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Research evidence supports cancer policymaking but is insufficient for change: Findings of key informant interviews from five countries

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ABSTRACT

Evidence-based policymaking values the use of research in the process of developing, implementing and evaluating policy. However, there is limited research attempting to understand how cancer policymaking occurs and the role of evidence in this process. Our study aimed to provide a deeper understanding of levers and challenges to the development and implementation of large-scale, health service policies or programs in cancer care. Within a realist framework, we conducted a thematic analysis of interviews with 13 key informants from five countries: Australia, Canada, Scotland, Denmark and New Zealand. Results identified a complex array of program mechanisms and contextual factors influencing cancer health-service policymaking. Research evidence was important and could form a rationale for change, such as by identifying unwarranted variation in cancer outcomes across or within countries. However, other factors were equally important in driving policy change, including advocacy, leadership, stakeholder collaboration, program adaptability, clinician and consumer involvement, and the influential role of context. These findings resonate with political science theories and health service reform literature, while offering novel insight into specific factors that influence policymaking in cancer care, namely clinical engagement, consumer input and policy context. Although research evidence supports policymaking, the complex ways in which cancer policies are developed and implemented requires recognition and should be considered when designing new programs and promoting the use of evidence in policymaking.

1. Introduction

Evidence-based policymaking refers to the use of research evidence in public policy development, implementation, evaluation and improvement [1]. It has supporters in academia and politics, for example, the concept was strongly pushed in the late 1990s by the Blair Labour government in the UK [2], while in 2008, the Australian Prime Minister called for "robust, evidence-based policymaking" [3]. However, despite this high-level endorsement, evidence-based policymaking is a disputed concept [4–7] with critics noting that randomised controlled trials (RCTs) favoured by some advocates are inappropriate in policy evaluation; that practitioner knowledge is under-recognised; and the benefits of research and systematic reviews are exaggerated [6,8]. Nevertheless, when such limitations are acknowledged, the inclusion of independent, methodologically rigorous evidence into the policymaking process may provide several advantages, including more balanced policy, less influence from political or external interest groups, and policies less susceptible to unintended consequences [8,9].

Evidence-based policymaking can be applied to many areas, including health service policies. Such policies can be particularly important for complex health problems like cancer care [10], where the organisation and management of health services can influence patient outcomes [11–13]. For instance, an Organisation for Economic Co-operation and Development (OECD) report examining 35 countries found variation in resources, care practices and governance features of cancer care systems were associated with five-year relative survival for breast, colorectal, lung and cervical cancer [11]. Given the clinical implications of such policies, understanding how they are made and the role of research evidence is important. However, there is currently limited research seeking to understand how and why policy change occurs in cancer care,

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and the interaction between the policymaking process and use of research evidence [14].

Political science theories and policy implementation research can be useful in conceptualising health policymaking [15]. For example, the theory of 'muddling through' suggests a process of incremental policymaking, where ideas build over time and small changes are gradually introduced [16,17]. The multiple streams approach suggests policy proposals, politics and problems converge in a particular time-period, or 'policy-window', which leads to policy change [18]. Others have noted the importance of context as a mediator of change, such as organisational and institutional context, and the need to understand existing culture, values and norms [19].

In the cancer field, few studies have sought to understand large-scale policy change for health service-related programs in different countries. Aggarwal, Ginburg and Fojo assessed how economic policies affecting cancer care are discussed and debated across Europe, the US and Canada [20]. Although their work focused on treatment costs, other factors also influenced policy change such as advocacy by patients, clinicians and organisations, and political and social values. A review of the implementation of cancer policies from the 1995 Calman-Hine report in the UK found that policies took longer to implement than anticipated, with workforce and resource limitations hindering progress; while public discontent, local and international evidence of variability in services or outcomes, and clear, simple policy recommendations aided implementation [21].

The current study aimed to further explore common levers and challenges to cancer health service policymaking across five high-income countries with universal health care: Australia, Canada, Scotland, Denmark and New Zealand. These countries are participating in the International Cancer Benchmarking Partnership (ICBP), a research program that aims to identify factors contributing to differential cancer outcomes between countries and to inform policy [22]. Given the program's objective to use evidence in policymaking, ICBP countries were selected for the current work.

2. Methods

2.1. Study design and methods

A qualitative, exploratory design was chosen as the research sought to understand how and why a phenomenon occurred [23]. This involved semi-structured interviews with key informants, defined as people with high-level involvement in a specific cancer policy, program or set of programs. The perspective of key informants can offer alternative insights to written sources, such as government reports, that may not identify or disclose all factors influencing the policy change process, particularly if these are politically sensitive.

2.2. Context

The current research was initiated in Australia, with Canada, Scotland, Denmark and New Zealand chosen for ICBP participation and similarities in social, economic and healthcare system contexts. All the selected countries are high income, developed nations with universal health coverage. Compared to OECD countries, the selected countries rank higher on several measures including employment rate, life expectancy, perceived health and overall life satisfaction [24,25].

2.3. Ethics

The project was approved by the Cancer Council of Victoria Human Research Ethics Committee (HREC1522).

