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## The International Cancer Benchmarking Partnership: An international collaboration to inform cancer policy in Australia, Canada, Denmark, Norway, Sweden and the United Kingdom ☆☆☆



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### ABSTRACT

The International Cancer Benchmarking Partnership (ICBP) was initiated by the Department of Health in England to study international variation in cancer survival, and to inform policy to improve cancer survival. It is a research collaboration between twelve jurisdictions in six countries: Australia (New South Wales, Victoria), Canada (Alberta, British Columbia, Manitoba, Ontario), Denmark, Norway, Sweden, and the United Kingdom (England, Northern Ireland, Wales). Leadership is provided by policymakers, with academics, clinicians and cancer registries forming an international network to conduct the research. The project currently has five modules examining: (1) cancer survival, (2) population awareness and beliefs about cancer, (3) attitudes, behaviours and systems in primary care, (4) delays in diagnosis and treatment, and their causes, and (5) treatment, co-morbidities and other factors. These modules employ a range of methodologies including epidemiological and statistical analyses, surveys and clinical record audit. The first publications have already been used to inform and develop cancer policies in participating countries, and a further series of publications is under way. The module design, governance structure, funding arrangements and management approach to the partnership provide a case study in conducting international comparisons of health systems that are both academically and clinically robust and of immediate relevance to policymakers.

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## 1. Background to and aims of the International Cancer Benchmarking Partnership

### 1.1. Introduction and aims

The International Cancer Benchmarking Partnership (ICBP) is a collaboration of policymakers, researchers and clinicians from six countries: Australia, Canada, Denmark, Norway, Sweden and the United Kingdom. The initiative for the ICBP came from the English Department of Health (DH). Survival from many cancers in England and the UK is lower than in comparable countries [1–5]. Poorer cancer survival can reflect a pattern of later presentation or diagnosis of cancer, because more advanced cancers are difficult to treat successfully. The comparatively low one-year survival in the UK suggests that late diagnosis may be a major factor. It is unclear whether patients present to health care later in the UK than elsewhere, or whether they are not being referred adequately by GPs in the primary care sector, or not being effectively investigated in secondary care. In order to address these questions and to examine the role of treatment variation in international differences in survival, an innovative international study of cancer survival was initiated.

The key aims of the ICBP are to update existing studies of international variation in cancer survival and to explore reasons for the differences that have been reported. Although the leadership for the ICBP has come from policymakers, close involvement of academics and clinicians at every stage has been essential. The work has involved many new approaches and analyses to ensure international comparability of datasets and valid benchmarking [6,7]. This article outlines the background to the ICBP, the methodologies, the results and the lessons that have been learned to date.

### 1.2. Background

Population-based cancer registration has enabled useful international comparisons of key cancer measures, including incidence, prevalence and survival. In particular, cancer survival is a key measure of health system performance, because variations in survival point to potentially avoidable deaths among jurisdictions with lower survival [8]. International comparisons of cancer survival have prompted new health policy in countries with low survival, and they help to inform global cancer control strategies [9–13]. However, decisions on how to reform the national provision of cancer care have often relied on other considerations than a sound knowledge-base.

Therefore, there is a need for comprehensive knowledge about the complex processes in the cancer pathway, from the very first symptoms of cancer in a person to their eventual investigation, treatment and care in the health system.

The major international studies of cancer survival are subject to three criticisms. Firstly, the delay between the period during which the patients were diagnosed and the publication of the report ranges from 9 to 14 years, during which interval significant changes in health policy or treatment may occur. These studies provide useful insights into recent patterns of survival, but may not provide contemporary information of direct relevance to policy-makers because they can rarely reflect the impact of recent national and local initiatives [12–15] (see Table 1).

A second criticism is the population coverage of the cancer registries. In some regions, such as Scandinavia and the United Kingdom, there is national cancer registration. In other countries population-based cancer registries only cover a small proportion of the national population (e.g. Germany 1%, France 11%, Spain 14%, Italy 25%), albeit with comprehensive population coverage in the registry areas.

Thirdly, international comparisons may quantify differences in cancer survival, but do not usually explain why they exist. For example, are they due to later presentation of cancers in countries with low survival, leading to reduced access to optimal treatment, hence prompting strategies to improve earlier diagnosis? Both CONCORD and EURO-CARE groups have conducted “high-resolution” studies to look in detail at disease, patient and treatment factors that may influence survival. These indicate that more advanced stage at diagnosis and the quality of treatment both have an impact on international differences in survival [17–20]. For some cancers (e.g. breast) most of the longer-term survival variation in Europe is due to low 1-year survival, because five-year survival amongst patients who survive one year is similar to the European average [21]. This suggests that low breast cancer survival in the UK is mainly attributable to late diagnosis or advanced stage. For other tumours, such as the kidney, both 1-year survival and 5-year survival conditional on survival to one year are low, suggesting both late diagnosis and treatment differences.

