ICBP
International Cancer Benchmarking Partnership

Jurisdiction Briefing: Northern Ireland interim overview

THE INTERNATIONAL CANCER BENCHMARKING PARTNERSHIP

CREATED BY THE ICBP PROGRAMME MANAGEMENT TEAM
CANCER RESEARCH UK
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CANCER RESEARCH UK

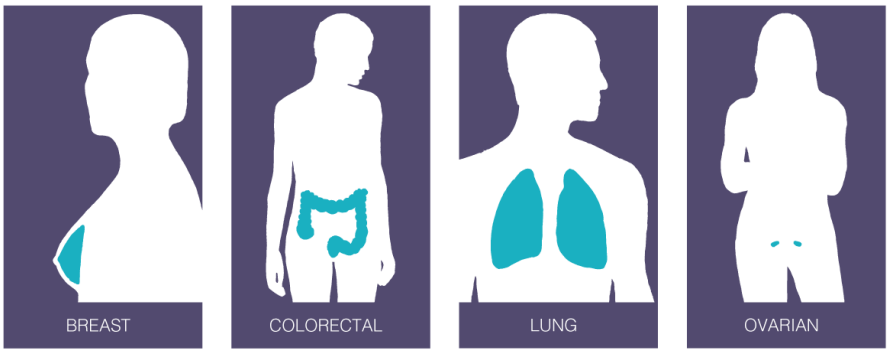
International Cancer Benchmarking Partnership – Northern Ireland Interim Overview

Contents

Background

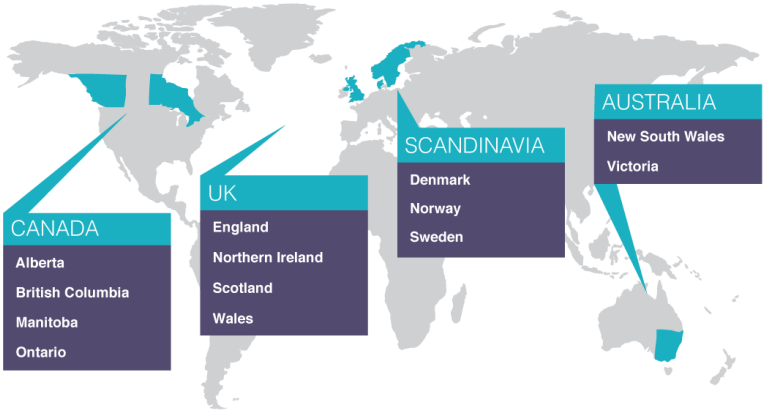
The International Cancer Benchmarking Partnership (ICBP) is a partnership of clinicians, academics and policymakers. It is the first of its kind, seeking to understand how and why cancer survival varies between countries/jurisdictions, looking particularly at **breast, colorectal, lung and ovarian cancer** (Figure 1).

Figure 1: Cancer types studied by the ICBP



It includes: **Australia** (New South Wales and Victoria); **Canada** (Alberta, British Columbia (BC), Manitoba and Ontario); **Denmark; Norway; Sweden** (Uppsala-Örebro and Stockholm–Gotland health regions)**; and the UK** (England, Northern Ireland, Wales and Scotland), as shown in Figure 2 below. Initiated in 2009, the ICBP is chaired by Dr Heather Bryant, and programme management is provided by Cancer Research UK.

Figure 2: ICBP Jurisdictions



The results showed that survival during the study period improved for patients in all jurisdictions but that differences remain. The gap in survival between the best performing countries (Australia, Canada and Sweden), the intermediate (Norway), and the lowest (England, Northern Ireland, Wales and Denmark), remains largely unchanged, except for breast, where the UK is narrowing the gap.

ICBP phase 1 is drawing to an end, with two more studies close to completion, and as such all the findings reported concern these cancer types and jurisdictions. Further information about ICBP phase 2 can be found towards the end of this overview document, on the ICBP website (www.ICBP.org.uk) or by contacting the ICBP programme management team (icbp@cancer.org.uk).

Outline of Modules

The ICBP works across 5 areas of research (modules). Each module looks at different aspects of the cancer pathway to identify possible reasons for international differences.

Module	Area	Research chair(s)	Summary description	Status/Progress
1	Epidemiology	Michel Coleman	Core benchmarking module of the ICBP. Comparison of cancer survival, and analysis of survival by stage and stage distributions, using registry data.	Six peer-reviewed papers published. • Survival benchmarking achieved and international comparison of survival by stage and stage distributions for each four cancers complete • Algorithm developed to map different staging systems to 'local', 'regional' and 'distant' classifications, allowing further comparison
2	Population awareness and beliefs	Jane Wardle, Amanda Ramirez	Telephone survey of general public (2000 men and women aged 50 or over per jurisdiction) about attitudes and beliefs around cancer using the 'Awareness and Beliefs about Cancer' (ABC) measure.	Two peer-reviewed papers published • 'Awareness and Beliefs about Cancer' measure developed • International comparison of the awareness and beliefs about cancer • Many local analyses published
3	Attitudes, behaviours and systems in primary care	Peter Rose	Web survey of 200 primary care physicians per jurisdiction combined with a mapping exercise of primary care systems. Survey combines direct questions and simulated patient vignettes.	Three peer-reviewed papers published • Systems mapping paper highlighting primary care factors that could be influencing patient and GP behaviour • Methods paper published outlining details of the survey, data collection and analysis • Main international comparison showing correlation between primary care physician 'readiness to refer' and survival for colorectal, lung and ovarian cancers.
4	Time intervals from symptoms to treatment	David Weller, Usha Menon, Peter Vedsted	Study of time intervals from first symptom to first treatment, although screened patients also participated. Paper survey of recently diagnosed cancer patients (200 patients per cancer type per jurisdiction), combined with primary and secondary care audit.	Data collection is complete and papers are being drafted. In total there will be eight international comparison papers published, with the methods paper already published. There will be great opportunity for local analyses using this rich dataset.
5	Exploring early mortality: association with co-morbidities and other factors	Jem Rashbass	Exploring factors impacting short-term outcomes – the effects of cancer registry practices in survival calculations and exploring the use of comorbidity measures from routine data sources to predict survival.	Two publications have been prepared: • Variation in cancer registry practices and their impact on 1-year survival estimates. • Creation of comorbidity measures from routine hospital data, and their use to predict 1-year lung cancer mortality, now published in Thorax.

Findings from ICBP phase 1

Key findings for Northern Ireland

- Survival estimates across the four studied cancer types (breast, colorectal, lung and ovarian) were among the lowest for patients diagnosed between 2005-07. Northern Ireland consistently ranked between 8th and 10th out of the 12 jurisdictions.
- 5-year conditional ovarian cancer survival estimates were among the highest in Northern Ireland at 55.7% (ranked 3rd).
- Northern Ireland was the jurisdiction with the most improved survival estimates for 5-year conditional breast survival between 1990-1995 to 2005-2007. However, 5-year and 5-year conditional survival for ovarian cancer decreased in Northern Ireland across this time period, and 5-year conditional lung cancer survival stayed the same.
- Northern Ireland provided stage at diagnosis data for all cancer types, which showed that more cancers in these recent years were diagnosed later (adverse stage distribution) for lung and ovarian data, compared to other jurisdictions.
- The proportion of missing data was quite high across all age groups and cancer types, but the proportion was consistently higher for patients aged 70-99 years old (up to 49.5% missing for lung cancer stage).
- Members of the general public in Northern Ireland had the lowest awareness that the risk of cancer increases with age, but were among the most able to identify cancer symptoms.
- Respondents in Northern Ireland were also among the most likely to identify embarrassment, worry about wasting the doctor's time, and worry about what the doctor might find as reasons for not visiting their doctor with a symptom that might be serious.
- Primary care physicians in Northern Ireland were among the least likely to take action at first consultation with hypothetical patients presenting with symptoms that were indicative of lung cancer, and had among the lowest 1-year cancer survival for lung cancer as shown in Module 1.
- Primary care physicians in Northern Ireland reported mixed access to diagnostic investigations – reported access was comparatively high for upper GI endoscopy but low for CT and MRI scans. Access to blood tests used for cancer diagnosis in Northern Ireland was among the highest reported internationally.
- Average waiting times for tests and their results were among the longest internationally, and PCPs in Northern Ireland were among the least likely to report access to advice and faster tests, with intermediate wait times between referral and first specialist appointment also reported.
- Unpublished findings on time intervals from patients first noticing symptoms to starting treatment have shown that these are long for the diagnostic interval in Northern Ireland, in particular for colorectal, lung and ovarian patients. Patient intervals were also among the longest seen internationally for colorectal and ovarian patients.
- Unpublished findings on differences in cancer registry practices and their impact show no impact on Northern Ireland's cancer survival estimates (using previously published Module 1 data).

Potential further research

- ICBP has explored primary care and beyond in several different facets (readiness to refer, access to diagnostic investigations and the speed at which patients move through the health system). Some findings do not immediately seem to fit with regard to each other. The relationship between primary care physicians' readiness to refer, access to diagnostics and interval lengths could be further explored and validated with local data or additional surveys.

Module 1 – cancer survival benchmark

The ICBP undertook cancer survival comparisons, including more than 2.4 million adults diagnosed with breast, colorectal (provided as colon and rectum also), lung and ovarian cancer during 1995-2007. Northern Ireland provided cancer registry data for breast, colorectal, lung and ovarian cancer. A series of papers were published following the completion of Module 1 and the data summarised below is reported in these.