2.4. Recruitment

Key informants were recruited using purposive and snowball sampling and interviewed between February and July 2016. Initially, potential informants were identified through professional networks of the authors and an introductory email sent outlining the study. Interested informants were then sent an information sheet and a time was arranged for interview. Participants were asked to identify another person who might be suitable for interview. Recruitment continued until two informants involved in a cancer policy, program or set of initiatives were interviewed from each country. At least one policy was discussed for each country, but the policy focus (e.g. health services targeted, cancer type) varied across countries. Two Australian-based policies were investigated to obtain more information regarding local factors influencing change. Theoretical saturation in each country was not possible as there are potentially many viewpoints from different stakeholders on a particular policy change. Instead, attempts were made to access informants in senior roles and collate themes across countries to enhance understanding of common processes.

2.5. Interviews

Semi-structured interviews were conducted with the first author by telephone. Although face-to-face interviews are often viewed as the 'gold standard' in qualitative research, there is little evidence of variation in results for phone versus face-to-face data collection [26]. Interview topics explored levers and challenges in the informant's experience of cancer policy development and/or implementation. The interview guide was not pilot tested as the major topic questions were specific to the study aims and the semi-structured format allowed for adaptation according to participant responses. Interviews were recorded and transcribed verbatim. The transcript was sent to the informant who could correct, exclude or add additional information. Data were then de-identified and managed in NVivo 10 [27].

2.6. Analysis

A thematic analysis was conducted, informed by a realist framework of causality, where context and mechanisms of change interact to produce outcomes [8,28]. After each interview, reflexive memos were written and reviewed during analysis [29]. Inductive coding of interview data commenced during interview conduct, and categories and themes were refined over time. The first author led the analysis, with summaries of interview content, coding and themes discussed in regular meetings with co-authors. Informants were emailed a set of provisional themes and asked for feedback on their relevance and accuracy, whether information was missing, and any additional thoughts or reflections. This member-checking allowed an assessment of the validity of results [30].

3. Results

3.1. Participants and policies

Fourteen potential informants were contacted. Of these, one had limited experience in policy development so did not complete an interview. Of the 13 interviews undertaken, ten were conducted via telephone, one face-to-face and two by videoconference (Skype). Four interviews were conducted with Australian informants, three Danish, and two informants each from Canada, Scotland and New Zealand. Informants worked mainly as directors or managers in a cancer agency, program or network (n = 10) with roles in organisational or program leadership and advocacy. Three informants were senior researchers or clinicians (e.g. nurse, surgeon) working

Table 1
Features of cancer policies/ programs.

Country	Program	Description	Policy level		Interview discussion	
			National	State/ Province	Development	Implementation
Australia	Regional cancer centres	Funding for capital works to build or extend health services dedicated to cancer care in regional/rural Australia (2009 budget announcement, implementation from 2011).	√		√	
	Surgical optimisation for oesophageal and pancreatic cancer	Reduce the number of small-volume hospitals performing complex cancer surgery (est. 2010, ongoing).		√	√	√
Canada	Canadian Partnership Against Cancer (CPAC)	Organisation created to deliver Canada's cancer strategy (est. 2007, ongoing).	√		√	√
	CPAC priority populations program: First Nations, Inuit, Metis communities	Specific program within CPAC for priority populations.	√		√	√
Denmark	Patient pathways/three-legged diagnostic strategy	Improve timeliness of cancer diagnosis and treatment (2007 announced, implementation from 2008, ongoing)	√		√	√
	Danish Multidisciplinary Cancer Group	Groups providing input to cancer strategies, such as patient pathways, surgical centralisation; and managing clinical cancer data (est. 2005, ongoing)	√		√	√
Scotland	Cancer Quality Performance Indictors (QPIs)	QPIs for cancer developed by clinicians (2008 Cancer Plan commitment, implementation 2010, ongoing)	√		√	√
NZ	Bowel cancer working group/colorectal cancer screening; general cancer disparities programs and research	Group providing advice to government on colorectal cancer-related programs (est. 2010, ongoing); rural and Maori cancer outcome disparities initiatives (ongoing).	√		√	√

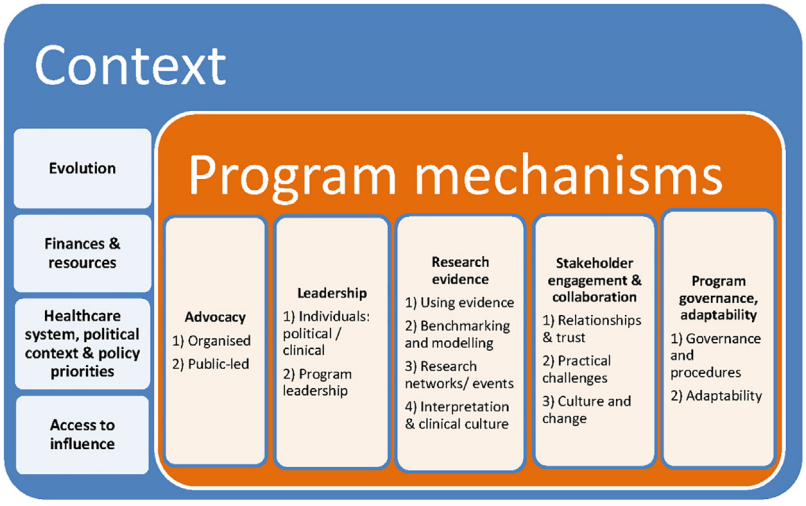

Fig. 1. Thematic framework: factors influencing cancer policy development and implementation.

in oncology who had participated in cancer program development committees. There were five female and eight male participants. The average length of discussion was 40 min. A range of large-scale health service-related cancer policies and programs were discussed (Table 1). Most were national-level initiatives. All policies were implemented from 2005 to 2010, although development may have commenced earlier.