With this background, the National Cancer Director for England, Professor Sir Mike Richards, established the International Cancer Benchmarking Partnership in 2009 ([www.icbp.org.uk](http://www.icbp.org.uk)) [22]. The partnership aims to identify and explain the relative contribution of different factors to cancer survival variations between high-income countries, so that the findings can be used to inform cancer policy and improve cancer survival.

**Table 1**  
Major international studies of cancer survival.

	Period of diagnosis	Last year of follow-up	No of countries and cancer registries in study	Date of publication	Main publication
EUROCARE-1	1978–1984	1989	30 cancer registries in 12 European countries	1995	Berrino et al. (1995) [1]
EUROCARE-2	1985–1989	1994	45 cancer registries in 17 European countries	1999	Berrino et al. (1999) [2]
EUROCARE-3	1990–1994	1999	67 cancer registries in 22 European countries	2003	Berrino et al. (2003) [3]
CONCORD	1990–1994	1999	101 cancer registries in 31 countries	2008	Coleman et al. (2008) [5]
EUROCARE-4	1995–1999	2003	83 cancer registries in 23 European countries	2009	Berrino et al. (2007) [4]
ICBP	1995–2007	2007	20 cancer registries in six countries	2011	Coleman et al. (2011) [16]

### 1.3. Identifying partners

To develop an international collaboration of countries, it was necessary to establish a group that was small enough to be manageable and which included countries that represented a range of cancer survival, and were comparable to the UK on key health policy issues and were keen to understand and improve cancer outcomes. Four key criteria were established: first, the countries should have high-quality and long-standing population-based cancer registration with good coverage, to ensure that cancer survival results were representative of national outcomes. Second, there should be universal access to health care, because health systems with substantial components of private and/or insurance-based healthcare will have different policy needs to those with more centrally funded systems. Third, countries should have broadly comparable wealth and broadly similar expenditure on healthcare provision as a proportion of GDP. Finally, countries should be willing to commit significant time, enthusiasm and funding to participate in an international collaboration.

After initial scoping work by the Department of Health in England (DH) Professor Richards, and a Programme Review Board that was formed, invited countries to participate. Six countries encompassing 12 jurisdictions agreed to join at the outset: Australia (New South Wales and Victoria), Canada (Alberta, British Columbia, Manitoba and Ontario), Denmark, Norway, Sweden and the United Kingdom (England, Northern Ireland, and Wales) with a total population in 2009 of 111 million (81% of the total national populations) (see Appendix). In all jurisdictions there is 100% cancer registration and population-based breast cancer screening.

### 1.4. Research aims

The ICBP aims to define and explain international variation in cancer survival, using a combination of analyses of routine data and primary research. The decision was taken to look specifically at a small number of cancers that might highlight reasons for international variations in survival and represent different pathways to diagnosis. Four cancers were selected: breast, colorectal, lung, and ovarian cancer. Breast, colorectal and lung cancers are common and contribute a large share of the cancer burden in developed countries, as well as exhibiting significant survival differences between countries. Breast cancer also had well-established mammographic screening programmes in most participating countries (not Denmark). Ovarian cancer is a less common cancer with a complex diagnostic pathway and large international variations in one and five-year survival.

Previous research into cancer survival has identified a range of factors that contribute to international differences [23]. These include:

- Stage at diagnosis and quality of treatment.
- Delay in diagnosis and treatment.

- Treatment differences, including access to surgery, radiotherapy and cancer drugs, and the co-ordination and organisation of treatment.
- Patient factors, including co-morbidity and age.
- Tumour and physiological/biological factors.

Many studies have found evidence to suggest that combinations of some or all of these factors explain survival differences [17–19,24–26].

## 2. Methodology

The ICBP research programme is divided into five modules. Module 1 is the core epidemiological analysis. Cancer registry data have been used to quantify survival differences between 1995 and 2007, thus extending and updating previous studies of international differences in survival under EUROCARE and CONCORD [16]. Analyses of survival by stage at diagnosis and by treatment are in progress, again using registry data. This module should help establish the extent to which variations in stage at diagnosis and/or treatment can explain international differences in cancer survival.

