R61_England)), as was the team supporting the national leadership role, which
28 was split into two after 2013, compromising their ability to drive change.

29 A similar range of leadership skills was noted by key informants in Ireland,
30 commenting on the recruitment, in 2007, of an Interim Director of the NCCP to oversee
31 implementation of the 2006 strategy:

1 *“He’s very clear on what he wants to achieve and will go about it very*
2 *quickly, and it was basically his leadership and his belief. Really, what is*
3 *being done in Ontario and in other provinces in Canada, the*
4 *regionalisation of care, he saw that as a success in Canada and began to*
5 *implement it in Ireland” R10_Ireland*

6 The 2014 implementation report said: “He engaged widely with radiation, surgical and
7 medical oncologists, GP and nursing representatives and voluntary agencies”.⁵¹

8 This form of intellectual leadership that combines vision with skills and is supported
9 by a strong political mandate could be seen to be a template for other countries.
10 Individual leaders were occasionally mentioned as influential in other contexts (for
11 example, a leader of Cancer Care Ontario, a head of the Scottish Cancer Taskforce, a
12 General Secretary of the Cancer Society in Norway). There were also examples of more
13 informal layers of influence, such as the ability to bring together different perspectives
14 or having the “ear of government and chief execs” (R77_Scotland) seen as important
15 features.

16 ***Clinical leadership***

17 Clinical leaders may be physicians, nurses or other healthcare professionals. Clinical
18 leadership was identified as key to driving change in most interviews, through ensuring
19 that strategies are evidence-based and clinically focussed and lending credibility to
20 official plans, getting people ‘on board’ in their local areas. In England, for instance,
21 we were told that clinical leaders help to ensure that national funding for cancer is
22 identified and used as intended at the local level, thereby increasing the probability of
23 a good outcome.

24 Clinicians can also act as ‘translators’, conveying needs of patients to policymakers:

25 *“So, bureaucrats don’t speak clinical language, they speak policy*
26 *language, and vice versa. And, what I feel that we do a lot of with the*
27 *clinical teams, is turn policy into clinical language, and how we can use*
28 *the policies as enablers to make a difference, and how we’ve got to keep*
29 *the clinical people with a seat at the table so that we actually get policy*
30 *that’s going to make a difference to the patients.” R60_Western Australia*

1 Many cancer strategies have placed clinicians at the core of planning and
2 implementation,^{38,49,52-60} and in all jurisdictions, clinicians were reported to sit on expert
3 or advisory groups, communicate issues to government, advise on action and
4 implementation, write cancer strategies, or develop guidelines:

5 *“...we have a network of clinical leaders, programme leaders, both*
6 *provincially and in every region of the province to help design that plan but*
7 *also then to be accountable for implementing it across the province”*
8 *R02_R03_Ontario*

9 *“What [they’ve] actually done in the Cancer Control Programme since its*
10 *inception was to bring clinicians into the programme here to give [them]*
11 *advice. To help [them] figure the right direction, the right investments so*
12 *[they] would have a number of clinical leads groups where each designated*
13 *cancer centre would send one member of staff to represent that hospital.”*
14 *R24_Ireland*

15 Local clinical leaders are frequently held to account for achieving and maintaining
16 regional or national targets (“we have to live up to these targets. So, it’s based in the
17 leadership system. We know our leaders, they will come after us if we don’t live up to
18 the demands” (R01_Denmark)), implying that clinical leaders need to be reviewing the
19 metrics that reflect their performance. Whether or not failure to reach targets (where
20 applied) is penalised varied between jurisdictions, ranging from “verbal” reprimand
21 (R67_Norway) to financial penalties in England, although this was not necessarily seen
22 as a bad thing but instead providing a case for more investment:

23 *“I think one of the joys of having a target is that you then have a really*
24 *good way of going back to policymakers, funders, government and saying,*
25 *“Yeah, really? Without the money?” Whereas if you have no target [...]*
26 *you don’t measure it, you don’t know what’s going on, so you get anecdote.*
27 *And anecdote is not a good way to argue any case with government, so I*
28 *think targets are a two-edged sword.” R63_England*

29 While clinical leadership was seen as important, lack of clinician buy-in can have
30 considerable impact, too. Rationalisation of services into fewer, larger hospitals was
31 slowed in Ireland, prompting one respondent to state:

1 *“...the Consultants have had a lot of power. I don’t think they have as much*
2 *power now but they’ve had things their own way a lot and they’re very*
3 *highly paid and they’ve practiced with not a lot of accountability and long-*
4 *term contracts and, you know, why would you change that?” R16_Ireland*

5 Some countries provided support, and even stipends for clinical leadership roles
6 (Ontario 2011-15⁶¹) while in others the historical under-development of clinical
7 leadership was acknowledged: “Effective implementation [of guidelines] requires
8 clinical leaders and a coordinated program of outreach, for which there is not adequate
9 funding at present” (p.21, Australia, 2003⁵²).