3.2. Member-checking

Five of the 13 informants provided feedback on an initial set of themes. There were no major changes suggested, with most informants reporting that themes resonated with their experience and agreed with the categories developed. One informant suggested further emphasis be given to the importance of clinical leaders in the Leadership theme. Another commented that collaboration, not just engagement, with stakeholders was an effective lever to change. These perspectives were incorporated in the final thematic framework, summarised in Fig. 1.

3.3. Thematic framework

Results were categorised under two overarching themes: program mechanisms and context. Program mechanisms included five sub-themes describing key mechanisms for how policies or programs were developed and implemented: 1) Advocacy, 2) Leadership, 3) Research evidence, 4) Stakeholder engagement and collaboration, 5) Program governance and adaptability. Contextual factors that were important in moderating these mechanisms were defined in four sub-themes: 1) Evolution, 2) Finances and resources, 3) Healthcare system, political context and policy priorities, 4) Access to influence. Policy levers and challenges were identified across these sub-themes. Levers were factors or strategies that enabled or enhanced policymaking, while challenges were per-

Table 2
Program mechanism themes and supporting quotations.

Theme	Sub-theme	Lever	Challenge	Quotations
Advocacy	Organised	✓		*. . .much more involvement with grassroots support in the development of the cancer control strategy. . .many advocacy groups involved in it and in helping to support it. . . [An earlier proposal] had well over 100 priorities, and once you've got over 100 priorities you don't have any priorities. (CAN1)*
	Public-led	✓		*. . .the process became autonomous. It was not the Cancer Society who fed the newspapers case stories. Case stories came from here and there and all over. . .we had reached the stage where a lot of healthcare bodies, a lot of people and politicians said, 'Now we can't talk anymore. We have to act.' And that was what happened. (DEN2)*
Leadership	Individuals	✓	✓	*Multiple clinical leaders were identified and supported to develop in the role. . .We are now in the position where multiple individuals see themselves as having key roles to play in driving improvements in clinical care and speak to their role within the programme. (SCOT2)* *. . .we couldn't get a policy leader. . .we couldn't really get strong surgical leadership. . .we probably didn't groom the clinical champions and put them at the front of the change process. And I think in hindsight that is what you would do. (AUS2.1)* *. . .it tells me a lot more about the need for leadership if you change something and implement change. Clear and well-described leadership from the absolute top. (DEN2)* *We're still a pretty small organisation for what we do. (CAN1)*
	Program	✓	✓	*I have to say we have a budget. It's not a big budget but it is enough to make it possible for us to meet in the groups and drive [change]. . . (DEN3)* *We are working with the Ministry yes. . .So it's not separate from the Ministry but it's not directed by the Ministry. . .And we do have some of their resources as well. So, if we want to get data that they have, or if we want to tender out a particular bit of information. . . then we get someone to do it. (NZ2)* *I think that, part of what happened was that we were seen as the bureaucrats sitting in our ivory tower. . . (AUS2.1)*
Research evidence	Using evidence	✓		*. . .a lot of the initial [advocacy] work making the case – there was certainly some useful research in the literature that articulated and. . .explained where some of those disparities were in respect of different outcomes. . .We did use consumer data that was in – patient data that was in the studies, around disparities in treatment outcomes. (AUS1.2)* *. . .in the pilot. . .we know how many [colonoscopies] are being done, we know how many more are likely to be done if we try to roll out a screening program. . .(NZ2)*
	Benchmarking and modelling	✓		*So for cancer, we compare ourselves against yourselves across the ditch [Australia] and our cancer outcomes are generally worse. So that was a response to our generally poor outcomes in cancer that we needed to improve. (NZ1)* *Because we had begun to get new information that Denmark was lagging compared to the other Scandinavian countries. (DEN2)* *The evidence has been in there for a long time. . .the question was, what's happening in Australia? (AUS2.2)* *. . .there was some modelling done that actually tried to look at what the potential impact of implementing a cancer control strategy could be. In terms of both reduced mortality but economic advantages. . .looking at what would happen in terms of incidence reduction for example, if we got to the level of tobacco use which was the best example in the Western world. . .If we could get to the lowest jurisdiction rate, then what would be the reduction in mortality? (CAN1)*
	Research networks/ events	✓		*There was a conference. . . that was all about those sort of disparities, and that helped give the issue some profile. (AUS1.2)* *I think that Australasian link has also helped influence policy here. . .what's going on in Australia as far as, for instance, the audit work that the college have done, has really come out of Australia and then been picked up here. (NZ1)* *The other part of it, which became quite good for us and for our willingness to keep pushing, was we created the international group. . .we said we needed to create an international network of researchers in the field. . .[that] in many ways empowered our thinking. (DEN2)*
Stakeholder engagement and collaboration	Evidence interpretation and clinical culture		✓	*Most did have some data but had never collated it in a way that looked at compliance with guidelines. So pulling that together and having the conversations. . .when you first start out with a group that has not done public reporting on that, there were sensitivities about what that could mean. (CAN1)* *. . .so they had had the data for three years. And nothing really was changing. (AUS2.1)*
	Relationships and trust	✓		*. . .that is a very critical thing in the way we operate. We have no authority. We have no ways to compel anyone to do anything. We work as a partnership organisation. . .it's a lot of engagement, but that is the key to success really. (CAN1)* *. . .I think there is good clinical buy-in across all of these strands of work in the different cancer types. And they are owned by the clinicians on the ground. (SCOT2)* *So one of the things that we also do is have knowledge-exchange workshops each year where we bring together representatives from each of the jurisdictions, including Elders, and we share what's going well with the initiatives, what they find challenging. . .So it's a really good opportunity to learn from one another. . . (CAN2)* *And we have been counselled every time there are big decisions in cancer care, if some decisions should be made. So in fact, we have had a rather central role in cancer care over the last 10 years. (DEN3)* *I represented the nurses group on that, but there was also patient and carer representation. There was again a cross-section and robust discussion. . .(SCOT1)*
	Practical challenges		✓	*So we were trying to engage with a whole lot of range of people that we didn't have established relationships with. . . by the time that you build these relations, then you get groups together, then you appoint staff, it has taken longer. . .(SCOT2)* *We had to go out and work hard at getting that political support. (AUS2.2)* *. . .the particular cancers about which we are talking do not have strong consumer groups. . . It's not like other cancers where there is a strong survivorship which can be a part of that. That is probably the key challenge in that space. (AUS2.2)*
	Culture and change		✓	*. . . it was a huge challenge, you would think that this was the easy bit – it was about patients and outcomes. And yet the conversation kept coming back to health professionals. . . It's not popular. Because intrinsic to this. . .is that you are saying that the system isn't working as well as it could. So, although the positive message is, the system can work better, it's not interpreted that way necessarily. (AUS2.2)*