Table 1: 1-year, 5-year conditional and 5-year survival comparisons for 2005-2007 between Northern Ireland and the jurisdictions with the highest and lowest survival (ranks given out of 12 jurisdictions) [Coleman et al, 2011]

Cancer site	NORTHERN IRELAND (2005-07)			LOWEST JURISDICTION (2005-07)			LEADING JURISDICTION (2005-07)		
	1-year survival	5-year survival	5-year conditional survival[1]	1-year survival	5-year survival	5-year conditional survival[1]	1-year survival	5-year survival	5-year conditional survival[1]
Colorectal	76.2% (10th)	55.2% (10th)	73.0% (8th)	73.6% Wales	52.3% Wales	71.1% Wales	85.1% Australia-VIC	66.4% Australia-NSW	78.4% Australia-NSW
Lung	30.6% (10th)	11.0% (9th)	33.8% (9th)	28.5% Wales	8.7% England	27.9% England	43.6% Sweden	20.1% Canada-MAN	47.4% Canada-MAN
Breast	95.0% (9th)	84.1% (8th)	88.9% (7th)	93.4% Wales	81.0% Wales	86.4% England and Wales	98.0% Sweden	89.1% Canada- BC	91.8% Canada- BC
Ovary[2]	63.9% (10th)	36.5% (6th)	55.7% (3rd)	60.5% Wales	28.8% Canada-MAN	39.1% Canada-MAN	77.6% Canada-BC	44.1% Canada-BC	57.4% Wales

[1] Of those people who survive at least 1 year after diagnosis, the proportion of people who then survive 5 years
[2] Sweden is not included in the analysis for ovarian cancer as their data was not provided in time for analysis

For the latest years of data (2005-07), Northern Ireland consistently 'ranked' towards the bottom in terms of survival for the 12 participating jurisdictions (Table 1). Northern Ireland's best survival statistics were recorded for 5-year conditional ovarian cancer survival, where Northern Ireland ranked 3rd with a survival of 55.7%.

Figure 3: 1-year survival across ICBP jurisdictions and cancer types, 2005-2007 [Coleman et al, 2011]

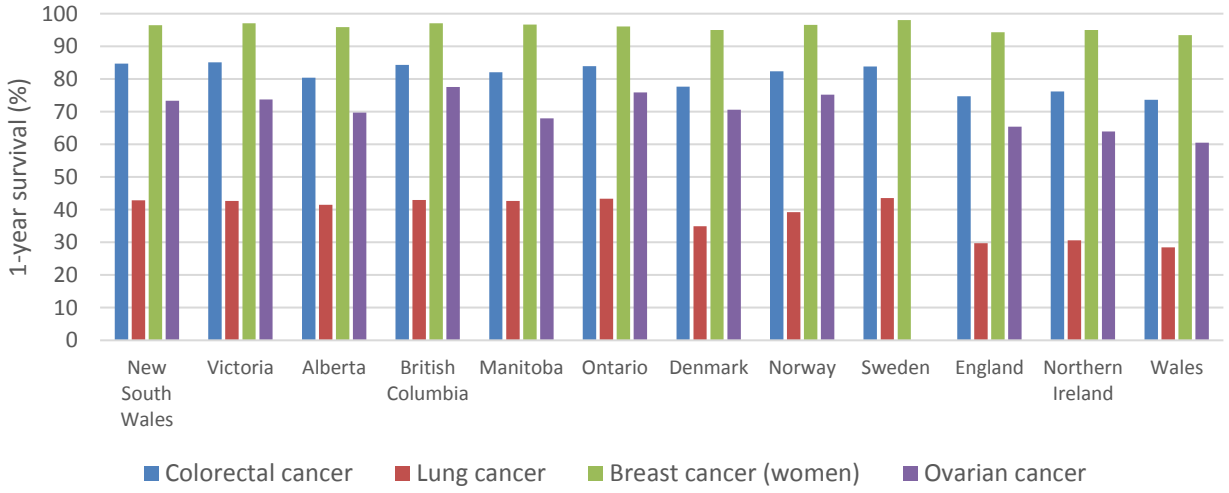


Figure 4: 5-year survival across ICBP jurisdictions and cancer types, 2005-2007 [Coleman et al, 2011]

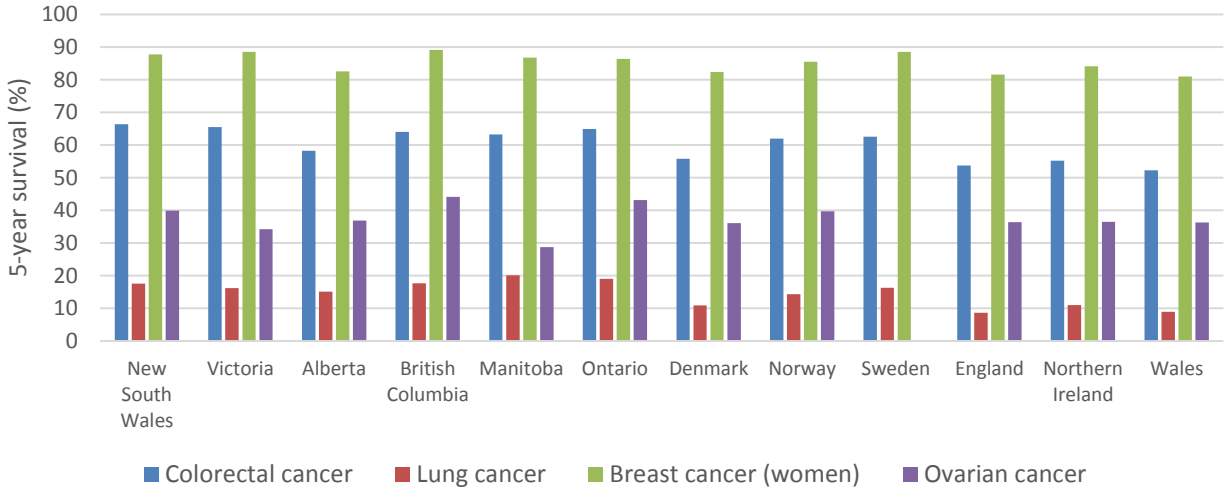


Figure 5: Conditional 5-year survival across ICBP jurisdictions and cancer types, 2005-2007 [Coleman et al, 2011]

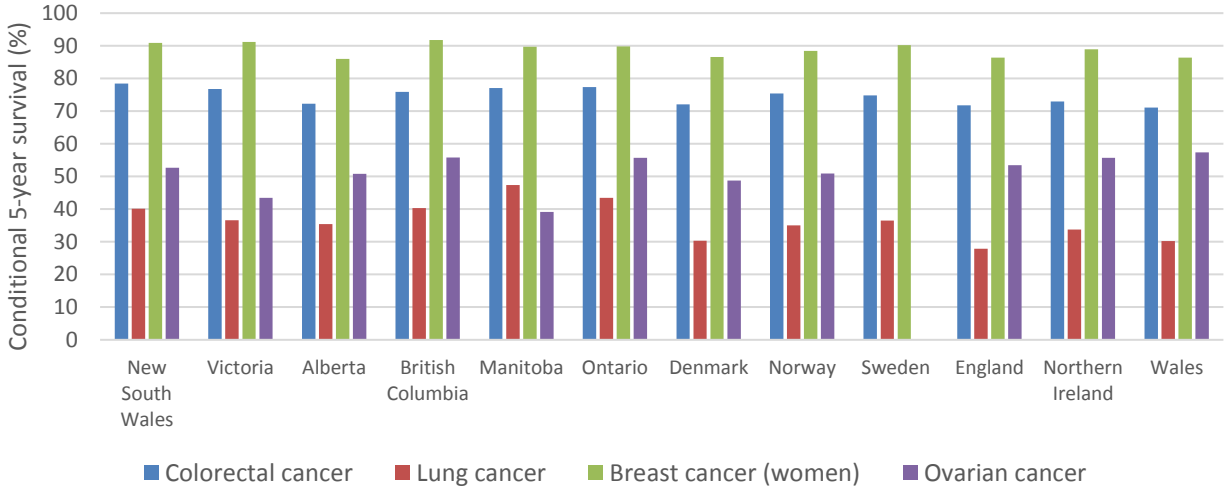


Table 2: Changes in 1-year, 5-year conditional and 5-year survival comparisons for Northern Ireland and the leading jurisdiction between 1995-1999 and 2005-2007 (ranks given out of 12 jurisdictions). [Coleman et al, 2011]

Cancer site	NORTHERN IRELAND			JURISDICTION WITH MOST IMPROVED SURVIVAL		
	1-year survival	**5-year survival**	**5-year conditional survival[1]**	**1-year survival**	**5-year survival**	**5-year conditional survival[1]**
Colorectal	+1.9% (12th)	+4.1% (10th)	+4.2% (3rd)	+6.0% Denmark	+7.6% Denmark	+4.9% Manitoba
Lung	+3.2% (11th)	+1.3% (11th)	0.0% (11th)	+8.5% Denmark	+3.8% British Columbia	+7.9% Manitoba
Breast	+2.4% (3rd)	+6.6% (3rd)	+5.3% (1st)	+4.8% Wales	+7.5% Wales	**+5.3% Northern Ireland**
Ovary[2]	+1.1% (9th)	-2.5% (9th)	-7.3% (10th)	+7.2% Denmark	+9.0% British Columbia	+10.1% British Columbia

[1] Of those people who survive at least 1 year after diagnosis, the proportion of people who then survive 5 years
[2] Sweden is not included in the analysis for ovarian cancer as their data was not provided in time for analysis

Almost all ICBP jurisdictions reported improvements in survival across every cancer type between 1995-1999 and 2005-2007. Greatest improvements, shown in Table 2, within Northern Ireland and internationally were seen in 5-year breast and colorectal survival (+6.6% and +4.1% respectively) and 5-year conditional colorectal survival (+4.2%). Northern Ireland's increases in survival estimates for breast compare favourably to other jurisdictions, showing that the gap to other jurisdictions is closing more quickly, but poor for other cancer types. In particular, survival between 1995-1999 and 2005-2007 stayed the same for 5-year conditional lung cancer survival, and decreased for 5-year and 5-year conditional ovarian cancer (-2.5% and -7.3% respectively).

