Celebrating 10 years of the International Cancer Benchmarking Partnership

Acknowledgements

This report is produced by Heather Wilson, Cancer Research UK.

Lucie Hooper and Samantha Harrison helped identify stakeholders and gave comments on a late draft. Sara Hiom and Heather Bryant also offered comments on the paper. The Cancer Research UK Infographics team produced the final version of the paper.

Thank you to everyone who generously gave their time to be interviewed, without whom this report could not have been produced. Special thanks to those who aided development and peer reviewed.

Errors and omissions remain the responsibility of the author alone.

List of Acronyms

ABC- Awareness and Beliefs about Cancer measure
ACE- Accelerate, Coordinate, Evaluate Programme
CT- Computed tomography
ICBP- The International Cancer Benchmarking Partnership
MDC- Multi-Disciplinary Centre
MDT- Multi-Disciplinary Team
PCP- Primary Care Practitioner
PET-CT- Positron emission tomography - computed tomography
## Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Foreword</td>
<td>1</td>
</tr>
<tr>
<td>Timeline of ICBP research</td>
<td>2</td>
</tr>
<tr>
<td>5 Key Impacts</td>
<td>3</td>
</tr>
<tr>
<td>Executive Summary</td>
<td>4</td>
</tr>
<tr>
<td>Introduction</td>
<td>6</td>
</tr>
<tr>
<td>Methods</td>
<td>7</td>
</tr>
<tr>
<td>Scoping: Document Review</td>
<td>7</td>
</tr>
<tr>
<td>Interviews</td>
<td>7</td>
</tr>
<tr>
<td>Analysis</td>
<td>7</td>
</tr>
<tr>
<td>Considerations</td>
<td>7</td>
</tr>
<tr>
<td>Findings</td>
<td>7</td>
</tr>
<tr>
<td>Policy Impacts</td>
<td>7</td>
</tr>
<tr>
<td>Cancer Plans</td>
<td>8</td>
</tr>
<tr>
<td>Policy into Practice</td>
<td>12</td>
</tr>
<tr>
<td>Public Awareness Campaigns</td>
<td>13</td>
</tr>
<tr>
<td>Clinical Impacts</td>
<td>14</td>
</tr>
<tr>
<td>Registry Practices</td>
<td>17</td>
</tr>
<tr>
<td>International Collaboration</td>
<td>19</td>
</tr>
<tr>
<td>Funding</td>
<td>20</td>
</tr>
<tr>
<td>Discussion</td>
<td>21</td>
</tr>
<tr>
<td>Conclusions, ongoing and future research</td>
<td>23</td>
</tr>
<tr>
<td>Appendix 1: Contributors</td>
<td>24</td>
</tr>
<tr>
<td>References</td>
<td>25</td>
</tr>
</tbody>
</table>
Foreword

The emergence of international cancer surveillance has provided new opportunities to compare population-level cancer trends and explore the reasons behind changes over time. This has provided researchers, clinicians and policymakers the ability to better understand population health and create and implement interventions to greatly benefit patient outcomes. The International Cancer Benchmarking Partnership’s (ICBP) aims and subsequent recommendations, have generated new questions and activities across the cancer research community, a clear testament to the immense value of this collaborative partnership.

While there are existing epidemiological studies comparing cancer survival on a wide international scale, the ICBP is the first research collaboration of its kind to compare high income countries, with similar healthcare systems and high-quality cancer registries. Since its inception ICBP has demonstrated how it is distinguished from other survival studies; it has brought together countries with similar health systems and expenditure, with multidisciplinary participants to explore cancer survival differences\(^1\), and crucially to attempt to explain those observed differences.

The careful selection of participating countries and close working with researchers, clinicians and cancer service leaders enables the examination of data across the board to be detailed and thorough, paving the way for meaningful comparisons to be made. The ICBP is an exemplar for further international studies to learn from and this impact report demonstrates the ways the research has influenced policy and clinical practice. As we move forward to the next phase of ICBP we expect further improvements in the surveillance of cancer and a continued impact on cancer services globally.

Dr Heather Bryant

Chair ICBP
## Timeline of ICBP research

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009</td>
<td>ICBP established. Participating Countries: Australia, Canada, Denmark, Norway, Sweden, UK and Northern Ireland.</td>
</tr>
<tr>
<td>2012</td>
<td>Stage at diagnosis and ovarian cancer survival: Evidence from the International Cancer Benchmarking Partnership, Gynaecologic oncology</td>
</tr>
<tr>
<td>2013</td>
<td>An international measure of awareness and beliefs about cancer: development and testing of the ABC, BMJ Open</td>
</tr>
<tr>
<td>2015</td>
<td>Lung cancer survival and stage at diagnosis in Australia, Canada, Denmark, Norway, Sweden and the UK: a population-based study, 2004–2007. Thorax</td>
</tr>
<tr>
<td>2016</td>
<td>Stage at diagnosis and colorectal cancer survival in six high-income countries: A population-based study of patients diagnosed during 2000 – 2007, Acta-oncologica</td>
</tr>
<tr>
<td>2017</td>
<td>Breast cancer survival and stage at diagnosis in Australia, Canada, Denmark, Norway, Sweden and the UK, 2000-2007: a population-based study, British Journal of Cancer</td>
</tr>
<tr>
<td>2018</td>
<td>The International Cancer Benchmarking Partnership: An international collaboration to inform cancer policy in Australia, Canada, Denmark, Norway, Sweden and the United Kingdom, Health Policy</td>
</tr>
<tr>
<td>2019</td>
<td>Differences in cancer awareness and beliefs between Australia, Canada, Denmark, Norway, Sweden and the UK (the International Cancer Benchmarking Partnership): do they contribute to differences in cancer survival? British Journal of Cancer</td>
</tr>
<tr>
<td>2014</td>
<td>Development of a survey instrument to investigate the primary care factors related to differences in cancer diagnosis between international jurisdictions, BMC Family Practice</td>
</tr>
<tr>
<td>2015</td>
<td>How might healthcare systems influence speed of cancer diagnosis: A narrative review, Social Science and Medicine</td>
</tr>
<tr>
<td>2016</td>
<td>Explaining variation in cancer survival between 11 jurisdictions in the International Cancer Benchmarking Partnership: a primary care vignette survey, BMJ</td>
</tr>
<tr>
<td>2017</td>
<td>An investigation of routes to cancer diagnosis in 10 international jurisdictions, as part of the International Cancer Benchmarking Partnership: survey development and implementation, BMJ Open</td>
</tr>
<tr>
<td>2018</td>
<td>Investigation of the international comparability of population-based routine hospital data set derived comorbidity scores for patients with lung cancer, Thorax</td>
</tr>
<tr>
<td>2019</td>
<td>Diagnostic routes and time intervals for patients with colorectal cancer in 10 international jurisdictions; findings from a cross- sectional study from the International Cancer Benchmarking Partnership (ICBP), BMJ open</td>
</tr>
<tr>
<td>2019</td>
<td>Impact of variation in cancer registration practice on observed international cancer survival differences between International Cancer Benchmarking Partnership (ICBP) jurisdictions, Cancer Epidemiology</td>
</tr>
</tbody>
</table>
5 Key Impacts