Table 2 (*Continued*)

Theme	Sub-theme	Lever	Challenge	Quotations
Program governance and adaptability	Governance and procedures	✓	✓	*[In the Pathway policy] If the GP said this could be cancer, then they [hospitals/specialists] had to do something within a couple of days. And that was really a new culture. The GP could say they should do something. That was a tough thing. . . So we have a change in culture of these pathways but it's taken a very long time. (DEN1)* *. . .everybody just keeps saying that . . . you need to give surgeons and hospitals a chance to get involved. But this consultation has been going on for five years. . .and from my perspective, that change is way too slow. (AUS2.1)* *. . .we took quite a while to define what that program would be. . .(SCOT2)* *So it is a learning process. . .at the end of the day, we will make far more rapid progress this time. (AUS2.2)* *. . .there are so many distinct challenges depending on the region. . . .You can't say all First Nations, Inuit and Metis are the same, and therefore have the same issues. There are three very distinct peoples . . . so it's a very complex system. (CAN2)* *It makes sense that you would do things differently given your context. However, can we get agreement at the beginning that we will all collect the same core information points on our programs. (CAN1)* *. . . within these limits, you were allowed to make local adaptation. . . that was a very good thing, because otherwise you would have seen a lot of systems going down. (DEN1)* *We also. . . adapted our processes as we encountered enablers and challengers. . . that we could adapt was a strength. (AUS2.2)* *It's just course-correcting and adapting as we go. (CAN2)*
	Adaptability	✓		

ceived barriers, problems, compromises or unforeseen difficulties. Some themes spanned both categories. For example, stakeholder engagement and use of evidence had both positive and challenging aspects during policy change.

Not all themes were relevant to each cancer policy, but individual programs involved at least several themes across countries. The advocacy theme was prominent in policy development but was generally absent in descriptions of program implementation. Some themes were mentioned regularly, such as finances and resources, while others were more apparent in specific programs, such as public-led advocacy in the Danish pathways policy. There were also some country-specific contextual factors, such as federated health system organisation in Australia and Canada. The program mechanism and context themes are described in the following sections with supporting quotations provided in Tables 2 and 3.

4. Program mechanisms

4.1. Advocacy

Advocacy was defined as efforts having an influence on political awareness and support for a cancer issue or proposal. Two main forms of advocacy were identified: i) organised, strategic advocacy, often undertaken by organisations, and ii) public-led advocacy, which was less-structured and commonly undertaken by consumers or the media.

Organised political awareness-raising was often driven by several organisations representing a diversity of stakeholders, including clinical, public health, consumer advocacy and research teams. Techniques used to raise awareness included meetings with politicians, engaging the media and consumers. Policy levers included having a consistent message from diverse advocates and clear aims, intended outcomes and organisational plan for new policy proposals. Advocacy from organisations with a large membership also meant a group could have strong political influence, particularly in smaller countries (see the access to influence theme).

Advocacy from the public and media was also powerful. In contrast to the strategic approach, this kind of advocacy was patient or consumer-driven and involved the use of individual's stories which could elicit strong emotional reactions to an issue and demonstrate deficiencies in the health system. In Denmark for instance, media promotion of discontent regarding treatment waiting times helped the problem become 'a political issue'.