Stage distributions

- **Breast** – There was a positive stage distribution (more patients diagnosed earlier) with 36.6% of patients of all ages diagnosed with TNM Stage 1 and 43.3% with Stage 2 cancer. There was a high proportion of missing data for patients aged 70-99 years of age (38.6% missing).
- **Lung** – The stage distribution for lung cancer was negative (more patients diagnosed later) with 28.4% of patients of all ages diagnosed with TNM Stage 3 and 48.3% with Stage 4 cancer. A small proportion of patients were diagnosed at earlier stages (stage 1 – 16.7%, stage 2 – 6.5%), however, there was also a large proportion of missing data (37.6% at all ages, increasing to 49.5% in 70-99 year olds).
- **Ovarian** – FIGO stage data was not provided by all jurisdictions, and so data was mapped to SEER Summary Stage 2000. Localised cancers accounted for 18.2%, regional for 23.4% and distant for 58.3%, showing a more negatively skewed distribution. Across all age groups, 19.0% of data was missing, but this increased to 34.8% for 70-99 year olds.
- **Colon** – Northern Ireland's stage distribution was fairly balanced, with most patients diagnosed either at Duke's stage B (33.3%) or C (35.1%). Across all ages, 22.8% of patients were diagnosed at stage D, and 8.8% at stage A.
- **Rectal** – The stage distribution was fairly balanced, with most patients diagnosed at Duke's stage C across all age groups, then either stage B (24.5%) or D (21.3%). Across all ages, 17.0% of patients were diagnosed at stage A, but 20.5% of the data was missing.

Data Considerations

When reviewing the above data for Module 1 it is important to consider the following caveats and limitations of the data. The ICBP implemented comprehensive quality control measures when reviewing and analysing data and, as a result of this, data from some patients/jurisdictions were excluded:

- The records of 102,305 patients whose tumour was benign, of uncertain or borderline malignancy, in-situ, or metastatic to the index organ from elsewhere.
- Of the 2,504,741 adults eligible for analysis, a further 102,997 patients were excluded from analysis.

Stage data was limited to time periods where stage data was most complete. Therefore, for breast and colorectal data was analysed between 2000 and 2007, whilst for lung and ovarian the period of analysis was 2004 to 2007. Analyses were further restricted to registries where over half of all patients had a valid stage and where there was no sudden changed in availability over time, and therefore several jurisdictions were excluded from some of the analyses.

To allow for international comparisons of all participating jurisdictions, stage data was mapped to the SEER SS2000 classification system for all cancers. Data was also analysed and presented for the cancer specific staging systems (TNM for breast and lung, Duke's for colorectal and FIGO for ovarian) as these classifications are seen to be more relevant to clinicians. Norway provided data for stage of colon cancer using their own local method.

Key publications:

- Coleman, MP et al. Cancer survival in Australia, Canada, Denmark, Norway, Sweden, and the UK, 1995–2007 (the International Cancer Benchmarking Partnership): an analysis of population-based cancer registry data. The Lancet, 2011 Vol 377 (9760), 127 - 138
- Walters S et al. 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 (2013) 108, 1195–1208. doi:10.1038/bjc.2013.6

- Maringe C, et al. Stage at diagnosis and colorectal cancer survival in six high-income countries: a population-based study of patients diagnosed during 2000-2007. Acta Oncol. 2013 Jun;52(5):919-32. doi: 10.3109/0284186X.2013.764008.
- Walters S at al. Lung cancer survival and stage at diagnosis in Australia, Canada, Denmark, Norway, Sweden and the UK: a population-based study, 2004–2007. Thorax 2013;68:551-564 doi:10.1136/thoraxjnl-2012-202297
- Maringe C. Stage at diagnosis and ovarian cancer survival: Evidence from the International Cancer Benchmarking Partnership. Gynaecologic Oncology, 2012. Vol127 (1), Pages 75–82

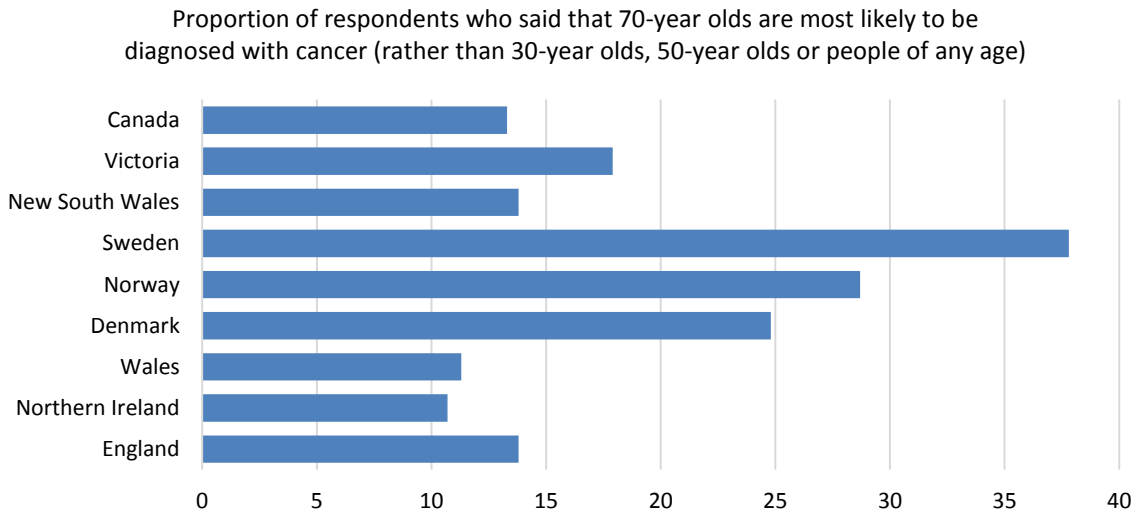
Module 2 – population awareness and beliefs

Over 19,000 men and women aged 50 or older (including 1,470 people from Northern Ireland) took part in a telephone interview survey. The results indicated that awareness and beliefs about cancer are unlikely to be a main factor in explaining observed international survival differences, with similar levels of awareness of cancer symptoms and similar beliefs about cancer reported across all jurisdictions.

Public Awareness and Beliefs about Cancer

- On average, 8 out of 11 key cancer symptoms were recognised by the people across all countries. Participants from Northern Ireland identified an average of 8.53 symptoms, which placed them 2nd out of the 9 participating ICBP jurisdictions (Canadian provincial results were analysed together). Only respondents in Canada recognised a higher number of symptoms (average of 8.7), compared to the lowest in Sweden (average 7.7).
- Overall awareness of cancer symptoms and risks was low in all participating countries (Figure 6). Awareness that 70 year olds are most likely to be diagnosed with cancer over the next year, compared to 30 year olds, 50 year olds, or people of any age, was lowest in Northern Ireland (10.7%). Awareness was highest in Sweden (37.8%).

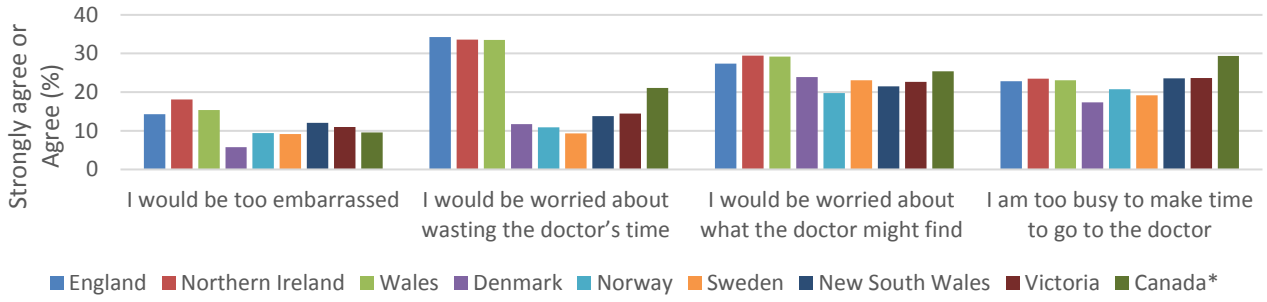
Figure 6: Awareness that cancer risk increases with age [Forbes et al, 2012]



Barriers to symptomatic presentation

- People in Northern Ireland often reported barriers to symptomatic presentation as a reason for not going to the doctor with a symptom that might be serious.
- Respondents were asked if any of the following would put them off going to the doctor with a symptom that might be serious:
    - 'I would be too embarrassed': 18.1% of Northern Irish respondents answered yes, the highest internationally.
    - 'I would be worried about wasting the doctor's time': 33.6% of Northern Irish respondents said yes, which is very similar to the other highest respondents, Wales (33.5%) and England (34.3%).
    - 'I would be worried about what the doctor might find': 29.5% of Northern Irish respondents answered yes, the highest internationally.
    - 'I am too busy to make time to go to the doctor': 23.5% of Northern Irish respondents answered yes compared to the lowest respondents in Denmark (17.4%) and the highest in Canada (29.4%).