10 ***Leadership at different tiers of the system***

11 Many countries included in this study have established national or provincial bodies,
12 programmes or roles from the late 1990s onwards to lead cancer policy development
13 and oversee its implementation. In several jurisdictions, sustained leadership with
14 political backing has been provided by a cancer agency that oversees cancer care
15 delivery and maintains control over at least some funding. This can improve
16 consistency in implementation of policies laid out in cancer strategies and ensure that
17 policies are followed through.^{52,53,62-64}

18

19 An example is Cancer Care Ontario (CCO), which was tasked in 1997 to coordinate
20 and integrate cancer treatment services across Ontario.

21 *“So, there was a bit of a shift and that was because of performance and we*
22 *were noticing long wait times in the province, poor outcomes and what it*
23 *resulted in was a shift in how cancer services are delivered in the province*
24 *was a concerted effort to look at delivery and improve delivery. So, I would*
25 *say that the role of CCO has evolved because of the need and the desire to*
26 *ensure equitable and safe patient care.” R19_Ontario*

27 It has been the agency “at the centre” (R02_R03_Ontario) of organising networks of
28 leaders, both across and within provinces, leading design of the cancer plan and for
29 holding these networks accountable for its implementation. Its control over funding for
30 cancer services has been cited as one reason for its success:

1 *“So, not only do they have oversight of the delivery and performance*
2 *measurements in management, they hold the funding levers. So, they’re*
3 *able to tie funding to performance and when performance doesn’t meet*
4 *standards...they’ve got that stick...to use with the regional cancer*
5 *programme.” R18_Ontario*

6 In Ireland, the NCCP, part of the Health Service Executive, is charged with providing
7 leadership, ensuring implementation of the strategy, and “set[ting] standards and
8 guidance for the delivery of cancer care and ensur[ing] the monitoring and oversight of
9 cancer services” (p.13). The most recent plan also sets out “an enhanced role in the
10 funding and commissioning of cancer services” (p.118, Ireland, 2017-2026⁶⁵) for the
11 NCCP. We were told:

12 *“[the NCCP] have a big element of control over the budgets for cancer*
13 *services. ... [The] budgetary levers are two-fold really. One is the budget*
14 *[they] send to hospitals to employ staff for over the course of the year, but*
15 *[they] have a much bigger degree of control over the cancer drug budget.”*
16 *R24_Ireland*

17 This was also the case when the cancer programme at the Nova Scotia Health Authority
18 took over from Cancer Care Nova Scotia, a body which “had a responsibility to advise,
19 but did not have the power to institute.” The cancer programme “now has budget
20 responsibility for all cancer in the province, outpatient cancer, how the operating rooms,
21 and that sort of thing” (R14_Nova Scotia).

22 In Western Australia, the Cancer Network is a focal point, bringing together clinicians
23 and “service provider executives”:

24 *“and really to break down those barriers around individual practice or*
25 *personalities, or fiefdoms etc, to say ‘no, we’re going to make a*
26 *determination about what we think is safe, quality care, and we’re going to*
27 *have some legitimacy about how we shape that’. And, that’s, I think, been*
28 *one of the things that the network’s been really helpful for, bringing*
29 *together different perspectives, but then an agreed determination about a*
30 *way forward, and some degree of endorsement around that...”*
31 *R57_R58_Western Australia*

1 Many jurisdictions also have bodies that might be named ‘agencies’, such as the Cancer
2 Agency in Saskatchewan, Cancer Institute NSW, Cancer Research UK and Cancer
3 Council Victoria, who have important advocacy roles, but a more limited
4 implementation responsibility. In these cases, it is often through the development of “a
5 network of valued relationships”⁶³ that the leadership role is pursued. Thus, they have
6 a role in coordinating the different types and levels of leadership across cancer care to
7 ensure a consistent message and alignment of effort. Continuity offered by these non-
8 governmental bodies can mean that the development and implementation of cancer
9 plans is seen through to completion despite leadership changes.