4.2. Leadership

Two forms of leadership were identified: leadership from influential individuals that supported and promoted a reform or leadership from the project group responsible for developing or delivering the new initiative. Strong leadership, such as promoting or taking action to support a policy, could be highly effective for introducing and maintaining momentum for change while a lack of leadership made change more difficult.

Top-down leadership from political or clinical individuals helped to endorse an issue as pressing and relevant to the group they oversaw: clinicians, health services, a country. Clinical leaders were influential among their peers and had credibility to challenge current practice. Some informants described how clinicians were supported to lead certain aspects of a program, promoting ownership and shared responsibility for the new policy (see Table 2, quotation by SCOT2).

A dedicated group responsible for organising and monitoring change was perceived as essential to maintaining momentum. These groups were often small but could be responsible for large programs of work with significant impacts on outcomes making them high value, cost-effective program leaders. While most groups had some government involvement which was helpful in obtaining funding, data resources or political leverage, it could also have negative implications if groups were perceived as bureaucratic by stakeholders.

4.3. Research evidence

Research evidence was seen as essential to policymaking. Subthemes reflect the variety of ways research evidence was used, the type of evidence needed to leverage change, and difficulties when presenting new research data to clinical stakeholders. Although evidence was necessary to support policy development and implementation, it was not sufficient for change.

4.3.1. Using evidence

Research evidence was used to define or describe the problem, set the political agenda, and to inform and influence decision-makers. Strategic publishing of relevant research in accessible formats could influence politicians, key organisations or clinicians. Program evaluation and health system performance data were important in several projects. Feedback on a service or clinician's practice was considered a lever for continued improvement, if the feedback was valued. Reporting to the public about performance was also perceived to motivate change.

Table 3
Context themes and supporting quotations.

Theme	Lever	Challenge	Quotation
Evolution	✓	✓	*It has been a 15-years-long organisational change. (DEN3)* *So there was a group set up in the late 1990s. . .by the government to advise the government. . .And that sort of morphed somewhat. . .I think the initiative for it came from that there was already a group. . .(NZ2)* *. . .the Cancer Plan which said we need look at. . .the whole quality program given where we got stuck with the previous program. But it needed to be quite different in terms of being lighter touch, being more responsive so we could update the indicators and have greater clinical buy-in than we perhaps had with the previous ones which. . .in some ways felt imposed than collegiately developed and owned. (SCOT2)* *We have a national Board of Health that are collecting all these problems or suggestions to change things. . .We just had a change last week. . .(DEN1)* *Actually the first document we put out anonymised according to Province. . .After the first publication, the Cancer Agencies in each Province themselves said. . .let's go forward and report. (CAN1)*
Finances/ resources	✓	✓	*The turning point. . .was the enthusiasm for providing capital funding for stimulating the economy that came out of the global financial crisis. . . (AUS1.2)* *. . .actually it was supposed to roll out as soon as the pilot finished. . .But they instead said they would fund the pilot for another 2 years. . .It was a way of trying to balance the books rather than getting on and doing the things we know we need to do, unfortunately. (NZ2)* *. . .it can be a simple resource issue, not every Province has the funding to do everything that's out there. So they have to choose what makes the most sense to act on at any given time. (CAN1)* *But that was the local adaptation because that was also depending on the resources and possibilities. (DEN1)* *Obviously that was very resource intensive and we don't really do it anymore. (SCOT1)*
Healthcare system, political context and policy priorities	✓	✓	*So the challenge is about [having the] resource to be able to carry out what you want to do. . .So there's a huge amount of work in the ministry to do that [another policy change]. So the amount of support they're giving to the other things. . .has significantly gone down. . .(NZ2)* *Healthcare system:* *I think the other challenge has been getting that policy into general practice which is less regulated. (NZ1)* *So we had a first line of the healthcare system, the GPs, that were actually in a position where they were caught between two very strong opinions, keep the patients out of the system. (DEN1)* *It's the downside in that growth in private healthcare. . .the motivation that many people [clinicians] have is no longer what it used to be, around the health of the population. (AUS2.1)* *In Denmark at that time we had the system was organised in about 50 or 60 demographic places, which in 2008 became five regions. So from that perspective it wasn't that difficult to centralise. (DEN3)* *Political context:* *. . .if we were going to take a federal position forward it would probably be on the basis of feasibility. . .We thought it would be unrealistic to expect the Commonwealth to do any more than provide the capital funding. . .(AUS1.2)* *It's just the reality of life when you have a federated system. . . if you can get three [Provinces] that are interested. . . if it does show benefit, the others will become more interested. (CAN1)* *. . .we were being kept from ministerial advisors who didn't want this to be an election issue (AUS2.1)* *We started the initiative and they were hiring staff and they needed to get the team in place. And then they had a provincial election and with the new government that came in, they put a hiring freeze for all healthcare. . .that was another challenge that was politically based, it was out of everybody's hands. (CAN2)* *All these things are political. . . the Labour government in power at the time, there was a new minister of health who. . .said just do it. . .Unfortunately Labour lost the election and the new minister of health then backtracked. . .But it took that political initiative to get colorectal screening going. (NZ1)* *Policy priorities:* *It came from the Cancer Plans headed by the national board of health. It was a chapter in the Cancer Plan that we have to create these multidisciplinary groups. (DEN2)* *They had clear guidance about improving cancer outcomes and reducing disparities. Most goals in the ministry of health have that dual goal. . . (NZ1)*
Access to influence	✓		*Well, I think that both politically, and then of course in the public, and also in the healthcare system, there has been an increasing acknowledgement of positive patient evaluations as well. And that was the big driver for many of the initiatives. (DEN1)* *I think governments have to raise the expectations. But consumers do as well. And the good thing about cancer is that there is a fairly strong consumer movement. (AUS2.1)* *From a Danish context. . .we are a small country. . .and we only have one Cancer Society in the country. And this Society has 450,000 members who pay their annual membership fee. And that means that some 10 to 12% of the adult population are members of the Cancer Society and that gives a tremendous power. (DEN2)* *New Zealand's quite good in that you can get access to Ministers quite readily and can get access to policy quite readily. . .Everybody knows somebody who knows a parliamentarian or knows their mother. (NZ1)* *. . .Scotland being a reasonably small country, we kind of all know each other pretty well in terms of being able to link back in. (SCOT2)*