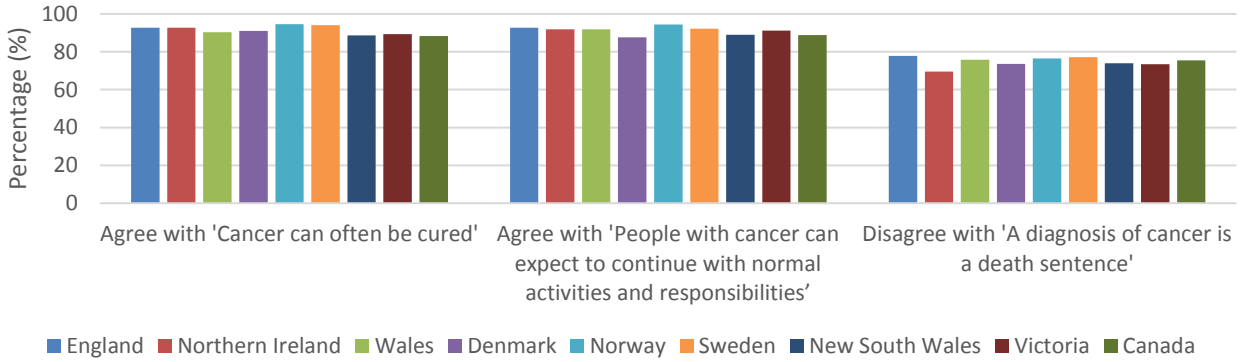
Figure 7: Barriers to symptomatic presentation: would any of these put you off going to the doctor with a symptom that might be serious? [Forbes et al, 2012]



Beliefs about Cancer

- There were generally positive beliefs about cancer internationally: for example, around 9 out of 10 respondents in each country agree that 'cancer can often be cured' and that 'people with cancer can expect to continue with normal activities and responsibilities'.
- Members of the public across all jurisdictions showed that many held both positive and negative beliefs about cancer at the same time.
- Northern Irish participants had relatively positive beliefs that cancers can often be cured (92.8%) and that people with cancer can expect to continue with a normal life (91.8%, Figure 8)).
- There was no evidence that the overall pattern of cancer awareness and beliefs followed the overall pattern of 1-year cancer survival across the countries.

Figure 8: Beliefs about outcomes [Forbes et al, 2012]



Data Limitations

As this data is based on the opinions of participants that were selected at random within each jurisdiction there is the possibility that results are not representative of the whole of the population. However, steps were built into the methodology to limit bias (harmonised surveys, single provider to carry out surveys, population weighting and controlling for differences).

Key publications:

- Simon AE et al. An international measure of awareness and beliefs about cancer: development and testing of the ABC. BMJ Open (2012) ;2:e001758. doi: 10.1136/bmjopen-2012-001758
- Forbes LJL et al. 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 (2013) 108, 292–300. doi:10.1038/bjc.2012.5

Module 3 – primary care and access to diagnostics

Between 2012 and 2013, 2,795 primary care practitioners (PCPs) took part in a validated online survey, including 130 PCPs in Northern Ireland. The survey had two parts; direct questions on primary care structure and practice relating to cancer diagnosis, and clinical vignettes, assessing management of scenarios relating to the diagnosis of lung, colorectal or ovarian cancer. The module also revealed significant differences in waiting times to access diagnostic investigations and the time taken to report the results of these investigations internationally.

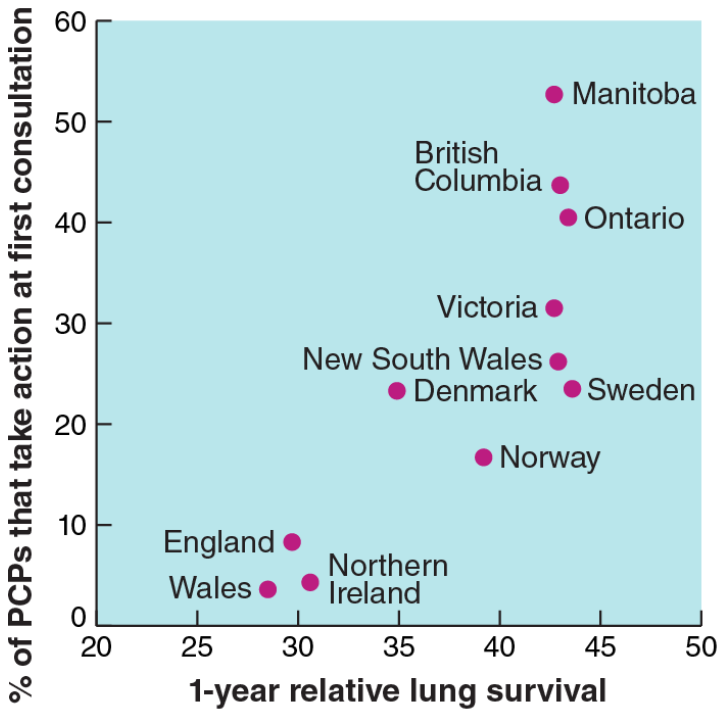
Readiness to refer

Survey findings suggest there is a correlation between the readiness of PCPs to investigate symptoms indicative of cancer at the patient's first consultation and ovarian, lung and colorectal cancer survival. Figure 9 shows the percentage of PCPs who indicate they would take action at a first consultation correlated to the 1-year relative lung cancer survival from Module 1.

In this example, PCPs from UK jurisdictions (England, Wales, and Northern Ireland), which had the lowest 1-year relative lung cancer survival according to Module 1 data, reported the lowest percentage of PCPs referring at first consultation (less than 10% across all nations). Conversely, PCPs in Canadian jurisdictions reported a higher readiness to refer and had previously been found to have higher 1-year relative survival.

The analysis did not find a consistent association between the readiness to refer and other factors that may be influencing PCP behaviour where information was available from the study. These factors included direct access to diagnostics, average waiting times for test results, practice administration (e.g. safety netting), education on cancer in the past year, the PCPs' attitudes to cancer, their perceived role in diagnosing cancer and access to specialist advice.

Figure 9: Readiness of primary care practitioners to investigate symptoms indicative of lung cancer and 1-year relative survival of lung cancer [Rose et al, 2015]



Access to diagnostic investigations by PCP

Northern Ireland's PCPs had mixed levels of direct access to diagnostic tests compared with other ICBP countries. Access to whole body imaging and endoscopy tests varied, as shown in Figures 10-12:

- Reported access to whole body X-rays in Northern Ireland was 89.9% compared to 100% in Victoria (the highest) and 74.3% in Norway (the lowest).
- Reported access to whole body CT scans in Northern Ireland was low at 27.5% compared to 100% in Victoria (the highest) and 21.5% in England (the lowest).
- Reported access to whole body MRI scans in Northern Ireland was the lowest at 11.0%, compared to 91.6% in Ontario (the highest).
- Reported access to ultrasound in Northern Ireland was intermediate at 79.8% compared to 98.9% in Victoria (the highest) and 70.9% in Norway (the lowest).
- Reported access to upper GI endoscopy was highest in Northern Ireland at 68.1%, compared to the lowest in British Columbia (7.4%).
- Reported access to flexible-sigmoidoscopy in Northern Ireland was low at 14.8% compared to 54.9% in Denmark (the highest) and 13.1% in British Columbia (the lowest).
- Reported access to colonoscopy in Northern Ireland was 19.8% compared to 61.9% in Victoria (the highest) and 7.9% in British Columbia (the lowest).
- Reported access to blood tests used to diagnose cancer was high in Northern Ireland, with 89.0% of PCPs agreeing, compared to 99.5% in Victoria (the highest) and 69.3% in Manitoba (the lowest).

Importantly, findings suggest significant variation exists between ICBP countries in the reported access to diagnostic tests, and these do not clearly correlate to previously reported survival differences.