1. Global focus on Early Diagnosis

   The ICBP produced the first international cancer survival paper to benchmark stage at diagnosis and survival by stage\textsuperscript{16}. The ICBP has been a major contributor to the now global focus on early diagnosis. There have been several global impacts, primarily focused on early diagnosis and a more standardised approach to patient’s cancer care pathways.

2. National health reforms in Denmark

   Danish reforms to cancer services and the implementation of cancer care pathways were informed by ICBP evidence, leading to the subsequent adoption of optimal cancer pathways in three further ICBP countries.

3. Successful implementation of public awareness campaigns

   For patients and health professionals alike, the ICBP has driven the development of educational programmes and public awareness campaigns to increase presentation to primary care practitioners (PCPs) and improve PCPs recognition of symptoms. The paper demonstrated more than just limited awareness of symptoms, but also identified that there were barriers to presentation that needed to be overcome.

4. Improvements in cancer registry practices

   The ICBP has highlighted the value of and need for high-quality, international registry data that is thorough, reliable and comparable. Consequently there have been established and ongoing improvements in cancer registry practices. Efforts continue to implement more efficient and consistent methods of data collection.

5. Successful funding for new initiatives

   Identifying differences in survival rates across the ICBP countries stimulated important forums of discussion around cancer outcomes. This led to funding being secured for new initiatives, enabling further research to understand how improvements in cancer services could be made.
Executive Summary

The International Cancer Benchmarking Partnership (ICBP) is a unique and innovative global collaboration of clinicians, academics, data experts and policymakers. It is the first of its kind seeking to quantify international differences in cancer survival and to explore factors that could be contributing towards these observed survival differences.

This report tracks the international impacts of the ICBP since 2009 with a specific focus on Modules 1-3 in Phase 1, as the research findings from these papers have had time to be embedded in policy and practice. The report considers how ICBP findings have influenced areas such as policy, clinical practice and cancer data quality. It also examines the development of further initiatives arising due to the ICBP’s work, essentially creating a secondary wave of impact.

Document review of the ICBP published papers and national cancer plans allowed identification of the areas of interest to be selected for further impact scoping. Interviews were then conducted with twenty-nine stakeholders (Appendix 1) relevant to the uptake of the ICBP research.

Policy and Cancer Plans:
All participating countries referenced the ICBP in their national cancer plans or strategies [1-14]. This demonstrates the relevance of the research delivered by the ICBP and the commitment countries have made to attaining international standards.

Registry and Data Practices:
The ICBP programme demanded improvements in data quality and comprehensiveness in data collection and consistency in registry practices. Registry practices have also improved across the board with some registries utilising up to 150 pieces of data to complete an individual cancer registration.

Clinical Impact:
Stakeholder interviews and policy documents demonstrated that several updates and reviews in clinical guidance were informed by ICBP evidence. The most notable example has been the extensive national reform seen in Denmark.

Campaigns:
The ICBP study, ‘Differences in cancer awareness and beliefs’ demonstrated international variations in the general public’s perceived barriers to visiting their GP and a low awareness of age-related risk across the board. This paper has been cited over 100 times and the findings stimulated the development of multiple international public awareness campaigns.

Funding and Political Impacts:
An overarching impact of the ICBP was the political interest in making direct comparisons between countries in terms of cancer outcomes. For the best performing countries this exemplified where cancer services seemed to be effective. For the worst performing countries, the publications delivered a key message, that efforts must be made to close the gap in survival. Such political pressure aided the securement of financial investment for a variety of areas within cancer services.
Lessons for the future

The ICBP enhances the evidence base around cancer survival and continues to aid cancer patients. The partnership demands resources and time from participating jurisdictions yet delivers high quality outputs and opportunities for unique improvements to global cancer services.

Phase 2 of the research programme looks to provide an updated survival benchmark and for the first time, with the inclusion of incidence and mortality data for an increased number of cancer sites: lung, colon, rectum, ovarian, oesophageal, liver, pancreatic and stomach. This is the current body of ongoing research and is more focused on diagnostics, access to treatments and the cancer patient journey. This paper will focus only on Modules 1-3, as these pieces of research have been published the longest and consequentially have had time to embed and produce measurable impacts to report on.

The ICBP will continue to contribute to the evidence base that will in turn develop improvements in cancer services. To do this successfully, it is important to understand the impact the ICBP has already had and build upon such learnings in the ongoing programme of research.

Many of the interviewees observed that they could disseminate ICBP findings more effectively in their own work than they do at present. This indicates the possible demand for the development of an effective communications strategy for individuals at local level to utilise. The work of the ICBP is ideal for local level engagement with health professionals, policymakers and clinicians. Through more effective dissemination of the ICBP’s research evidence, the programme would be able to better translate findings into practice. This may broaden the uptake of ICBP research and promote the wider impacts of the programme at local, national and international levels.

Aims and Objectives

This report describes immediate and secondary impacts of ICBP findings. Following the development of the ICBP, all participating countries have made bold commitments to improving cancer services at a national and international level.

This report does not attempt to detail all impacts of the ICBP in Phase 1. Instead this report draws on cancer plans, public awareness campaigns and oral evidence from key stakeholders, policymakers and opinion leaders involved in the delivery and facilitation of ICBP modules 1-3. For a full list of those interviewed, see Appendix 1.