Modules 2, 3 and 4 are investigating various aspects of time intervals (delay) in cancer diagnosis and treatment. Time intervals can be broken down into different stages, such as patient, primary care and secondary care based on specific milestones (Fig. 1) [27].

Module 2 builds on the existing evidence that patient interval to presentation contributes to delay in diagnosis and thus poorer survival, and that factors influencing patient delay include lack of awareness of cancer symptoms, negative beliefs about cancer, and barriers (both perceived and real) to seeking health care [28,29]. Through a telephone survey of people aged 50 years or more, it tests the hypotheses that people living in countries with poorer cancer survival have lower cancer awareness, more negative beliefs about cancer, and more barriers to presentation. The findings here will be compared to the findings in module 4 to compare patient intervals with awareness.

Module 3 explores primary care delay, based on the hypothesis that it is associated with poorer survival, and that the factors influencing primary care delay include the knowledge and attitudes of primary care physicians, the behaviour of primary care physicians regarding examination, investigation and referral, and differences in primary care systems such as referral pathways and access to investigations in primary care [29–32]. This module incorporates a web-based survey of general practitioners: it includes a series of exercises in which the GP is asked to set out the clinical response (investigations, referral, etc.) in hypothetical patient vignettes, and direct questions. It also includes an exercise to map differences in primary care systems through desk research and expert input. This module should provide evidence to test hypotheses that international differences in knowledge, attitudes and behaviours of primary care physicians are associated with international differences in cancer survival.

Module 4 aims to gather data on the time intervals experienced by cancer patients from their first symptom to their diagnosis and first treatment, testing the hypothesis

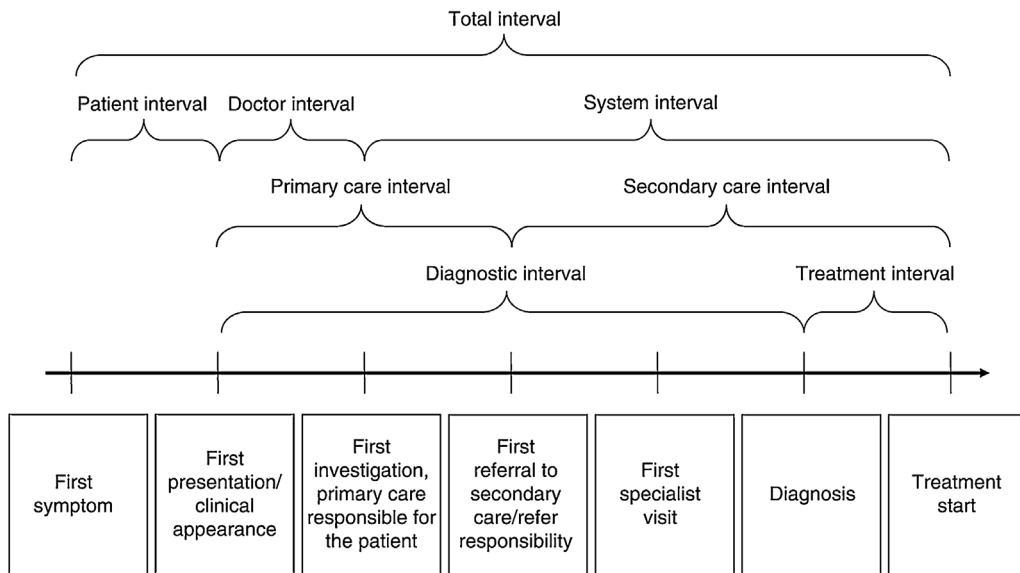


Fig. 1. Categorisation of intervals in cancer diagnosis and treatment [27].

that longer time intervals will be experienced by patients in countries with lower cancer survival. Data are being collected by postal survey of recently diagnosed cancer patients, combined with surveys of the same patients' primary care and specialist doctors. The instruments have been developed from surveys previously conducted in some member countries, and they adhere to a recent international methodological consensus regarding best practice in the measurement of time intervals in the cancer patient pathway [27].

Plans for module 5 are under development, but the intention is to build on the data collected through module 1 to explore routinely available data on patients' pathways through diagnosis and treatment, and to investigate how treatment differences may contribute to differences in cancer survival.

### 3. Governance and funding

A defining feature of the ICBP is that it is a collaborative partnership between policymakers, researchers and clinicians. The formal governance structure for the ICBP is shown in Fig. 2.