10 Central leadership was seen by respondents everywhere as essential to drive change
11 and ensure consistency in policies from national through to local level. This was
12 reported to be easier in smaller jurisdictions, such as Scotland and Western Australia:

13 *“When you’re trying to introduce a new initiative, or look at what’s going*
14 *on with a certain population of patients within Perth, there’s definitely less*
15 *people to get around the table to influence, or to have input from, so I think*
16 *we have a few less egos to deal with.” R60_Western Australia*

17 Centralisation of oversight was seen to ensure consistency of service delivery, which
18 was argued to be the case in Manitoba, Nova Scotia and Norway. In the latter, there had
19 been fragmentation across 19 counties, but more recently adherence to cancer care
20 pathways has been monitored centrally and “the political control is extremely strong”
21 (R67_Norway). We also heard similar arguments from respondents in Nova Scotia
22 (NS) where the system had changed from nine independent district health authorities
23 into a single health authority, the Nova Scotia Health Authority (NSHA); Cancer Care
24 NS was moved into NSHA.

25 A failure to assign a central leadership role has proved problematic, hindering progress
26 in cancer care. Key informants from New Zealand highlighted the challenges posed by
27 the system’s fragmentation of cancer services across 20 district health boards (DHBs)
28 (“20 different health systems effectively”, R29_New Zealand). The 2003 cancer control
29 strategy was widely seen as a means to overcome this fragmentation (“actually a
30 stunning strategy, really comprehensive, really well considered, and we saw a number
31 of exciting things like regional cancer networks pop up which was the implementation.”
32 R31_New Zealand) but it did not lead to sustained action. The 2005-2010 cancer plan

1 in New Zealand⁶⁶ did lay out the establishment of “a Cancer Control Collaborative
2 which will foster the collaboration at a national level of various groups and activities
3 involved in cancer control” (p.iii) but this does not yet seem to have affected
4 implementation of policies on the ground.

5 The fragmented structures created by multiple health boards in Scotland has also been
6 perceived as creating challenges. Participants reported that three large cancer centres
7 “are not linked by any governance or any accountability or any financial strings”
8 (R72_Scotland) which made it difficult to implement national changes, and that “things
9 just start getting done in different ways in different health boards” (R66_Scotland). We
10 were also told that there is “a reluctance amongst health boards to give up some of their
11 authority” (R66_Scotland) which was viewed to be needed to reduce variation in how
12 systems are implemented across the country.

13

14 **Discussion**

15 This study suggests that strong leadership, at a variety of levels of the cancer care
16 system, is perceived as important for improving cancer outcomes, as is political
17 leadership that enables progress on a cancer strategy to be sustained. This often relies
18 on giving a mandate to central bodies and/or individual leaders who have oversight of
19 and authority in the system, but it also needs the expertise and influence of clinicians,
20 advising on strategy and making changes on the ground. These various facets of
21 leadership should, when effective, lead inevitably to quality improvement^{35,36,67} and
22 therefore improved outcomes for patients.

23 ***Political leadership***

24 Our findings suggest that political leaders often responded to impetus from external
25 sources such as international benchmarking studies and pressure from clinicians. Strong
26 political leadership can impact cancer outcomes through the development and
27 implementation of a national (or provincial) strategy,^{31 30} one that has been developed
28 by policymakers and experts (clinicians) within the system, that is regularly revisited
29 and updated, that steers cancer care and remains focussed on improved outcomes, but
30 that also takes account of local pressures and allows local leaders to adapt to the local
31 context. Cancer plans have been published in high income countries for decades and

1 have been credited with transforming standards of care in many places. The issue of
2 leadership only appeared explicitly in a few of the ‘earlier’ plans we studied,^{52,56,59,66,68}
3 but has become more commonly integrated in recent times.^{57,58,61,65,69-74} The essential
4 characteristic of leadership is that it “creates a clarity and unity of purpose, encourages
5 team building, ample participation, ownership of the process, continuous learning, and
6 mutual recognition of efforts made”.³² Here the central role of sustained political
7 leadership is clear.

8 The increasing incidence of cancer in our aging populations⁷⁵ means that cancer care
9 will likely remain high on the political agenda for some time,⁷⁶ but this is in a world of
10 increasing competition for scarce resources and complexity of treatments that are
11 already beginning to stretch expertise, capacity and infrastructure. This may be
12 particularly relevant in under-served populations, such as First Nations peoples in
13 Canada and the Maōri population of New Zealand, where leadership including those
14 groups will be important in addressing inequity. Stability of “a core of the leadership
15 team” at least is key⁷⁷ so that implementation of strategies and their promised resources
16 can be assured over time. Commitment to sustained and predictable investment from
17 government to support the capacity needed for the growing cancer population is vital;⁷⁸
18 without this, the best leadership is still likely to founder in its goals.