The aim of this report is to outline key areas where the ICBP has had significant impact and consider how we can further increase and expand the impact ICBP research can have. There are considerable areas to explore and utilise as lessons learned for the ongoing programme of research and similarly to raise the profile of current impacts. 2019 marks the ten-year anniversary of the ICBP, an ideal time to reflect on the research impacts this partnership has encouraged in real world settings.
Introduction

Background

Since its beginning, the ICBP has employed a wide range of approaches to deliver high quality and policy-relevant findings. The research programme is split into two phases. The first phase studied 1- year, and 5-year conditional survival for breast, lung, colon, rectal and ovarian cancer. The subsequent research modules in Phase 1 focused on different parts of the cancer pathway, from public awareness of signs and symptoms, to Primary Care Practitioner (PCP) readiness to refer and measuring timeliness across the patient pathway. Phase 2 expanded to include liver, pancreatic, oesophageal and stomach cancer, but did not continue to collect data for breast cancer as survival was found to be consistently high, with less room for improvement across ICBP countries. Phase 2 also collects data for incidence and mortality, enabling a more comprehensive picture of population health trends to be established.

This paper will focus only on Phase 1 Modules 1-3, as these pieces of research have been published the longest and consequentially there are measurable impacts. A brief overview of all Phase 1 modules is included below:

- **Module 1** looked to provide a detailed, international benchmark for cancer survival, stage at diagnosis and survival by stage at diagnosis. An analysis of 2.4 million cancer patient records explored survival between 1995 and 2007. The main findings from the research found that:
  
  i. Denmark and the UK had lower survival, Norway intermediate survival, whilst survival was persistently higher in Australia, Canada and Sweden.

  ii. Further research on stage at diagnosis indicated that both early diagnosis and access to optimal treatment were likely to play a role in international survival variation, with different explanations for different cancers. There is some evidence of later stage diagnosis in the UK contributing to lower survival compared to other countries, notably for lung and colorectal cancer.

- **Module 2** found that awareness of cancer risk increasing with age was lower in the UK, Canada and Australia and that barriers to symptomatic presentation were highest in the UK, with patients being particularly concerned about wasting the doctors time.

- **Module 3** found a correlation between primary care’s readiness to investigate or refer to secondary care and cancer survival rates across jurisdictions.

- **Module 4** explores variation in time intervals from first symptom until diagnosis and treatment, identifying differences between jurisdictions that may affect the outcomes of patients with suspected cancer.

- **Module 5** investigates factors that may impact short term survival such as differences in cancer registry practices and the impact of comorbidities.
**Methods**

Scoping: Document Review

The methodology for this report firstly composed of a document review of Modules 1-3 published ICBP papers. The review enabled identification of countries’ performance within each module and allowed the recommendations for each country to be collated. These informed the development of an informal questionnaire for interviews with individuals from that jurisdiction.

Following the formulation of questions for each jurisdiction, a list of potential candidates for interviews was collated. This list included programme board members that are engaged with the ICBP at present, or at the time when Modules 1-3 research was being embedded into cancer services.

Interviews

Semi-structured interviews were conducted using an informal questionnaire. Conversations organically included recommendations for other useful contacts. A snowball approach was taken for follow up areas. Notes were taken during the interviews and were then transcribed.

Analysis

Analysis of the transcribed interview notes, enabled themes and patterns to be drawn out which formulated the key impacts explored in this report. Quotes were ascertained from interviewees and are used throughout this report. The main themes formulate the sections of this report and are identified as the top five impacts of the ICBP.

Considerations

The research was conducted in a transparent manner and no recording of the interviews took place. Field notes were taken and transcribed, but these have been anonymised, unless otherwise agreed with the interviewee. Consent was ascertained from individuals regarding the use of direct quotations.

**Findings**

Policy Impacts

The widespread use of ICBP evidence within cancer plans outlines the value of the ICBP and the commitment of participating jurisdictions in driving improvements both nationally and internationally. This section will discuss the cancer plans and their value in driving an international approach to cancer services.

*…The impact of the ICBP has been perhaps greater in the policy sphere, but those core pieces of policy work have trickled down to clinical practice, and this will probably happen increasingly over time…*

Dr John Butler, ICBP Lead Clinical Advisor and gynaecological oncology surgeon, The Royal Marsden NHS Trust Foundation

In England, the ICBP contributed to an evidence base for the implementation of the Accelerate, Coordinate, Evaluate (ACE) programme. The ACE programme demanded policy measures stressing the importance of earlier and more timely diagnosis, and the fundamental need for a focus on secondary care. Such policy work successfully demonstrated the need for funding and consequentially the initial pilots of ACE were brought into practice. Further details of this programme are detailed in the clinical impacts section of this report.

In addition, there has been incorporation of ICBP evidence in the drive for improved workforce in jurisdictions such as Canada and Wales, to aid the delivery of diagnostic services. ICBP research also demonstrated that a delay in patient pathways was a major factor in poor survival outcomes. For example, the observed lower survival rates in Denmark and the observed lower lung cancer survival rates in Alberta\(^23\) when compared to the other Canadian jurisdictions. As a result of this, there has been work across the board to reduce national wait times.
Cancer Plans

For all jurisdictions involved in the ICBP, there have been clear and ambitious commitments to perform at a consistently high international level. The ICBP has been used as an evidence base in multiple cancer plans and strategies, including direct references in the plans of Scotland, Ontario, Norway, England, Wales and Denmark.

**Ontario: Ontario Cancer Plan IV 2015-2019**

Ontario’s cancer plan specifically references Cancer Care Ontario’s participation in the ICBP. The Cancer plan utilises the survival publication in the *Lancet* as a positive reinforcer that Ontario remains one of the top performing jurisdictions within the ICBP partnership. This reinforces a positive message around the achievements of current services and as motivation to remain one of the top performing Canadian jurisdictions. This knowledge has become embedded in the delivery of services and maintains a core driver to remain at the top of the survival benchmarking:

…”These findings really delivered a positive message that Ontario was doing some great work and that received pick up from politicians, and clinicians… it became a motivator, not only for those wanting to catch up with Ontario, but also for Ontario to consider why they were doing so well and how to maintain that…”

Dr Heather Bryant, Vice President Cancer Control at Canadian Partnership Against Cancer

**British Columbia: Strategic Plan 2013**

In British Columbia cancer services perform well and the cancer plan is extremely concise, also emphasising the focus on developing international affiliations. Partnerships are central to British Columbia’s strategy and the plan details a commitment to establish and formalize networks between similar Canadian organisations, which would position British Columbia as a leader in the field.

Dr Anthony Fields, former Vice President, Cancer Care, Alberta Health Services

**Manitoba: 2016-2021 Manitoba Cancer Plan**

Similarly, Manitoba’s cancer plan does not directly reference the ICBP, but has a consistent emphasis on international research and standards within cancer services.
New South Wales: NSW Cancer Plan, A statewide plan for lessening the impact of cancers in NSW 2016.