Figure 10: PCP reported access to whole body imaging investigations by jurisdiction [Rose et al, 2015]

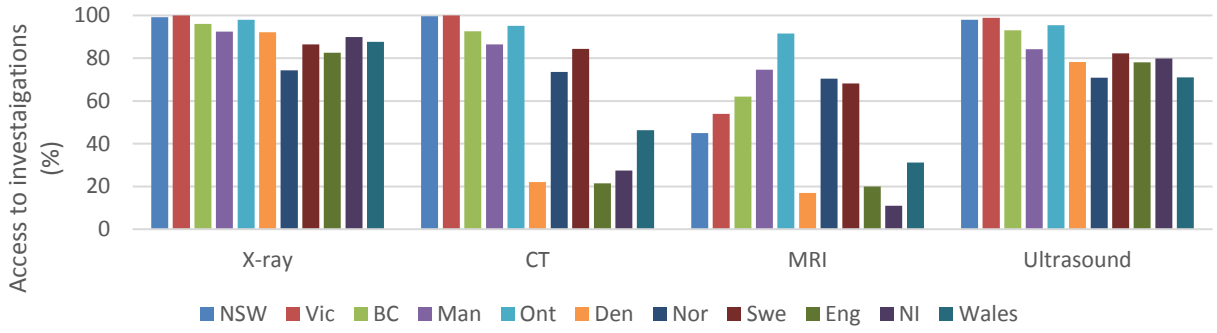


Figure 11: PCP reported access to endoscopic investigations by jurisdiction [Rose et al, 2015]

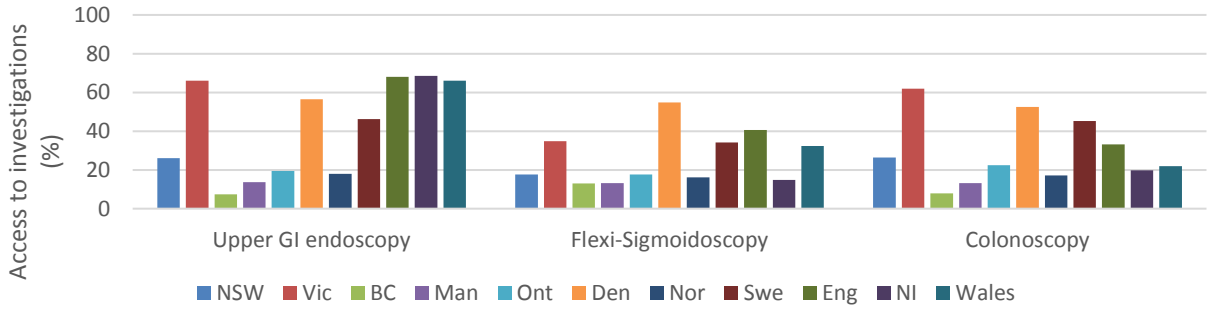
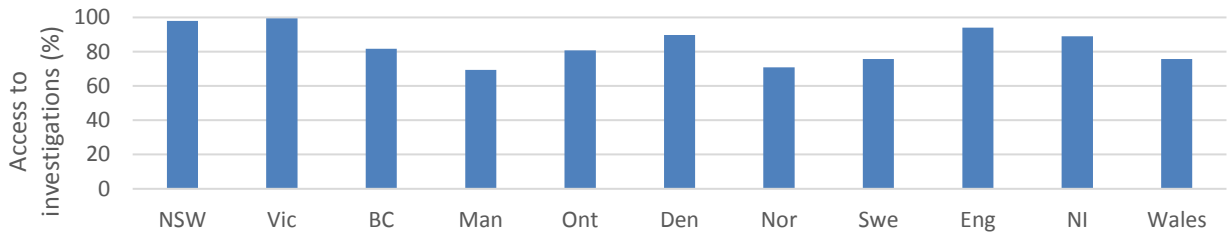


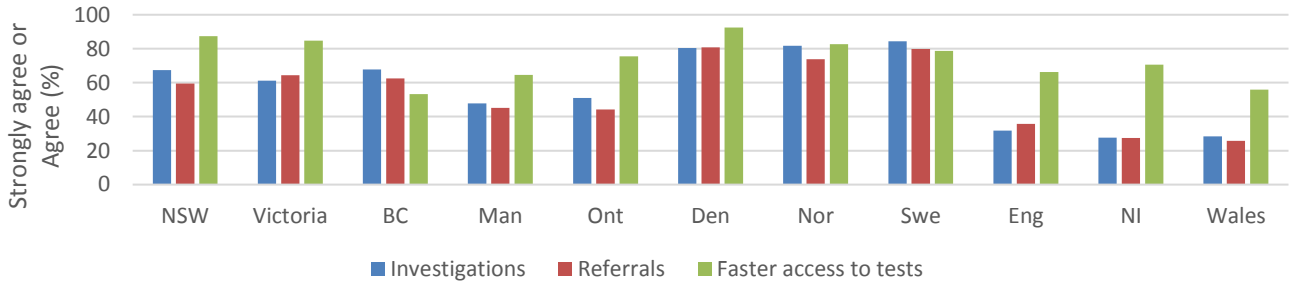
Figure 12: Reported access of PCPs to blood tests used for cancer diagnosis by jurisdiction [Rose et al, 2015]



Access to advice and faster tests

PCPs were asked if they were able to access advice from specialists regarding investigations and referrals, and if they could arrange faster access to tests for patients (percentages who agree or strongly agree, Figure 13). PCPs in Northern Ireland reported among the lowest levels of access to advice about referrals (27.5%, the highest was Denmark with 80.7%), and the lowest levels of access to advice about investigations (27.6%, compared to the highest of 84.4% in Sweden). Faster access to tests was reported by 56.0% of PCP respondents, compared to a high of 92.5% (Denmark) and low of 53.3% (British Columbia, Canada).

Figure 13: Reported access of PCPs to advice and faster tests [Rose et al, 2015]



Waiting and reporting times for tests

Differences in wait times can be seen between Northern Ireland and other jurisdictions for some tests, with Northern Ireland having the longest combined wait times for test and results for X-ray, CT and ultrasound (Figures 14 and 15). The reported wait time between referral and a first specialist appointment in Northern Ireland was intermediate at about 14 days; the longest reported waits were in Manitoba (19.2 days), and the shortest in Denmark (5 days, Figure 16).

Figure 14: Average waiting times for diagnostic imaging tests and results (weeks) by jurisdiction [Rose et al, 2015]

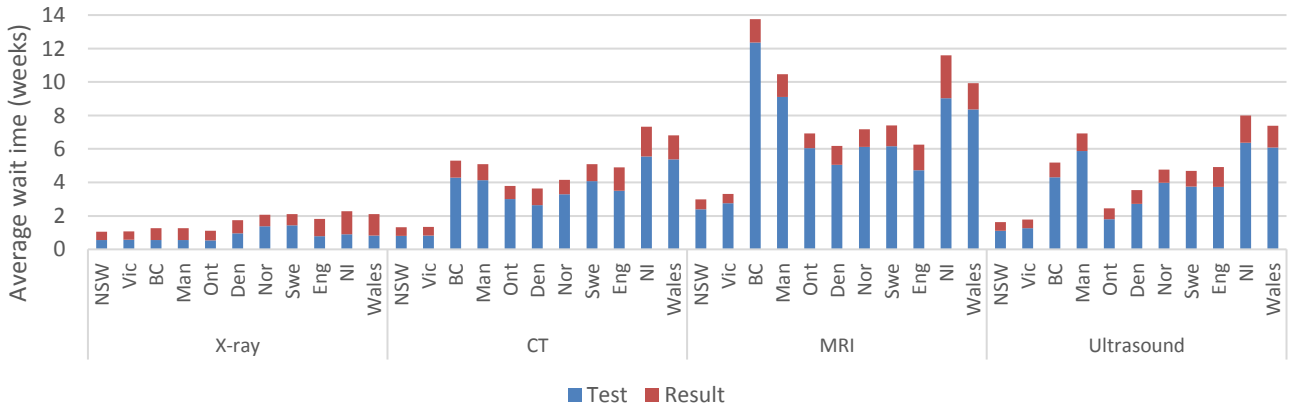


Figure 15: Average waiting times for diagnostic endoscopy tests and results (weeks) by jurisdiction [Rose et al, 2015]

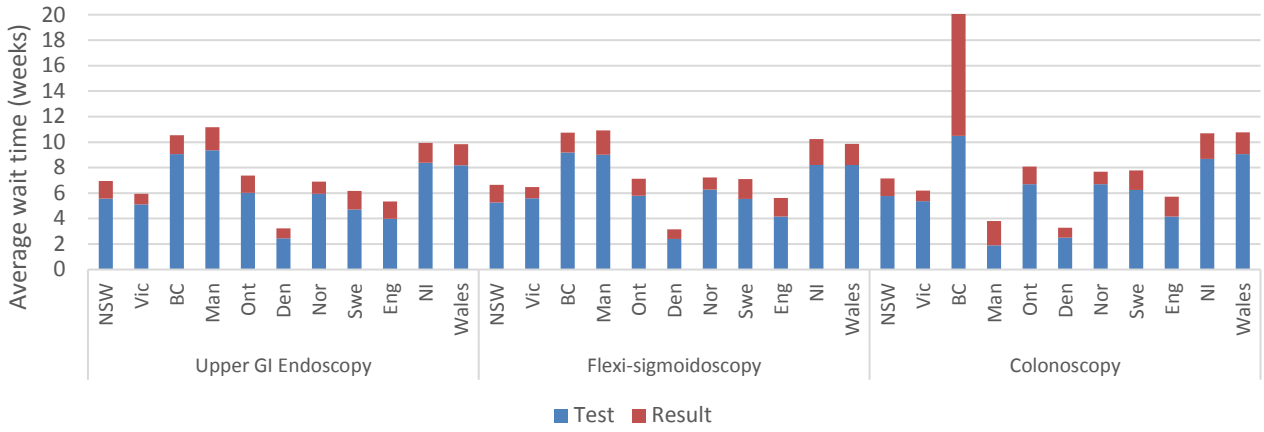
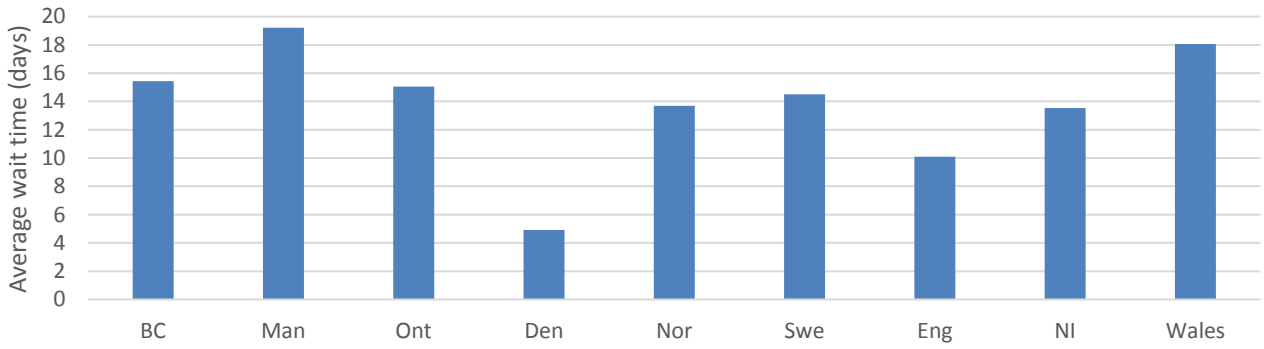