An international Programme Board, chaired by Professor Richards, includes representatives of the governments or cancer agencies in each country. The Board provides oversight and strategic direction. Many Board members have a clinical or academic background in cancer prior to or alongside their current senior administrative roles. The Board meets via teleconference every one to two months to review progress and make major decisions such as approving study protocols and contributing to draft publications.

Day-to-day management and co-ordination is provided by a sub-contracted Programme Management function, initially the responsibility of McKinsey & Company, but transferred to Cancer Research UK during 2010. This change was made to reduce management costs and to engage a

specialist charity with wide experience in managing cancer research and in contributing to cancer policy.

The Programme Management team acts a secretariat to the Board and working groups, manages the finances and contracts involved in the project, and supports the module chairs and local teams in their duties. A Programme Review Board in England meets monthly to hold the Programme Management team to account for progress and resolve day-to-day management issues as necessary.

Each module is led by a central academic team comprising experts in the relevant disciplines, appointed by the Programme Board. The central team comprises the principal investigators and lead researchers for each module. Each central team works with academic leads identified by Programme Board members in each of the participating jurisdictions. The central team and local leads have worked together to develop the study protocols and carry out the research.

Many of the academics involved are also practising clinicians. However, to provide further formal clinical input, particularly into the interpretation of registry data under module 1, the ICBP also has a clinical committee of expert senior oncologists and cancer surgeons in each cancer type, with membership from all countries.

Module 1 was funded by the Department of Health and the National Cancer Action Team in England, after a commitment made in the Cancer Reform Strategy for England [15]. Modules 2–5 are funded collectively, with each participating jurisdiction contributing a proportion of the costs.

### 4. Results

As of March 2013, eight articles have been published or are in press, including two methodological papers [6,7,16,33–38].

The first paper from the ICBP was published in *The Lancet* in 2011 and received local and international media

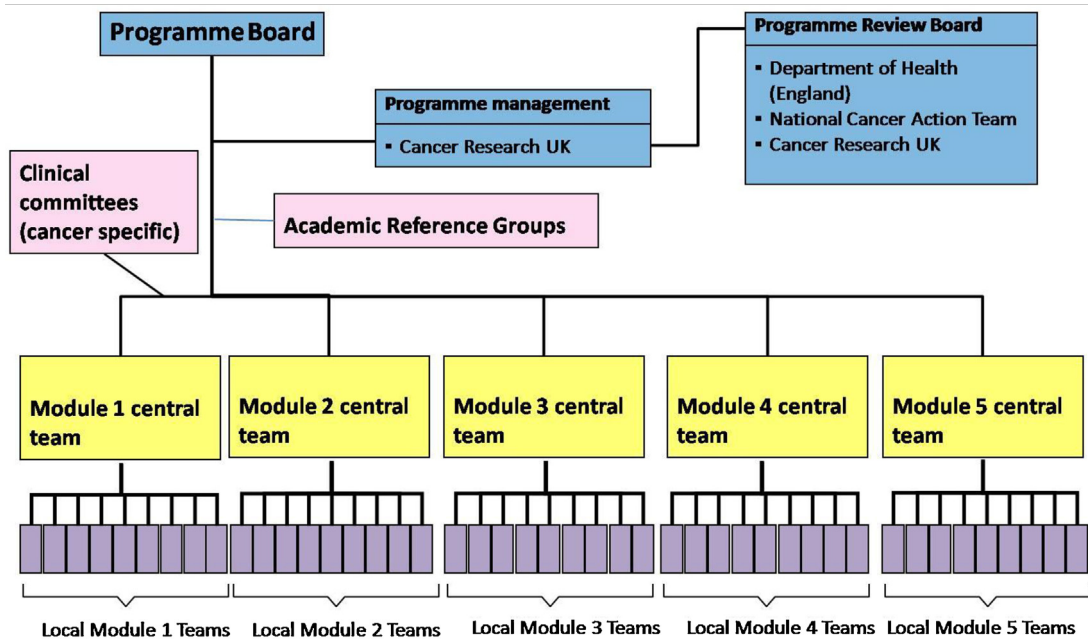


Fig. 2. Governance structure of the ICBP.

coverage. Survival had improved in all countries for all four cancers from 1995 to 2007. However the gap in survival between the best performing countries (Australia, Canada, and Sweden) and the lowest (UK and Denmark) remained largely unchanged, other than for breast cancer, where it had narrowed. Norway had intermediate survival (see Appendix) [16].