The New South Wales (NSW) Cancer Plan acknowledges the jurisdiction’s strong position as a national and international leader in cancer services, with reference to referral pathways. The plan directly references international benchmarking as a key element to improving NSW’s capacity to report on the quality of the cancer system. The survival data from the ICBP has been directly referenced in the overarching impact of cancer in NSW, demonstrating the use of ICBP data to contextualise the reality of cancer cases in the state.


In Victoria, the cancer plan details the state’s commitment to remaining at the forefront of international approaches to improve cancer outcomes. The cancer plan has a section dedicated to the main findings of ICBP research for Victoria and adds that Victoria has expanded all the programmes studies to explore regional differences between metropolitan and regional areas. The readiness of PCPs to refer is also demonstrated as a key evidence base for improvements in the jurisdiction. The cancer plan is underpinned by ICBP evidence and this is a strong impact. The expansion of ICBP research demonstrates the value of the ICBP programme and the clear positive developments that have occurred in Victoria as a result.


Norway’s cancer plan mentions it is positioned behind Sweden, Canada and Australia for one-year survival in lung cancer and a new focus on this cancer site. The plan details key objectives and broadly confirms that cancer patients in Norway shall be offered diagnosis, investigation, treatment, follow-up and rehabilitation at a high international level. This is core to Norway’s cancer plan and ongoing work, that the international ethos covers all areas, not just research or the survival benchmark:

…The ICBP, is an indicator of good work… it has led to a demand for international efforts on more than just survival and the work as a result of that benchmark… the other modules have also created a great amount of ongoing discussion which is in the cancer plan…

Ole Alexander Opdalshei, Norwegian Cancer Society


The first national cancer strategy was launched by Swedish Government in 2009, and does not specifically detail the ICBP nor the international drive for improvement aside from continued efforts for international research. This is unsurprising considering Sweden’s existing high survival rates and their consistent high ranking within the benchmarking. The cancer plan does detail plans by government to standardise pathways and improve Sweden’s renowned long wait times. Such reforms were driven by an evidence base that did include ICBP publications:

…Sweden was doing well, so the survival benchmark led to little change in Sweden, it did raise awareness of good performance and was seen as high-quality research
Module 2 did initiate discussion on the awareness on symptoms. Extensive waiting times led to SALAR and the government introducing standardized care pathways that were based on Denmark’s model. For Sweden the healthcare reforms were the main development in the cancer plan in 2009…

Gunilla Gunnarsson, Coordinator of Cancer Strategy Department of Health and Social Care, Swedish Association of Local Authorities and Regions.


The Cancer Strategy for England demonstrates the drive to remain one of the world’s leading cancer care providers. The bold name of England’s plan indicates the significant commitment to ensuring England remains at the forefront of the cancer care leaders. The plan details at length a commitment to early diagnosis, with the implementation of rapid diagnostic and assessment centres.

…The last cancer plan acknowledged the need for international benchmarking and stated that the UK’s survival continued to be poor, but really this plan detailed why survival was poor, it was reduced workforce and a need for earlier diagnosis… in 2011, the cancer strategy’s use of figures comparing the deaths to other countries really hit home, that was more of a driver than any percentage figure could be…

Professor Sir Mike Richards, Former National Cancer Director, Department of Health.

The plan demonstrated the need for education and symptom awareness amongst both the public and PCPs. This is covered more thoroughly later in this report, although it is important to state that the cancer plans progress report\(^\text{17}\) does emphasise the success of the Be Clear on Cancer Campaign and the roll out of further training for PCPs.

Northern Ireland: National Cancer Strategy, Northern Ireland\(^\text{11}\).

Northern Ireland has seen the international element of cancer care play into their national cancer strategy on a far greater level than previously seen. Throughout the strategy it is demonstrated that a commitment to maintaining international standards is highly important to the Northern Irish focus. This includes participation in international trials, international genomics and the dedication to early diagnosis. The plan pledges to see patients referred to specific diagnostic testing more readily, to ensure cancer patients are treated to the best possible international standards.

Wales: Cancer Delivery Plan for Wales 2016-2020. The highest standard of care for everyone with cancer\(^\text{12}\).

The Welsh cancer plan considers the ability of the health service to ‘absorb anticipated future levels of demand’, a strategy to cope with limited capacity is detailed, stating the need to uptake learnings from international practice. The report acknowledges that Wales is lower ranking within international comparators for survival and recognises that early diagnosis is the key to improvement. The plan is a direct response to ICBP findings and a commitment to improvement, of which change has already been implemented in practice:

…The ICBP findings provided multiple indicators contributing to poor outcomes in
Wales compared to all other jurisdictions and it was clear that changes to the service needed to be made. This was built into the cancer delivery plan, but also led to further research to make sure patient pathways were more appropriately measured and improved. There was considerable focus in Wales on where patients point of suspicion arose from and their route into the system showing considerable patients outside the accelerated cancer pathways where many were emergency admissions with late stage diagnoses. The plan really aimed to combat that…

Dr Gareth Davies, Associate Medical Director Welsh Cancer Network

Scotland: Beating cancer: Ambition and Action\textsuperscript{13}.

An ambition of the Scottish Cancer Plan is to ‘become one of the highest performing cancer healthcare systems internationally.’ Such a statement unequivocally exhibits that the Scottish Government deems the role of international cancer care as a worthwhile and highly motivating endeavour. Interestingly, this statement is followed by the data section of the cancer plan, highlighting the need for complete and improved data sharing, an element of which has been a core impact of the ICBP’s work. The report details the ICBP’s exploration of the interface between primary and secondary care and the possible prevention of individuals referral. At ground level, efforts are being made to explore this, but workforce capacity is a limiting factor requiring change.

Denmark: National Cancer Plan II Denmark\textsuperscript{14}.

In 2004 the Danish Prime Minister announced that a new National Cancer Plan would be introduced, with the primary aim of bringing cancer services in line with the highest performing countries. The cancer plan focused on reforms to the cancer patient pathway, with specific emphasis on early diagnosis and the role of primary care. The cancer plan committed to further improving Danish registry practices to ensure that data quality would have international comparability. Similar to multiple other jurisdictions, the plan outlines a national drive to partake in international research.
Policy into Practice

The utilisation of ICBP evidence in cancer plans demonstrates the wide uptake and engagement with the research findings. Further, it demonstrates the commitment of countries to maintain their standards as some of the best cancer services in the world. For countries not performing so well, the ICBP became central to improvements and measures to ensure the gap between the best and worst performing countries continues to be closed.