19 As the key informant interviews did not set out to analyse governance arrangements, it
20 was not possible to assess more fully the influence of governance structures, or the
21 locus of decision-making in each jurisdiction, although these will have an impact. This
22 study clearly highlights, however, the importance of both leadership and governance in
23 cancer services and future work should examine these additional issues in greater depth.

24 ***Intellectual and clinical leadership***

25 The development of cancer strategies involved clinicians to some extent in every
26 jurisdiction. They were involved at various different tiers in decisions about the
27 organisation of cancer care, and they were seen as important levers for change.⁷⁶
28 Research into quality improvement mechanisms has shown that, at a local level, clinical
29 involvement in implementation is enhanced by clinical leadership and that the
30 involvement of ‘physician leaders’ in developing and implementing strategies is key.⁶⁷
31 The culture of organisations,³⁶ support from senior management (which would be

1 politicians in this context), and performance monitoring (via benchmarking and
2 targets)³⁵ have all been found to be important to improving outcomes.

3 Leadership also needs to be “visionary and strategic,”⁷⁹⁻⁸³ to have an overview of the
4 long-term goals,⁸⁴ the needs of the system and potential challenges ahead. This can be
5 difficult in times of system reorganisation and when scarcity of resources mean that
6 leaders do not have the time to devote to strategic planning. Individuals involved ‘on
7 the ground’ can play an important role here: “expertise-driven practice” as Taylor et al
8 call it, is vital³⁵ and “clinician leadership is seen as being essential to make health care
9 work” (p.12).⁸⁵

10 Strong individual leaders were seen to be important, but it should be remembered that
11 they all operated in a context of political commitment that was supportive of their work:
12 an individual in isolation is unlikely to have achieved similar results. In addition, the
13 system must also be “nimble” enough (R5_Ontario) to not rely on single leaders. The
14 WHO, in their guidelines for national cancer control programmes, asserts that a
15 programme coordinator should have a wide range of technical skills and political
16 influence, as well as a plethora of management, communication and personal skills.³²

17

18 *Leadership at different tiers*

19 Effective cancer care relies on leadership at multiple levels³⁰ to be organised,
20 implemented and delivered. Priorities operate at different levels: the national agenda
21 dictates what should happen but this cannot always be translated into action at local
22 level because of competing priorities. Strong cancer leadership that operates at the
23 different tiers of the system (national, regional, local) to drive change and improve
24 outcomes is therefore important.⁸⁴ Leadership at the local level is key,⁸⁵ allowing a
25 vision that has been adopted at national level to be implemented locally, with all
26 adhering to the same goals, and encouraging the integration of primary, secondary and
27 tertiary care that is so necessary for smooth flow through the patient pathway.⁷⁷
28 Fragmentation of a system where each health board or area makes their own decisions
29 was seen as a clear impediment to this coherence of vision and implementation of

1 change, as was the frequent or large reorganisation of services that led to discontinuity
2 in leadership structures.

3 Leaders need to ensure transparency and hold other system actors accountable.²⁹ This
4 implies the “management of relationships between various stakeholders in health”³¹
5 something that we heard cancer agencies can play a large role in. Cancer agencies can
6 offer “transformational leadership [which] can bring key stakeholders together with the
7 aim of improving the cancer system as a whole” (p.7).³⁰ The ability to build coalitions
8 and effective communication between stakeholders is vital here, and this was also cited
9 as a characteristic of effective individuals.⁷⁶

10

11 *Strengths and Limitations*

12 This study drew on interviews from a large number of key informants representing a
13 wide range of stakeholders in the cancer care system. To maintain representation across
14 countries, only a limited number of informants in each jurisdiction could be
15 interviewed. We had a broad approach to recruitment, using initial suggestions from
16 the ICBP project board, although avoiding interviewing people directly involved in
17 ICBP projects. We tried to minimise any bias from only using personal
18 recommendations by also using internet searches to identify people in relevant roles.
19 However, we heard a pattern of similar responses from a variety of participants in each
20 jurisdiction, regardless of their position, including representatives from patient
21 organisations and charities, suggesting that our findings were not particularly
22 influenced by recruitment method.

23 Many informants held senior positions in their organisations, thus affording us a broad
24 and deep overview of the cancer care system in their jurisdiction. However, we are
25 aware that these were perspectives of individuals and we cannot assume that our study
26 captured all possible views. In addition, our approach to data collection, based around
27 a necessarily brief topic guide, means that certain themes may have been reported more
28 in some jurisdictions than others if we did not specifically ask about it. However, the
29 issue under consideration was apparently seen to be of crucial relevance among those

1 participating in the study from that jurisdiction, as some themes emerged despite not
2 being specifically elicited from the guide.