Examination of survival by stage proved complex, because the participating countries use several different systems of classifying and coding stage at diagnosis, and the completeness of data on stage at diagnosis was variable and often low, especially for patients diagnosed before 2000. This constrained the number of data sets that could be included in international comparisons of stage-specific survival. It proved necessary to devise a new algorithm to harmonise the disparate classifications of stage, in order to achieve comparable estimates of the distribution of both stage at diagnosis and stage-specific survival. The algorithm has been published as a guide to help improve international comparisons of cancer survival by stage, along with recommendations to improve the quality and international comparability of stage data [6].

The impact of stage at diagnosis on international differences in cancer survival has been examined. For ovarian cancer, survival in the UK was particularly low for women diagnosed at an advanced stage, although the stage distribution in the UK did not appear to be worse than countries with higher survival. This may be explained by later diagnosis of advanced stage disease or inferior treatment quality in the UK. In Denmark, by contrast, the distribution of stage was more adverse, potentially due to differences in diagnostic delay or staging procedures [33].

For lung cancer, survival in the UK was lower than in the other countries at each stage of disease, both for small-cell and non-small cell lung cancer, suggesting incomplete

access to optimal treatment at each stage of disease. The proportion of patients diagnosed at an early stage of disease was also lower in the UK and Denmark, suggesting that differences in both stage at diagnosis and the diagnostic investigations to determine the stage could also contribute to lower overall survival [34].

For breast cancer, one-year survival for women with early (stage I) disease was close to 100% in all six countries. International differences in survival for women with advanced disease were wide, however, ranging from 53% in the UK to 67% in Sweden at one year and 28% (UK) to 42% (Sweden) at three years [35]. In Denmark, early diagnosis was much less common than in the other countries, but stage-specific survival was similar, suggesting that comparatively low overall survival was primarily due to late diagnosis: Denmark was the only country not to have implemented nation-wide mammographic screening before 2006. The low survival was particularly marked for older women in the UK. Taken together, the findings suggest that women diagnosed in the UK at age 70 years or older, and those with advanced disease at diagnosis, are not being treated as aggressively as in other countries.

The patterns of stage at diagnosis for colorectal cancer varied widely between the six countries, with more late disease in Denmark and more regional disease in Australia, Norway and the UK [36]. Differences in one-year survival were also wide, ranging from 67 to 71% for colon cancer in the UK and Denmark to around 80% in the other countries. The pattern was similar for rectal cancer, but the differences were less marked, with one-year survival around 75–79% in Denmark and the UK, and 82–84% in the other countries. Stage-specific survival at one and three years was low in the UK for each stage of disease. These patterns suggest that stage at diagnosis explains some of the international differences in colorectal cancer survival,



with more advanced disease contributing to comparatively low overall survival in Denmark, but the differences in stage-specific survival at each stage of disease also suggest unequal access to optimal treatment, particularly in the UK.

Module 1 studies have also highlighted deficiencies or variations in cancer registration in several jurisdictions, leading to programmes to improve recording. In England, the eight regional cancer registries are migrating to a new system of cancer registration and data acquisition that will include stage and treatment information – English National Cancer Online Registration Environment (EnCORE). Cancer Council Victoria has also started a programme to improve the recording of stage at diagnosis.

Module 2 papers reported little difference in awareness of cancer symptoms and beliefs about cancer outcomes between the countries. However, the study revealed significant differences in people's barriers to symptomatic presentation. Being worried about wasting the doctor's time was particularly common in the UK (34%) and least common in Sweden (9%). Embarrassment about going to the doctor with a symptom that might be serious was most commonly reported in the UK (15%) and least in Denmark (6%). The study also found that awareness of the risk of cancer being higher in older people varied significantly across countries, being lowest in Canada (13%) and the UK (14%) and highest in Sweden (38%) [7,37].

Further papers from subsequent modules including system mapping in primary care are in press or being drafted.

##### **5. Overall 'methodological' lessons learned about conducting a partnership in this way**

To the best of our knowledge, there has been no similar collaboration of equivalent magnitude between policy makers, academics, cancer registries and clinicians. This has led to both significant benefits and challenges. Beyond the particular methodological issues that have arisen for each study within the ICBP, there are also methodological and practical challenges and lessons that emerge from the ambitious approach of the ICBP as a whole.

One practical issue has been the lack of opportunities for face-to-face meetings and the difficulties of scheduling teleconferences at convenient hours for all participants. The major challenges however have been timescales and funding. The co-ordination of a programme of work as complex as the ICBP requires detailed management, with significant associated costs. The ICBP studies therefore cost money to the countries involved even before the research protocols are finalised, since the academic teams and the Board need to be supported throughout this process.