**Denmark Case Study**

In many of the interviews conducted, the impact of Denmark’s cancer plan was a point of interest. Denmark had some of the lowest survival rates and consequently action was taken nationally to see much faster routes to diagnosis, through the implementation of improved referral practices, and streamlined and centralised patient pathways. In 2008-2009 Denmark was performing sub-optimally and so new health regions for cancer services were developed to reduce delays, thus setting the precedent for further implementation of policy into practice.

The main element of the Danish model detailed access to diagnostics. Following symptomatic presentation, patients are now referred by their PCP or emergency services, to a standardised cancer pathway. If a patient is referred to oncology services independently (i.e. not on a standardised pathway), the oncology triage department should then ensure the patient's referral is changed to involve a pathway. Following the initial, standardised diagnostic phases of the pathway, a multi-disciplinary team (MDT) is involved to confirm the diagnosis and to determine which treatment the patient should undergo.

The length of the initial diagnostic phase of the pathway correlates to the time-frame of the standardized pathway. Following the MDT discussions, a time-frame that relates to the patient’s treatment pathway is allocated. The timeframes are considered as goals for each stage of the pathway and are shorter than previous targets for suspected cancer referral following presentation.

Following the reforms, Denmark has seen the introduction of national monitoring of the pathways, which has been useful in highlighting not only the success of the changes, but also the new ability to monitor the capacity of the health service and workforce.

Elements of the ‘Danish model’ have been adopted in other ICBP countries policy and clinical practice including Sweden, Wales, England and Norway. Specifically, the Welsh cancer plan modelled the Danish ‘three-legged’ system of referral and a plan to introduce these into a pilot project. An MDT from Wales undertook a visit to Denmark to learn about the Danish model in practice and following that visit considered the implementation of similar practices into the Welsh cancer services. In practice, the pilot project saw the introduction of two rapid diagnostic centres in Wales following the securement of an innovation fund that was fundamentally won with the use of ICBP evidence. The two diagnostic centres have been running for over two years, with the treatment of over one thousand patients in each centre.
Public Awareness Campaigns

Another clear and recurring theme of ICBP research is the development and delivery of public awareness campaigns. The paper ‘Differences in cancer awareness and beliefs between Australia, Canada, Denmark, Norway, Sweden and the UK (the International Cancer Benchmarking Partnership): do they contribute to differences in cancer survival?15 had significant impact on the development of various public awareness campaigns. Since publication, this paper has been cited over 1,600 times.

The paper was the first study of its kind, examining the differences in cancer awareness and beliefs in high income countries. Although international variation for beliefs and attitudes to cancer was found across participating countries, there was no correlation between survival and awareness of cancer signs and symptoms. The Module 2 survey has since had requests for replication in the United States, Japan, Brazil, Spanish-speaking countries and Iran. This has seen the tool be translated into a range of languages, including Spanish and Farsi.

The ICBP Countries clearly saw the value of tackling the public’s perceived barriers to presenting to their PCP with symptoms. It was clear that patients with prominent barriers to presentation needed to be encouraged to access their PCP and to reduce patient anxiety. The UK had relatively poor survival and lower awareness of age as a risk factor associated with cancer, as well as more perceived barriers to presenting to PCPs, such as wasting doctors time.

…the Module 2 paper did not demonstrate a concrete link between survival and awareness and beliefs, perhaps more importantly it did demonstrate that patients in the UK worry and that was important to know, because if patients worry presenting to their PCP about possible cancer symptoms they likely worry about presenting for a whole host of concerns…

Professor Sir Mike Richards, Former National Cancer Director, Department of Health.

It was clear that patients needed both education and encouragement to visit their PCP and this presented opportunity to break down barriers for multiple patient groups across all cancer sites. In 2011 the UK launched the ‘Be Clear on Cancer’ campaign, aiming to raise public awareness of the signs and symptoms of cancer and encourage attendance to their PCP without delay. ‘Be Clear on Cancer’ utilised the ICBP as a core evidence base. The campaign was initially a partnership between the Department of Health and Cancer Research UK, it is now a collaboration between Public Health England, the Department of Health, NHS England with some Cancer Research UK involvement. The campaign has seen the development of specific campaigns for bowel, lung, breast, oesophago-gastric, ovarian and kidney cancers. A breast cancer campaign was also run, aimed at women over 70 years following the ICBP identification that older women were a cohort less likely to present with symptoms.

The ‘Be Clear on Cancer’ campaign has generated considerable interest internationally, triggering the implementation of a similar campaign model in Wales. The campaign has also stimulated the development of a PCP training programme that aims to educate and promote the awareness of cancer symptoms alongside raising PCPs awareness of the publics presumed barriers to presenting. In Northern Ireland, public health awareness campaigns have incorporated ICBP evidence to ensure that the campaigns tackle perceived barriers to presenting with suspected cancer symptoms. In Denmark, there were several campaigns aiming to raise awareness of general cancer symptoms, as well as specific cancers with poorer outcomes, such as colorectal cancer. Similarly, there were campaigns run to target patient groups, such as elderly men whom were identified as less likely to attend the PCP.

Such campaigns were evidently needed and have been praised thoroughly by all interviewed in the development of this report. Interestingly it emerged that while the ICBP had stimulated many discussions around the need for campaigns, the
campaigns were unable to run in some countries, because of the limited capacity of cancer services:

…there are still discussions around running public awareness campaigns, but really there is concern that even if people presented earlier, we have a system that would not be able to cope with an influx of more patients…

Gunilla Gunnarsson, Coordinator of Cancer Strategy Department of Health and Social Care, Swedish Association of Local Authorities and Regions.

Many individuals acknowledged the benefits of efforts to raise public awareness of symptoms or encourage presentation to PCPs. However, there are global challenges in driving these campaigns because health systems and existing workforces have limited capacity to cope with an influx of patients requiring diagnostic testing. There was specific concern regarding the volume of patients that may present and the possibility the system would be unable to cope. For some jurisdictions, such as Norway, those concerns stimulated decisions to run alternative public awareness campaigns such as standardizing tobacco packaging, rather than running a campaign specifically focused on encouraging GP presentation. The resistance in running public awareness campaigns is attributed to workforce capacity for newly presenting patients. This is a threat to improved public engagement and the resulting impact upon early diagnosis.