4.3.2. Benchmarking & modelling

Evidence from cancer benchmarking and modelling studies was mentioned regularly and perceived as effective levers. Benchmarking studies that demonstrated unwarranted variation in cancer outcomes were a powerful stimulus for policy change. For example, the EUROCARE-II studies showed poorer cancer survival and slower improvements in Denmark compared to other European countries and were perceived to spur on change [31]. In Canada, the use of predictive modelling studies on anticipated survival, mortality and economic benefits of a proposed cancer program was perceived to influence government decision-makers.

4.3.3. Research networks/events

Some informants noted that research activities, events and networks could help raise the profile of an issue. This included presenting evidence at scientific conferences and having an international network of researchers investigating a problem which could influence local agendas.

4.3.4. Evidence interpretation and clinical culture

Despite these advantages, there were also challenges in using research evidence to drive change. This was most apparent when engaging clinician stakeholders. Key informants identified a number of anxieties and resistance from clinicians regarding research

data, particularly when data regarding their activities were published or presented for the first time. Clinicians raised concerns about data accuracy and completeness, and negative implications of the data on themselves or their institution. Key informants reinforced the need to be aware of the sensitive nature of new data, and to build trust and understanding of the evidence.

4.4. Stakeholder engagement and collaboration

Stakeholders were defined as any person or organisation with an interest in, or who might be impacted by, a cancer policy or program. Stakeholder engagement and collaboration was a key component of all programs. Diverse stakeholders were involved, including clinical professional bodies, government representatives, consumer groups or individuals, Indigenous groups, health service executives or managers, politicians, researchers, quality and safety organisations and members of industry (e.g. private health insurance companies). Stakeholders varied depending on the policy focus and country context. For example, programs aiming to reduce population disparities engaged with Indigenous populations (Canada and New Zealand), while in the surgical optimisation program in Australia, stakeholders included private health insurers. Sub-themes included levers like building trust and relationships with stakeholders, and challenges categorised as practical or cultural. Most key informants accepted these challenges, with resistance perceived to be normal for any initiative that seeks to change working practices, not just in cancer care.

4.4.1. Relationships and trust

Relationships and building trust with stakeholders and stakeholder groups was important. Such groups included working groups, steering committees, taskforce, operational groups, advisory groups or networks. Giving stakeholders a sense of involvement, influence and ownership in the program improved engagement. For example, in Scotland, development of performance indicators by a group of clinicians was perceived to enhance trust and acceptance of the initiative by peers.

Consumers and patient organisations were important stakeholders. Consumer engagement was particularly important for initiatives with Indigenous populations. Cultural sensitivity, listening and relationship-building helped to build trust, leading to the development of relevant, community-endorsed programs.

4.4.2. Practical challenges

Practical challenges included identifying relevant stakeholders and the time required to establish and maintain relationships. Generating support through engagement took considerable energy and effort. As views could differ between stakeholders, consulting widely was important, and compromise was sometimes necessary to take an initiative forward. Consumer engagement could be difficult for some programs, such as the Australian surgical optimisation initiative for pancreatic and oesophageal cancers, where the cancers targeted have poor survival and organised consumer groups or survivor advocates were limited.

4.4.3. Culture and change

Several informants identified resistance from stakeholders, namely clinician stakeholders. Key informants posed several reasons for such resistance, including specialist culture. For example, oncologists were perceived to be more concerned with treatment-related aspects of care, such as equipment improvements or better drug treatment, than other areas of the cancer pathway such as cancer prevention or early detection. This was challenging when cancer policies spanned community-based care, such as general practice, and specialist oncology care.

Some key informants suggested changes may challenge clinicians' values or perceptions of professional skill. In several cases, even with extensive stakeholder engagement, clinical culture change was perceived to be slow (see also the evolution theme).

4.5. Program governance and adaptability

4.5.1. Governance and procedures

Timeliness of policymaking was also impacted by governance or procedural aspects. Good governance structures and pragmatic approaches to implementation led to better support for programs but could take time. Other factors that slowed progress included lack of resources or staff turnover. Changes in political context could also affect timelines. However, over time, processes were faster and governance arrangements more effective.