Throughout every part of the programme, the modules have taken longer than initially anticipated by the Board. This is due to a number of different factors. The original timescales proposed were arguably too ambitious and did not factor in sufficient time for the collaborative intellectual, design and testing phases that were necessary in the early phases of each module. Each module has also faced unforeseen challenges as the work has progressed: this is perhaps typical of complex international comparative research in which new research instruments and methodologies are required to answer its questions. Module 1

faced considerable challenges in the availability, comparability and quality of data on cancer stage. Further delays have occurred with work progressing at significantly different paces in different countries/jurisdictions, depending on available resources – in particular local academic resource to develop the local protocols necessary to establish the feasibility of each study for that country.

Given the programme management structure adopted by the ICBP, these delays cost money and so are arguably more directly problematic than they would be with traditional research. Related to this, the funding structure adopted for modules 2–5 – where countries pay their share of costs once they have decided that they are definitely able to participate – has meant that countries ready to sign up early (and in some cases needing to sign up at particular times to ensure funding from a particular financial year remained available) can be unclear as to the total cost since the final number of participating countries is not known and may not be for some considerable time. Modules would have been much easier if there had been cross-government commitment at the outset, but this would have been difficult to obtain as we could not provide a definite protocol and for many jurisdictions 3rd sector cancer charities provided significant funding. A further challenge is that the countries with lower survival, generally Denmark and the UK, may seem to have more to gain than high-performing countries. Ultimately all involved with the ICBP have learned lessons about how to conduct such a partnership and we believe the current approach is an appropriate model for similar undertakings.

Fundamentally, many of these challenges relate to the fact that there are natural motivations and practical factors that tend towards the ICBP progressing slowly, but also a need to push the work on as quickly as possible to minimise costs and deliver results in a timescale most useful to policymakers. On the one hand, the ICBP has a strong ethos of shared decisions and collaboration, and of recognising and adapting to the different needs, resources and issues faced in each participating country, in order to make the work as inclusive and relevant as possible for all involved, and to give sufficient time for all relevant methodological challenges to be fully discussed, tested and resolved to ensure the academic rigour of the work. On the other hand however, the ICBP does seek to achieve results in a timely way, with value for money. To some extent, a requirement on all countries to provide some funding upfront and a more realistic assessment of likely timescales involved could help any future similar endeavours avoid some of the challenges faced by the ICBP.

In terms of benefits, the continued leadership and collaboration of senior policymakers at the Programme Board helps to ensure that the research questions being posed will be directly useful to policymakers in each country, and helps encourage the policymakers to act on and use the findings and recommendations from the research. Given the expertise of many of the Board members, the Board also provides invaluable expert review, ensuring that the studies are not only relevant to policy, but also rigorously designed and academically robust.

Running a set of concurrent studies that collectively tackle the priority research questions for policymakers also

provides potential for the results to be considered as a whole, alongside each other. By testing a range of different hypotheses for what might be causing international differences in cancer survival, policymakers are more able to build up a sense of where policy interventions might provide the greatest return in terms of survival gain.

A further important benefit is the building of enduring partnerships, both at Board level and amongst the research teams. The partners have been very committed to continuing with the work, recognising potential benefits to their own jurisdictions and to other countries in the future. The ICBP has created an interest network, which it is hoped will outlast the current studies. Academic teams involved are already planning further analyses and collaborations based on the work done so far, and the Programme Board has begun to discuss the potential for further comparative work looking at other types of cancer and other research questions. These include examining the costs of cancer, use of diagnostics, hospital beds, chemotherapy and quality of life. This model of international collaboration may be of interest for other disease types such as cardiovascular disease.

The work of the ICBP has already contributed to policy development in the UK including the setting of levels of Ambition for the NHS Outcomes framework [38,39]. In Canada the module 2 population awareness survey was extended to all provinces to ensure a national picture of public perceptions was obtained. Lung cancer survival variation in Canadian provinces had led to new initiatives to reduce the time from diagnosis to surgical treatment. In Wales, England and Victoria lack of staging and treatment information has led to policies to improve the quality of registry recording of stage [38,40].

## Appendix A.

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## Appendix B. Supplementary data

Supplementary data associated with this article can be found, in the online version, at <http://dx.doi.org/10.1016/j.healthpol.2013.03.021>.

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