The ICBP research contributed to an evidence base that resulted in multiple clinical impacts. Such clinical impacts have been relatively specific to geographical location and cancer site. It is apparent that ICBP evidence was used either alongside other work emerging at that time or as confirmation of discussions that were already happening between clinicians, service management and indeed politicians.

The clinical implications for all participating jurisdictions are mainly focused on early diagnosis and in many jurisdictions, particularly in Norway and Scotland. Discussions at senior level are now gaining traction regarding the need for PET-CT scanners to be more readily available in practice. While the interviewees discussed the need for improved diagnostic equipment, it is also considered that PET-CT scanners would drive better staging of cancers and therefore treatment.

The ICBP prompted an evaluation in Scotland into PCP’s direct access to CT scanners, the findings of which are reinforcing the drive for PET-CT to be more accessible. Similarly, in Australia and Canada discussions were stimulated around the improvement of diagnostic services in both rural and urban areas to ensure equity in cancer care throughout the pathway.

In England, the ICBP contributed evidence in the early stages of forming the ACE programme, an early diagnosis programme that supports the NHS outcome of ‘preventing people from dying prematurely.’ The ACE programme is currently running pilots for new diagnostic pathways for patients with ‘non-specific but concerning symptoms’ – the pathway incorporates a Multidisciplinary Diagnostic Centre (MDC). The aim of the pathway and the MDCs is to prevent patients with unclear symptoms from repeatedly visiting their PCP for further referrals and testing. Wave 2 of the pilot is now underway, which aims to test how feasible this referral route will be for NHS England - a recommendation outlined in The Independent Cancer Taskforce’s strategy.®
In the UK, the ICBP has had further clinical impact as an evidence for the National Institute of Clinical Excellence (NICE) and the development of NICE guidelines (NG12). The NICE guidelines outline appropriate investigations in primary care and the selection of individuals to refer for a specialist opinion.

In Canada, there have been considerable efforts to implement screening programs for cancers for which there is good evidence of the positive impact of screening. Lung screening has not yet been widely seen in Canada. However, there has been a pilot screening programme in Ontario for lung cancer that cited ICBP and supported the securement of funding for the programme. While there is not yet an established screening process, the pilot is an important milestone for Canadian cancer services. Canada further utilised ICBP evidence to secure funding to run a breast cancer day surgery pilot in Alberta which was successful and saw immediate roll out to other jurisdictions, without the need for an initial pilot.

Case Study: Alberta, Canada.

Alberta saw one of the greatest clinical impacts that occurred as a result of the ICBP’s survival findings. In Alberta, it was identified that lung cancer survival was the poorest out of the Canadian jurisdictions and this was attributed to poor, convoluted diagnostic pathways and access to diagnostic tests.

Clinicians, politicians and senior health leaders were quick to pick up on these findings and funding was secured for a new initiative to improve lung cancer survival, underpinned by ICBP evidence. This initiative was the simultaneous introduction of both a diagnostic pathway and two Rapid Access Clinics. In the development of both elements, the ICBP was used as a core piece of evidence in the development of the strategy and service mapping.

The pathway sees patients referred through either their PCP or from emergency presentation. If a patient is only identified following diagnostic testing in an emergency setting then the radiologist can directly flag a patient to the clinic, and the clinic practitioners can follow up with the A&E doctor or the PCP. Crucially, once identified after diagnostic testing, the patient is referred to a specialist practitioner. The patient is then under the care of the clinic and a multi-disciplinary team determines the course of treatment.

In Alberta patients were waiting for up to 180 days from symptom presentation to treatment. Today, the target is for patients...
to be seen within 30 days. In addition, patients previously would face waits of up to three weeks for biopsy, but now wait up to seven days. Patients are now only waiting on average seven to ten days for a PET-CT scan and a further five for the report to be reviewed by a senior clinician.

The incidence of lung cancer has increased, and this is directly attributed to the effectiveness of the Rapid Access Clinic. Patient anxiety has been reduced despite individuals often being overwhelmed at the speed of admittance and diagnosis. The success of the two clinics has driven expansion of workforce in both centres, in Calgary there are now three nurse practitioners and five doctors, whilst in Edmonton there are three nurse practitioners and seven doctors.

...The Rapid Access Clinic is part of a provincial-wide initiative in Alberta which has set standards in expediting diagnosis and treatment for those patients with suspected lung cancer. We have seen significant reductions in wait times from the patient’s first CT scan of suspicious lung malignancy to treatment decision. Nurse practitioners are well utilized in this program, triaging for the team, seeing patients independently in their own clinics, and having the opportunity to hopefully make a difference in the patient journey...

Nadine Strilchuk, Advanced Nurse Practitioner

On account of the formalized pathway and increased engagement of health professionals with patients, the volume of accessible data has increased. Data is collected more regularly throughout the patient pathway and consequentially is more thorough and accessible. In turn this has encouraged staging and registry practices, enabling learning for the registries for other cancer sites.

...The ICBP paper really drew attention to lung services and Alberta’s underperformance, it then became an interesting discussion whether this was solely because of clinical issues or could this be put down to registry and data issues… it was perhaps a combination of both, but we have seen a huge improvement in the clinical element of thoracic oncology and as a result of that an improvement in registry and data practice has also occurred...

Dr Alain Tremblay, Lead Clinician Rapid Access (Lung) Clinic

Run by Nurse Practitioners the clinic is a dynamic environment and seems to have a similar, collaborative nature that is reiterated across the ICBP. The clinic sees referral from emergency practitioners, PCPs and radiologists. This collaborative, multi-disciplinary approach has meant the clinic has become embedded in practice, setting a fantastic example for other jurisdictions to utilise the recommendations developed by the ICBP.
Registry Practices

Throughout the interviews conducted, it was highlighted that the improvements in data and registry practices were one of the fundamental impacts of the ICBP. Across all jurisdictions, the ICBP was a central driver in the need for improved data to successfully monitor and evaluate cancer care and survival outcomes across the board.

...The benchmarking process through ICBP encouraged the Victorian cancer registry into discussion and consequently we now have a better recording of stage, for many cancer sites. Overall ICBP interaction has had a significant effect on registry practices amongst partners...

Dr Bob Thomas, Chief Advisor on Cancer, Victoria State Department

The improvements in cancer data progressed over time, but fundamental changes to staging practices were driven by a need for comparable data. If one jurisdiction’s data practices were more advanced than another’s, the differences in survival were possibly being attributed to different registry practices\textsuperscript{19}. In all jurisdictions the ICBP highlighted where improved data was needed and demonstrated that the higher the quality of the data, the more detailed the recommendations for each country.