Figure 16: Average waiting time between a referral and a first specialist appointment (days) by jurisdiction [Rose et al, 2015]



Key publications:

- Rose PW, et al. Development of a survey instrument to investigate the primary care factors related to differences in cancer diagnosis between international jurisdictions. BMC Family Practice 2014;5:e007212. doi:10.1136/bmjopen-2014-007212
- Rose PW, et al. Explaining variation in cancer survival between 11 jurisdictions in the International Cancer Benchmarking Partnership: a primary care vignette survey. BMJ Open 2015;5:e007212. doi:10.1136/bmjopen-2014-007212

Module 5

Workstream 2: An investigation of the international comparability of population-based comorbidity scores derived from routine administrative hospital datasets for lung cancer patients

The cancer survival benchmarking study highlighted that international variation in 1-year survival might be partly explained by patients suffering from additional health condition(s) (comorbidities). Patients who die shortly after a cancer diagnosis may be more likely to be living with comorbidities, which could affect their chances of surviving. This study looked at the feasibility of generating comparable data on lung cancer patients living with one or more comorbidities.

No international studies have investigated the extent to which differences in comorbidity explain the observed variations in cancer survival. This is the first study to make international comparisons of commonly used measures of comorbidity derived from routine, population-based administrative health datasets. Cancer registry records of 233,981 lung cancer patients diagnosed between 2009 and 2012 were linked with routine hospital admission datasets in Australia (New South Wales and Victoria), Canada (Alberta and Ontario), Norway and the UK (England, Wales, Northern Ireland, Scotland).

Three measures of comorbidity were derived: the Charlson score, the Elixhauser score and total hospital stay based on each patient's hospital admissions in the three years prior to their lung cancer diagnosis. Analyses explored whether these scores were comparable and robust enough to investigate whether international differences we see in survival were explained by levels of comorbidity in each country's lung cancer population.

Results showed that across all the comorbidity measures, similar patterns were observed with 1-year survival and the prevalence of comorbid disease in the lung cancer population. For example, comorbidity is highest in the UK and lowest in Canada and 1-year lung cancer survival is high in Canada and low in the UK.

The study demonstrated, however, that whilst it is feasible to generate comorbidity scores in each jurisdiction and they were predictive of survival, their inter-jurisdictional comparability was limited. Hospital admission patterns and coding practices varied considerably between each jurisdiction and this limited the comparability of the comorbidity scores. Further work is required to standardise comorbidity data collections to enable investigations into the impact on international cancer survival differences.

Data Limitations

In the absence of truly independent data, such as those that would come from a high-resolution study involving detailed review and standardised coding of the medical histories of population-based cohorts of individuals from each jurisdiction, it is not possible to truly quantify any relevant differences in the datasets and, hence, the impact they may have on the comorbidity measures derived.

A lack of comparability of key prognostic measures for cancer between jurisdictions has been previously observed. For example, international comparisons of the influence of stage of disease at diagnosis on survival have been hindered by differences in the recording of stage between jurisdictions. Likewise, there is also evidence that differences in the registration practices of cancer registries may account for some of the variability in survival observed. Whilst such differences do not appear to entirely explain the international survival variation observed, they remain influential. Significant further work to standardise data collection is therefore required to enable such robust comparisons.

A further limitation of this study is the relatively short survival time of those diagnosed with lung cancer. With survival being poor and early mortality high even among more healthy patients, the additional effect of comorbid disease over and above the cancer on the number of people who die rapidly may be relatively small.

Key publications:

- Lüchtenborg M et al Investigation of the international comparability of population-based routine hospital data set derived comorbidity scores for patients with lung cancer. Thorax 2017. doi: 10.1136/thoraxjnl-2017-210362

ICBP phase 2

Building on the success and impact of phase 1, a second phase of the partnership was launched in 2016, including an expansion of cancer types, jurisdictions and new research topics. These research topics will build on the findings of phase 2, to further explore areas that may be causing this variation in outcomes.

Phase 2 research topics

- Updated international cancer survival benchmark
- Access to diagnostics
- Access to optimal treatment
- Cancer patient pathways
- Health system organisation

Figure 25: Phase 2 cancer types

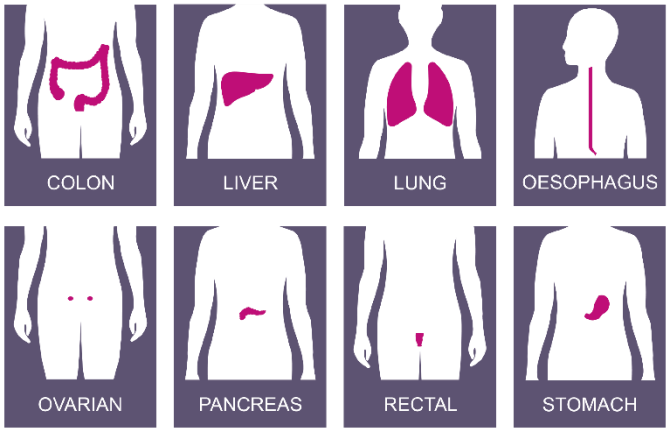
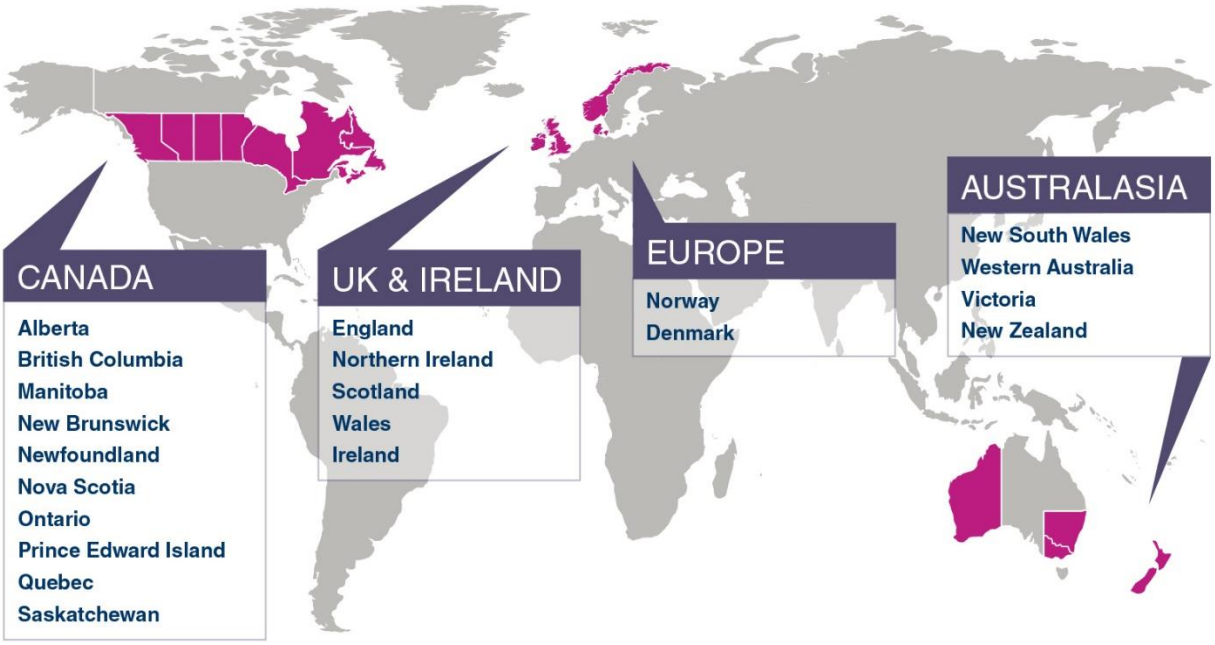


Figure 26: Phase 2 jurisdictions



Appendix

Figure 1: 1-year age-standardised net survival by country for rectal cancer 2000-2007
[Coleman et al, 2011]

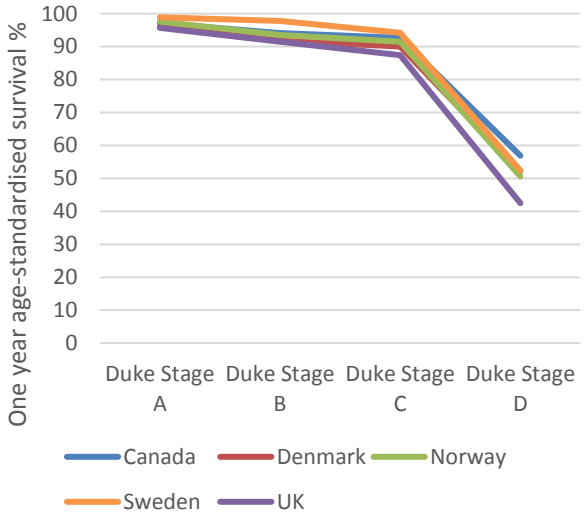


Figure 2: Observed stage distribution at time of diagnosis by country for rectal cancer 2000-2007
[Maringe et al, 2013]