4.5.2. Adaptability

Adaptation to local context was an important aspect of successful change in a number of initiatives. This was particularly true for national projects that engaged local stakeholders or involved minority groups such as Indigenous populations. Adaptability was often presented as a pragmatic, necessary component of implementation and hence an important lever to change.

5. Context

Contextual factors moderated how and why programs progressed. Four main sub-themes were identified: evolution; finances/resources; healthcare system, political context and priorities; and access to influence.

5.1. Evolution

This theme captures the lengthy development time of most policies. Several informants noted that their program had evolved from prior programs or was part of an ongoing change process. In some cases, having a natural history of change or similar initiatives in the past was helpful in gaining support for a new program. Some informants involved in quality of care initiatives noted how progress had been made in some cancer types, namely breast cancer, but not others. Such differences could spur on change and provide a template for success.

The evolution of a policy did not stop once established. Ongoing changes were often made in recognition of limitations in the original policy or the need to be responsive to new developments in clinical practice, new evidence, technological advances or resource availability.

5.2. Finances and resources

Financial and resource factors were important at a global and local level. At the global level, some informants identified how the global financial crisis had variable impacts on their cancer policy. For some, the crisis made projects difficult as funding and resources became scarce. However, for the Australian regional cancer centre policy, the federal government's response to the crisis – to stimulate the economy by increasing infrastructure spending –supported the development of this policy.

At a local level, financial and resource issues were important in determining whether and how programs operated in different contexts. In an example from New Zealand, funding issues were perceived to have delayed the bowel screening program progressing from pilot to full implementation. Rapid change could be difficult at a national level due to funding limitations, so some informants described engaging with 'willing partners' first. Adapting

programs to address resource limitations was also noted, linking with the adaptability theme.

5.3. Healthcare system, political context and policy priorities

Healthcare systems such as public and private health sectors, political contexts such as federal and state actors, and current policy priorities were important contextual factors.

5.3.1. Healthcare system

Structural and operational aspects of healthcare systems impacted cancer policies. Structurally, health systems with public and private providers complicated policy design and evaluation. How healthcare systems were organised also influenced clinician attitudes and behaviour. For example, one informant noted that GPs acting as 'gatekeepers' might avoid referring patients to prevent overburdening hospitals. These attitudes could be challenging when introducing change.

While a lack of regulation was perceived to make change difficult, redesign in other areas of the health system, or internationally, could be levers for change. For example, in Denmark centralising cancer surgical services was perceived to be relatively straightforward, in part because of other structural changes to health service delivery occurring at the same time.

5.3.2. Political context

Structural elements of political systems, such as the federated system of government in Canada and Australia, were particularly important in explaining the kind of policies proposed. In the Australian regional cancer centre policy, change at the federal level meant only certain policies (capital funding) were feasible. Some informants also noted issues if engaging with politicians or government officials close to or after elections, which could lead to reduced policy support. However, political drive was also important to initiating programs, even if this support varied over time.

5.3.3. Policy priorities

Cancer policies were developed and implemented in the context of other policies, including cancer-specific, general health, and non-health policies. Informants noted how policy priorities, such as cancer plans, could facilitate change. Another feature of the policy landscape was a focus on engaging consumers in healthcare and implementing patient-centred care. Informants perceived that consumer engagement and involvement was likely to be an important factor in promoting policy change in the future.

5.4. Access to influence

The final context theme links the smaller population of a country with an increased ease of access to political or other stakeholders. Access and links to decision-makers in smaller contexts, such as in New Zealand and Demark, led to relationships which could influence policy development and change. Also, as noted in the advocacy theme, organisations with a large membership-base in these contexts could be powerful lobby groups.

6. Discussion

This study explored levers and challenges to generating and implementing large-scale, cancer-related health service policies in five countries. Policymaking was complex, with multiple actors, processes and influencing factors: as one Scottish informant noted, "it's multifactorial as to why…" Themes highlighted influential mechanisms for change with both positive and challenging aspects, which were impacted by contextual factors. While research evidence was used to draw attention to an issue, inform program proposals, persuade stakeholders or evaluate policies, research evidence by itself was insufficient for producing new policies or ensuring implementation. Other important mechanisms included engagement and collaboration with consumers, and more importantly with clinicians, and the adaptability of policies to local circumstances. The need for adaptability of policies highlights the importance of contextual factors in policymaking, including the evolutionary nature of policy change and political, resource and health system factors. Our findings extend previous research into evidence-based policymaking [32] by examining more broad-level factors that may impact the policymaking process.

Consistent with previous literature, informants identified several types and forms of evidence helpful to making policy-related decisions [33–35], with international comparisons, evaluation data and modelling, rather than evidence from RCTs, the most common. Similar levers were identified for cancer services policy in the UK [21], and a US study has shown the growing use of cancer performance measures, such as cancer mortality, economic impact and patients' experiences, in informing health policy [36]. Thus, although RCTs have been proposed as an ideal form of evidence to inform policy [5], they did not feature strongly in our study. This may be due to practical or ethical difficulties in testing policy-level RCTs. Previous research has also found a variety of types of evidence are used during different stages of the policymaking process and that this depends on contextual factors such as political influences and stakeholders involved in decision-making [37], and the policy issue being addressed [38]. Given our small sample of key informants and diversity of initiatives, it was unclear which were the most influential types of evidence in each policy at each stage. However, international comparisons of cancer outcomes or practices appeared to be particularly effective in the policy formation stage. Thus, our data confirm the potential for international research programs such as the ICBP to influence cancer policy.