Jurisdictions have used the ICBP as an evidence base for improving registry practices and have utilised ICBP evidence to secure funding for such endeavours. For most jurisdictions, the improvements were focused on improving the quality and quantity of data to ascertain a clearer picture of the cancer cases within areas.

...We’ve seen major improvements in Northern Ireland’s cancer registry... comorbidities are now available in the register and these will facilitate outcome analysis which may be influenced by comorbidities...

Dr Anna Gavin, Director of the Northern Ireland Cancer Registry

Additional sources of data can include pathology, radiology and molecular reports. In Denmark, as in many of the jurisdictions, the data developments have utilised various data sources to build up a holistic overview of the ICBP cancer patient data. Registry experts can now utilise up to 150 separate pieces of data for one individual registration. England has seen perhaps the greatest progress in terms of registry improvements, with the ICBP underpinning the reforms that have occurred. Far more data is being logged, improving the picture of individual registrations for multiple registries and increased data items were stored and linked.

In addition to the very specific registry practices that have seen developments, there have also been changes to clinical coding practices. Healthcare services operate on the functionality and usefulness of data and many of the impacts of the ICBP have driven the uptake of improved data practices. For example, in the Rapid Access Lung Clinic in Alberta, there is more readily available data and consequently a far more complete picture on individuals care and clinic performance. This not only indicates the pivotal position that data and registry practices have within global cancer services, but equally highlights the impact of the ICBP in accelerating the modernisation of data practices. This has been demonstrated through the extent to which data can be used to improve services and instigate clinical change.
Case Study: England, United Kingdom

In England, the development of the ICBP raised awareness of the differences in registry practices across the country, and concerns were raised regarding the possible effects this variation could have on survival estimates. As a result, considerable efforts were made to standardise practices across England, ensuring that every patient had a consistent level of quality within their registration and subsequently a clear picture was developed for each region, and the country. At the time, England was operating as eight independent, regional registries that were using varied methods across the board. Each registry was also using different data sources to code, classify and register cancer patient’s data.

Since the development of the ICBP and the drive for a more thorough data picture, the eight individual registries have become one centralised registry and the eight entities are now drawn in as local offices. Similarly, the registry now uses over 170 healthcare providers, that vary from acute trusts to private providers. The process uses twelve data sources, including national screening data, patient surveys and cancer waiting times data in addition to the more traditional sources such as pathology, radiotherapy and molecular reports. There are now more than 500 local data systems. ICBP was one of the components that gave clarity to the inclusion criteria for the English cancer registry and raised awareness of the necessity of whole pathway data linking at record level.

Practice across England is now considerably more complete and useful for the successful delivery of more responsive cancer services. The improved quality of information collated has also increased the uses of the data. The information is now used to inform reports, further research, deliver effective clinical services while acting as a quality measure and provide up to date cancer statistics for the NHS and local authorities. For patients too, a visualisation tool utilises the data to display a clear picture of cancer trends in that area.

Another element of the improvements in registry practices include the advancements in stage data. In England, the staging data for multiple cancer sites is now beginning to become more uniformed and consistent throughout the registry process. This means that English cancer data is comprehensive and comparable.

… In England, there has been registry training to enable staging practices to be conducted by registry staff in addition to clinical teams. There are now more comprehensive processes and England has good staging data for a period of 3 years, for the majority of cancer sites...

Dr Jem Rashbass, National Director for Disease Registration and Cancer Analysis at Public Health England

England has seen an extensive transformation of registry practices and these improvements have continued to have impact on Phase 2 of the ICBP. For England, Phase 2 has seen the research body utilise the improved stage data, yet for countries that have not seen such modernisation, concerns exist regarding the comparability of data against England’s consistent and complete data by stage.
International Collaboration

The nature of the ICBP as a global partnership between clinicians, researchers, field experts and policymakers lends itself to a collaborative approach. It is evident that the international cooperation borne out of the ICBP is a major impact of the programme.

As explored, the adoption of the Danish model and the subsequent health reforms in countries such as Sweden, Norway, England and Wales are an excellent example of the international cohesive working that has occurred because of the ICBP. Such collaboration extends to the multiple conferences ICBP members have attended to present their research findings, and often the conferences offer a platform for knowledge sharing and professional networking.

ICBP research has been used to enhance collaboration both between countries national jurisdictions and across nations. In Canada the Canadian Partnership Against Cancer used the ICBP as a supporting evidence base allowing the fluid integration of networks to occur. In Scandinavia the Nordic Cancer Union have also seen uptake of ICBP evidence and again, the ICBP has been used as a further network of collaboration within similar countries.

Further research has been modelled on specific modules of the ICBP, leading to a replication of research tools. For example, the Module 2 ABC tool, which has been translated into multiple languages and used in in the United States, Japan, Brazil, South East Asia, Spanish-speaking countries, and soon, Iran.

...The ABC measurement tool has been picked up by other countries outside of the ICBP jurisdictions, and there are talks ongoing regarding the possible translation of the project into further languages...

Dr Kate Brain, Professor of Health Psychology, Cardiff University

The expansion of the ICBP is a credit to the high-quality policy research produced in Phase 1 and indeed the impacts of that research. It has been widely reflected in the interviews that the ICBP is a highly worthwhile programme, namely due to the unique cross-party nature of the research and the ultimate wider effects that occur.
Funding

It is clear from the previous sections of this report that there have been a wide variety of initiatives, healthcare reforms and improvements that have occurred either directly as a result of ICBP evidence or from a collective evidence base that included ICBP research. The nature of the programme and the direct comparison between jurisdiction’s survival gained the interest of a wider audience than many other healthcare studies. The interviewees included in this report discussed the political impact the publication of the overall survival paper had. The publication was a performance measure and raised political awareness of the countries’ position in the global setting.

For the countries with the highest survival, the pickup was positive for cancer services, with praise coming from senior policy-makers and political leaders. The possibility for strategic improvements established a political interest to ensure that these jurisdictions remained one of the top performers. For jurisdictions with lower survival, weight was given to campaigns and efforts to improve cancer services. It is clear to see that the ICBP survival benchmarking certainly raised awareness of the poor survival and the under-performance of national cancer services. The media interest in this publication was internationally widespread.