3 We also acknowledge that there are many definitions of ‘leadership’,²⁸ often in
4 combination with, stewardship⁸⁶ and governance.^{27,29,87,88} We have laid out how we
5 have understood leadership but accept that it may be understood differently by different
6 audiences, influencing how the notion of leadership is conceptualised in strategy
7 documents and by study participants.

8

9 Finally, is important to acknowledge that, ultimately, it is not possible to causally link
10 a particular form of leadership and organisational structure directly to survival (and
11 other cancer outcomes) given the range of elements in the system that are working
12 together. Each health system is characterised by a particular set of relationships between
13 the different professionals and institutions that deliver care, and it cannot be assumed
14 that a particular strategy or service model developed in one setting can be transplanted
15 to another, because of the particulars of the local context that are so crucial in
16 determining of ‘what works’. There are several components that seem necessary to
17 improve outcomes but removing one or another will not impact in a predictable way; it
18 is therefore difficult to say which component is more important than another one. In a
19 similar way, we have only been able to suggest, without being definitive, patterns of
20 approaches to what might drive change and facilitate improvements in outcomes.

21 **Conclusions**

22 Our study points to several components that appear to be conducive to achieving
23 consistent progress in cancer outcomes. Involvement of clinicians at every stage of
24 strategy development appears to be core for the successful implementation of policies,
25 including involvement in developing or defining quality measures and performance
26 targets. Presence of a lead agency or body at central or regional level, with an explicit
27 political and financial mandate to lead the whole system, and tasked with ensuring a
28 transparent and coherent approach to cancer care, is likely to lead to more sustained
29 progress in policy implementation at each tier of the system. Similarly, strong
30 leadership of cancer care at a local level, with a mandate to make changes and

1 implement agreed policies, can ensure implementation of sometimes aspirational or
2 intangible aims of national cancer strategies.
3 Of crucial importance will be the involvement of the community being served: many
4 cancer strategies are developed with the input of patients and the public, but it is unclear
5 to what degree they can influence the direction or are involved in the implementation
6 of the aims. This is an aspect we did not explore in this study, but which should be
7 looked at in future.

8

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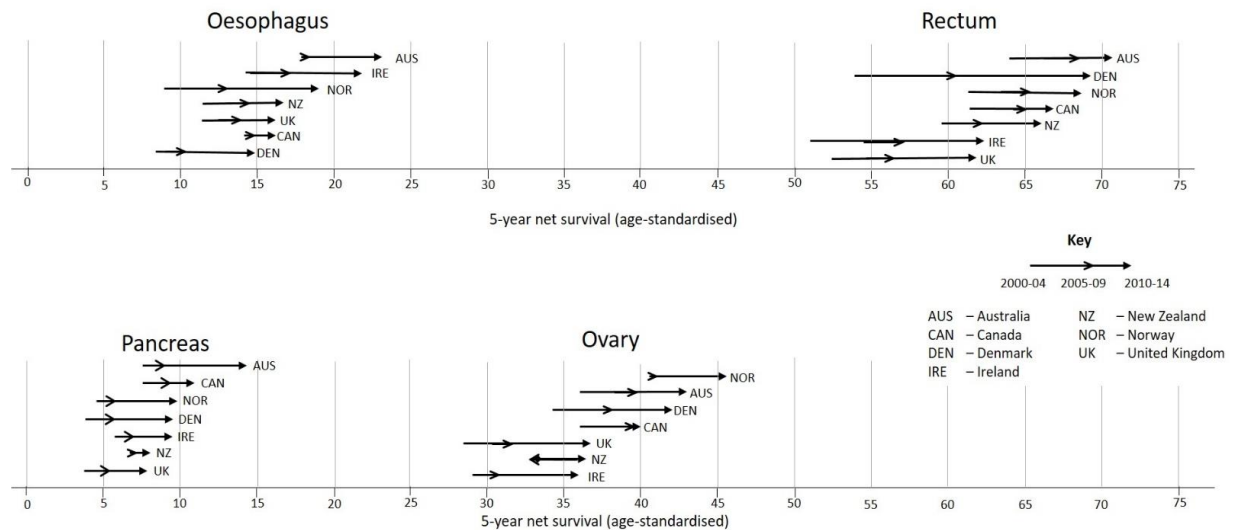
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21 **Appendix**

22 **Appendix 1 – Trends in survival from selected cancers, 2000-2014**



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24 Source: adapted from Arnold et al, 2019²