Although research evidence was an important feature of the policymaking process, we found a multitude of factors influenced policy development and implementation. Many of these were shared across countries, particularly the importance of contextual factors, stakeholder engagement and collaboration, and program adaptability. These findings are similar to results from two reviews examining the diffusion, dissemination and implementation of innovations in healthcare [39], and factors influencing large-system transformation and healthcare reform [40]. Similar to our findings, these reviews identified that change was complex and that policy context, adaptation and engagement of consumers and clinicians in the change process were important levers to reform [39,40].

The policymaking processes identified in our study also resonate with several political science theories [19,41]. For example, we found that many policies developed as a result of small, incremental changes over time (evolution theme), echoing the ideas of Lindblom and Heclo [16,17]. Consistent with the multiple streams theory [18], a policy window was created in Australia by convergence of the global financial crisis, government response to this crisis, strong advocacy and evidence of disparities for rural cancer patients. Others have similarly identified a period of increased policy action in rural health in Australia from 2007 [42,43].

These theories are useful in placing results in the broader policymaking literature, but we also identified factors of particular importance for cancer policy more specifically. Clinician engagement in particular was important in both policy development and implementation yet was also a major challenge. Across many of the program mechanism sub-themes, clinicians were key: in advocacy, leadership and stakeholder collaboration. However, in line with others [21,44–47], we found that engaging clinicians could be time consuming and clinical culture could act as a barrier when introducing new ways of working. Interventions to improve the uptake of evidence into clinical practice could be helpful in pol-

icy implementation [48]. A review of 67 systematic reviews found action and monitoring (e.g. audit and feedback), or educational and informational interventions, were more effective than persuasive (e.g. social leaders) techniques at improving evidence translation into clinical practice [49]. Whether these interventions are effective in helping to implement new policies into clinical practice is uncertain, particularly when our findings, and those of others [21,50], suggest that persuasion techniques like stakeholder engagement and use of clinical leaders are important in facilitating health reform. Further research is warranted to understand and address challenges in policymaking with health professionals.

Other cancer-relevant findings were the role of consumers and policy context. Consumer involvement was considered an important lever, with cancer perceived to have relatively strong public interest. Others have suggested that grassroots advocacy from the public, including through the media, may be a more powerful lever than researcher–policymaker collaboration [51]. While our data found this to be true in some settings, such as the influence of media stories regarding delayed cancer diagnoses and formation of the Danish patient pathways policy, when the cancer type was rare and organised consumer advocacy groups uncommon, such strategies may not be feasible. Regarding policy context, cancer was often noted as an important policy area for governments across countries. Informants also noted the influence of cancer planning policy documents in directing cancer care priorities. This special status of cancer in health policy, and the growing prevalence of cancer diagnoses in high-income countries, will likely ensure cancer remains high on government agendas.

7. Strengths and limitations

A broad range of policies were discussed with informants from five different countries. Most informants held senior roles, were heavily involved in policy development and/or implementation and provided ample detail on these processes. Methodological strengths include the explicit use of a realist paradigm for thematic data analysis and validity checks of findings with key informants.

Limitations include the relatively small number of informants interviewed from each country. This limits the perspectives of events: different informants may have had different views on levers and challenges, though there were similarities between informants commenting on the same program. Informants may have censored responses they or their employers did not want published and nominated other participants with similar views to themselves, potentially limiting the reliability and diversity of informant perspectives. In addition, although some informants participated in political processes, the lack of government policymaker perspectives means other forces influencing policy decisions, such as political relationships and structure, are likely to be missed [51,52]. We also did not explore the potential influence of the private sector, such as lobbying and donations by private health insurers, pharmaceutical or medical corporations. Generalisability is also limited due to the select number of initiatives examined in high-income countries. Furthermore, policies in our study targeted different aspects of cancer care, leading to uncertainty as to whether observed differences between countries and programs were due to local policy processes or the focus area of the initiative. Further research is required to explore the perspectives of a greater number and diversity of informants including government officials, to explore policy-specific development and implementation challenges across countries, and to examine cancer policymaking in low and middle-income countries as well as countries with larger populations and different health systems, to determine whether the themes identified in the current study are applicable in these broader settings.

8. Conclusion

This study identified how research evidence influenced cancer health-service policy development and implementation. While evidence was important, it was insufficient for policy change. When forming and implementing new health service policies in cancer care, research evidence should be considered alongside factors such as policy context, leadership, advocacy and clinical engagement. Understanding and harnessing these factors could be useful in future efforts to influence policy change.

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Conflict of interest

The authors declare no conflicts of interest.

CRediT authorship contribution statement

Rebecca J. Bergin: Data curation, Formal analysis, Investigation, Methodology, Project administration, Writing - original draft, Writing - review & editing. **Jon Emery:** Conceptualization, Data curation, Formal analysis, Methodology, Supervision, Validation, Writing - review & editing. **Ruth Bollard:** Conceptualization, Data curation, Formal analysis, Methodology, Supervision, Validation, Writing - review & editing. **Victoria White:** Data curation, Formal analysis, Methodology, Supervision, Validation, Writing - review & editing.

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