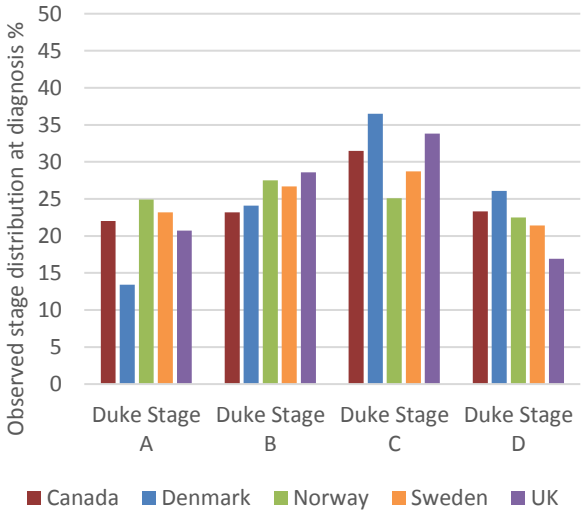


Figure 3: 1-year age-standardised net survival by country for ovarian cancer 2004-2007
[Coleman et al, 2011]

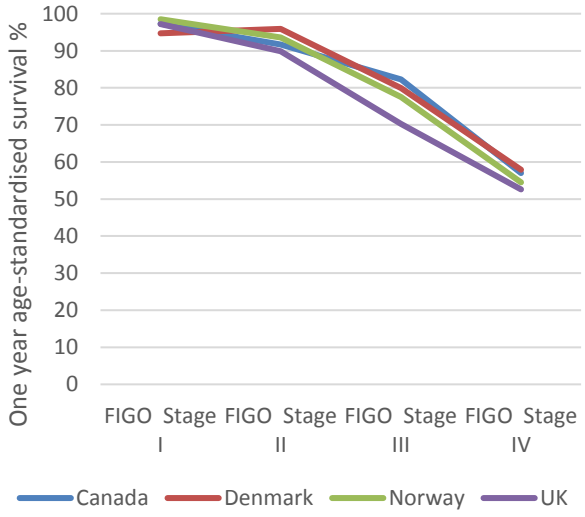


Figure 4: Observed stage distribution at time of diagnosis by country for ovarian cancer 2004-2007
[Maringe et al, 2012]

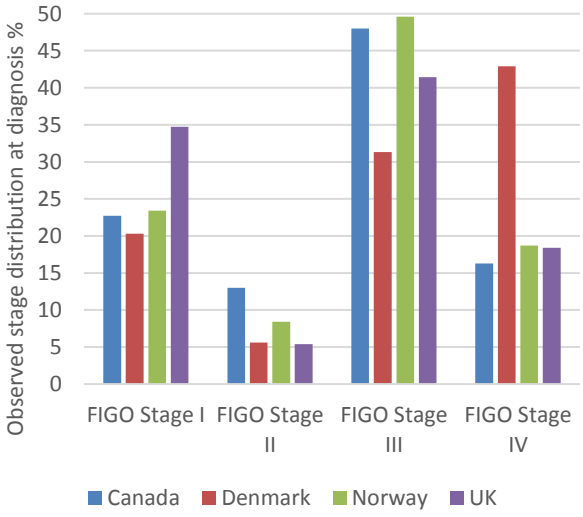


Figure 5: 1-year age-standardised net survival by country for non-small cell lung cancer 2004-2007 [Coleman et al, 2011]

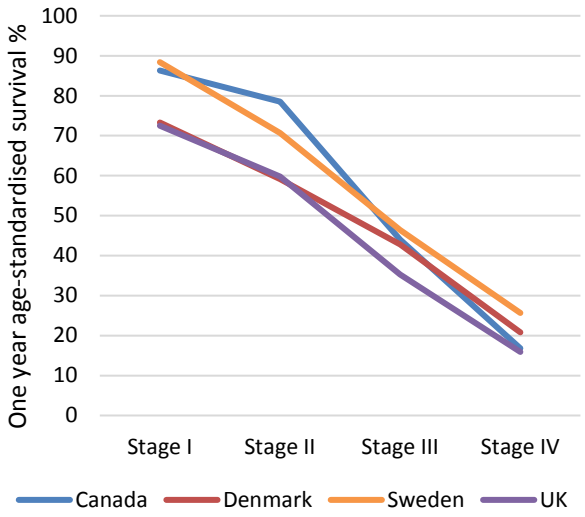


Figure 6: Observed stage distribution at time of diagnosis by country for non-small cell lung cancer 2004-2007 [Walters et al, 2013a]

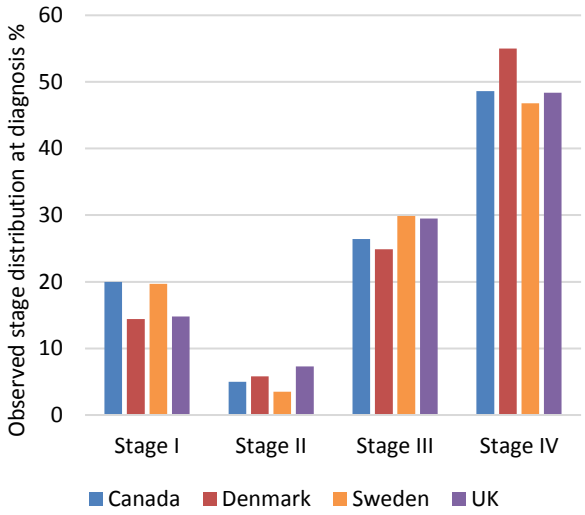


Figure 7: 1-year age-standardised net survival in breast cancer by country 2000-2007 [Coleman et al, 2011]

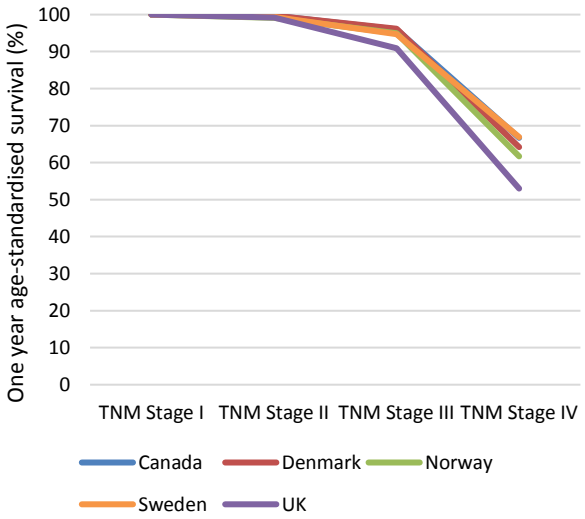


Figure 8: Observed stage distribution at time of diagnosis in breast cancer by country 2000-2007 [Walters et al, 2013b]

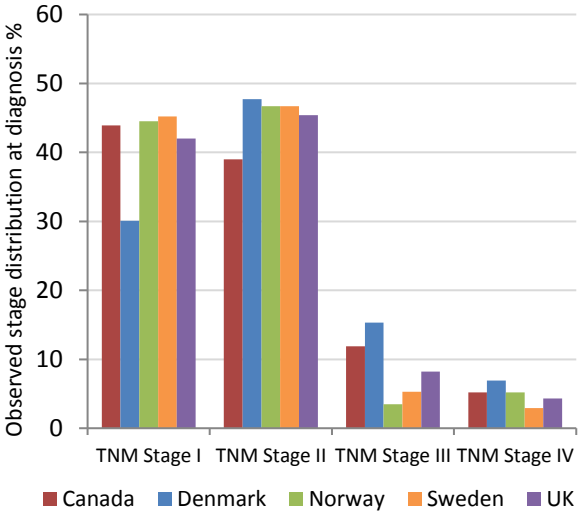


Figure 9: 3-year age-standardised net survival in breast cancer by country 2000-2007 [Coleman et al, 2011]