…the ICBP survival publication emphasised that the UK was ‘lagging behind other countries’ and these were powerful findings and statements the likes of which had not previously been so clear... The interest was widespread and really encouraged efforts to improve services…

Sara Hiom, Director of Early Diagnosis, Cancer Research UK

The evidence provided by the ICBP showed how cancer survival compared internationally, which was a strong driver and incentive for investment with the aim of ultimately improving cancer services. In the UK this led to the use of the ICBP as an evidence base to secure funding for a variety of new initiatives and public health campaigns. In Denmark, the political interest encouraged extensive healthcare reforms which were a significant investment. The reforms have been widely praised and the government is using the cancer care reforms as a specific example of healthcare improvements they have overseen in the run up to the next political elections. Efforts to model the Danish reforms have seen investment from other countries, demonstrating the level of interest from senior government bodies across the globe.

…Denmark has seen considerable changes in cancer services, namely patient pathways and as a result timeframe for diagnosis has been improved greatly. The efforts to improve Danish cancer survival by implementing cancer pathways were motivated by discussions at senior, political level

Ole Andersen, Danish Health and Medicines Authority, Copenhagen, Denmark

Early diagnosis remains the focus of policy efforts to improve cancer survival across the board. In some areas there is a lack of data surrounding treatment and diagnosis. Following Phase 1 research there has been growing pressure to improve the data around diagnostics, expand the diagnostic workforce and to see a reduction in the inequalities that exist in accessing diagnostic services. In Canada and Australia, geographical inequalities often lead to delays in diagnosis and because of the ICBP research, this remains a concern on the political agenda.
...Twenty years ago, people did not believe delays in diagnosis were the problem, it was a controversial statement, now the ICBP has demonstrated that early diagnosis is central to improved survival and it has garnered, political interest and crucially funding...

Professor Sir Mike Richards, Former National Cancer Director, Department of Health

The political interest in the ICBP remains a driving force for the programme, with reference to the expansion of the ICBP in Phase 2 and the recruitment of more jurisdictions, of which the financial investment has enabled an expansion of the programme. Similarly, it is important to consider that the investment in the ICBP is a worthwhile one that can drive equally viable outputs both internally to the jurisdictions, across countries and across the globe. The partnership exists because of collective funding from participating jurisdictions, this is a large commitment, which demonstrates the credibility of the partnership and exemplifies the growth that can occur from ICBP participation.

Discussion

This report presents an overview of the various impacts the ICBP has had over the past decade. The report is focused on Phase 1 of the partnership, specifically on modules 1-3, as these are the publications that have been embedded in cancer services globally. Drawing on cancer plans, national reports and testimony from twenty-nine interviews, it has established an extensive picture of the impacts the ICBP has had from improvements in registry practices to innovative nurse-led clinics.

One of the main objectives of this report was to identify the core areas of impact that the ICBP has had across the globe and to ascertain which elements of the programme were being successfully transferred into policy and practice. It was clear before embarking on this report that it would be challenging to pinpoint direct impacts from ICBP research. This is attributed to the frequent lack of direct referencing in overarching documentation and an inability to actively track research uptake due to some research papers not being published as open access. Instead, it became apparent in the early stages of developing this report that ICBP data was an underpinning contributor to the bigger picture of cancer care services. The publications were impactful yet were often considered one crucial part of a greater evidence base.

This is not a negative factor for the ICBP, and in fact it could be argued that by contributing to the wider body of evidence the publications have had more impact than they would have done independently. The uptake of the ICBP has been in a range of areas that aim to improve cancer care and survival, but as part of the wider picture. For example, improving registry practices cannot directly improve survival, but they can aid the delivery of effective services and provide information on patients cancer journeys. Through the contribution of information to a host of areas, the ICBP has undoubtedly had a positive impact in the field of oncology.

Considering the learning from the main themes of this report, it is important to detail that the
core elements are reliant on the input from the interviewees that informed this report. Those included were closely involved in the development, management and delivery of the research and its incorporation into policy and practice. Such individuals include clinicians, managers, data experts and leaders in cancer services.

Central to the success of the partnership is the international element of the programme and the enablement of cross collaboration between professionals across nations. The impact of the ICBP is reflected at policy level, with the partnership’s research referenced in the majority of participating jurisdictions cancer plans. Such bold commitments to international standards of cancer care are of clear importance yet as time moves forward and new cancer plans are developed, it is essential that the international element of policy and cancer plans remain central to the efforts to deliver quality cancer care.

The Module 2 paper\textsuperscript{15} has informed and stimulated the running of various public health campaigns across the globe. Several interviewees reported that planned campaigns had not run due to concerns that existing health systems could not cope with an influx of patients attending their GP with symptoms. This is a particularly concerning finding of this report, and it must be considered that the capacity of healthcare systems is detrimental to survival. It is recommended that countries that have run successful campaigns share their learnings with those who are concerned about implementing similar interventions.

In clinical practice the ICBP contributed to an established evidence base that promoted the creation and delivery of a range of new initiatives including; the Rapid Access Lung Clinic in Alberta, the ACE pilot project and the Danish Cancer Care reforms. Many elements of the clinical impacts of the ICBP focus on the importance of early diagnosis and as the programme continues to develop, it is essential that a stable contribution is made to a growing body of research in the clinical setting.

Cancer registry and data practices have seen improvements as a consequence of the ICBP, as have wider developments of cancer surveillance services. The ongoing demand by the ICBP for detailed, quality data will encourage registries to continue to improve and adopt innovative methods of practice. This in turn will aid the delivery of improved oncology services, contributing to global efforts to improve cancer survival, for all cancer sites.

Within every section of this report, the impacts of the ICBP are accounted to increased political interest in global cancer survival and the subsequent securing of funding for the development of initiatives. The ICBP continues to produce high-quality research that will certainly lend itself to be used as an evidence base for innovative changes on an international scale. It is paramount that advocates of the ICBP drive the papers onto the political agenda to ensure political interest and future investment in cancer services and specifically the need for early diagnosis and treatment.
Conclusions, ongoing and future research

This report details multiple examples of the ways in which the ICBP has had impact over the last decade. Fundamentally, the impacts stem from the unique international collaboration between clinicians, policymakers, data experts and global cancer leaders. The complexity of delivering cancer services are ever present and it is remarkable that despite constant, evolving challenges the ICBP has been able to evidence developments and contribute to a growing body of resources. The ICBP has had a significant impact in a variety of areas of cancer services and the continued efforts of the programme stimulate momentum for improved cancer survival and will continue offering opportunities for a host of professionals to make lasting change.
Appendix 1: Contributors

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