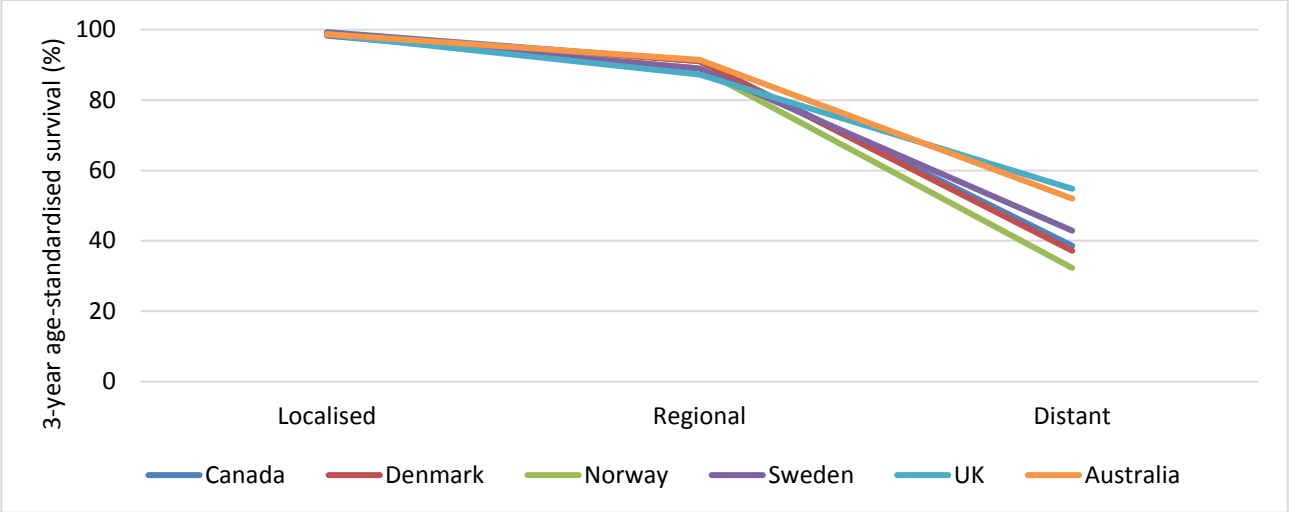
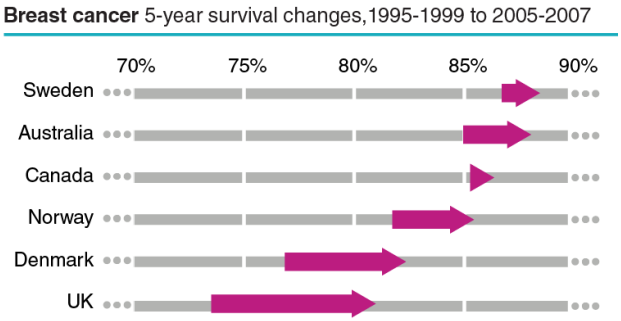
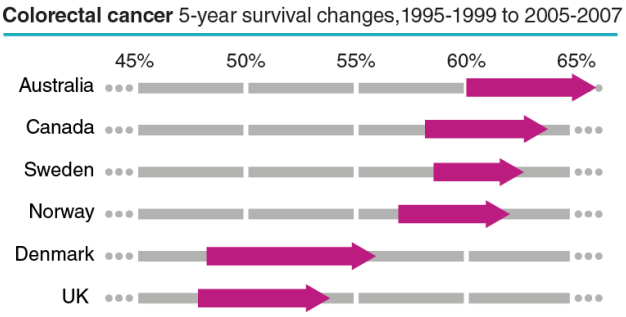
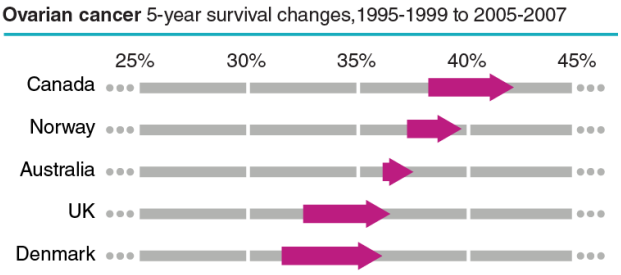


Figure 10: 5-year cancer survival improvements between 1995-1999 and 2000-2005 across ICBP countries [Coleman et al, 2011]







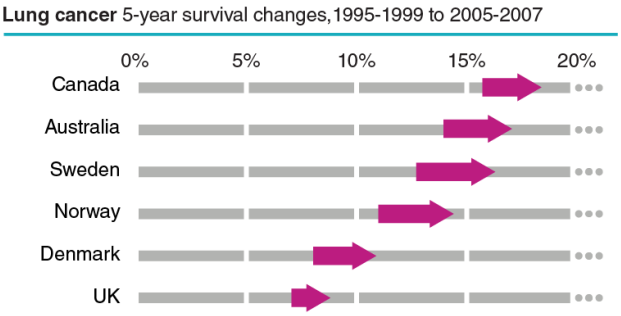


Table 1: Survival data from 1995-2007 ranked from highest to lowest [Coleman et al, 2011]

			New South	Victoria	Alberta	British Columbia	Manitoba	Ontario	Denmark	Norway	Sweden	England	Northern Ireland	Wales
Colorectal cancer	1-year	1995–99	80.3	79.6	77.6	80.7	79.8	78.7	71.7	78.6	81.8	70.2	74.3	68.3
		Ranked	*3*	*5*	*8*	*2*	*4*	*6*	*10*	*7*	*1*	*11*	*9*	*12*
		2000–02	83.2	81.6	79.8	82.4	80.4	81.7	73.9	78.7	82.8	72.9	76.8	72.3
		Ranked	*1*	*5*	*7*	*3*	*6*	*4*	*10*	*8*	*2*	*11*	*9*	*12*
		2005–07	84.7	85.1	80.4	84.3	82.1	83.9	77.7	82.4	83.8	74.7	76.2	73.6
		Ranked	*2*	*1*	*8*	*3*	*7*	*4*	*9*	*6*	*5*	*11*	*10*	*12*
	5-year	1995–99	61.2	58.4	56.3	59.8	57.6	58	48.2	56.9	58.5	47.8	51.1	45.9
		Ranked	*1*	*4*	*7*	*2*	*6*	*5*	*10*	*8*	*3*	*11*	*9*	*12*
		2000–02	65.1	61.1	58	61.5	59.6	61.3	51.7	58.8	60.6	51.2	54.3	50.3
		Ranked	*1*	*4*	*8*	*2*	*6*	*3*	*10*	*7*	*5*	*11*	*9*	*12*
		2005–07	66.4	65.5	58.3	64	63.3	64.9	55.8	62	62.6	53.7	55.2	52.3
		Ranked	*1*	*2*	*8*	*4*	*5*	*3*	*9*	*7*	*6*	*11*	*10*	*12*
	Conditional 5-year	1995-99	76.2	73.4	72.5	74.2	72.2	73.8	67.3	72.3	71.6	68.2	68.8	67.2
		Ranked	*1*	*4*	*5*	*2*	*7*	*3*	*11*	*6*	*8*	*10*	*9*	*12*
		2000–02	78.2	74.9	72.5	74.8	74	75.2	70.1	74.7	73.3	70.3	71.1	69.7
		Ranked	*1*	*3*	*8*	*4*	*6*	*2*	*11*	*5*	*7*	*10*	*9*	*12*
		2005–07	78.4	76.8	72.3	75.9	77.1	77.4	72.1	75.4	74.8	71.8	73	71.1
		Ranked	*1*	*4*	*9*	*5*	*3*	*2*	*10*	*6*	*7*	*11*	*8*	*12*
Lung cancer	1-year	1995–99	38.6	37.8	36.4	36.6	41.7	39.6	26.4	32.3	35.7	24.3	27.4	23
		Ranked	*3*	*4*	*6*	*5*	*1*	*2*	*10*	*8*	*7*	*11*	*9*	*12*
		2000–02	41.5	39.9	36.3	37.5	44.1	40.5	31.3	32.2	36.6	27.5	28.3	25.9
		Ranked	*2*	*4*	*7*	*5*	*1*	*3*	*9*	*8*	*6*	*11*	*10*	*12*
		2005–07	42.9	42.7	41.5	43	42.7	43.4	34.9	39.2	43.6	29.7	30.6	28.5
		Ranked	*2*	*4*	*7*	*5*	*1*	*3*	*9*	*8*	*6*	*11*	*10*	*12*
	5-year	1995–99	14.2	13.4	13.8	13.9	16.6	16.6	8	11	12.7	6.9	9.7	7.5
		Ranked	*2*	*5*	*4*	*3*	*1*	*1*	*9*	*7*	*6*	*11*	*8*	*10*
		2000–02	16.2	13.6	13.1	14	19.4	16.7	9.6	11	11.6	8	9.7	7.6
		Ranked	*3*	*5*	*6*	*4*	*1*	*2*	*10*	*8*	*7*	*11*	*9*	*12*
		2005–07	17.6	16.2	15.1	17.7	20.1	19.1	10.9	14.4	16.3	8.7	11	9
		Ranked	*4*	*6*	*7*	*3*	*1*	*2*	*10*	*8*	*5*	*12*	*9*	*11*
	Conditional 5-year	1995–99	35.9	34	37	37.2	39.5	41.3	28.6	32.1	35.1	26.6	33.8	29.2
		Ranked	*5*	*7*	*4*	*3*	*2*	*1*	*11*	*9*	*6*	*12*	*8*	*10*
		2000–02	38.1	33	35.6	36.5	44.2	40.5	29.4	32.8	31.5	27.4	31.8	27.7
		Ranked	*3*	*6*	*5*	*4*	*1*	*2*	*10*	*7*	*9*	*12*	*8*	*11*
		2005–07	40.1	36.6	35.4	40.3	47.4	43.5	30.3	35	36.5	27.9	33.8	30.2
		Ranked	*4*	*5*	*7*	*3*	*1*	*2*	*10*	*8*	*6*	*12*	*9*	*11*

			New South Wales	Victoria	Alberta	British Columbia	Manitoba	Ontario	Denmark	Norway	Sweden	England	Northern Ireland	Wales
Breast cancer (women)	1-year	1995–99	95.8	95.6	95.4	97.1	96.2	95.5	93	95.4	97.6	90.5	92.6	88.6
		Ranked	4	5	7	2	3	6	9	7	1	11	10	12
		2000–02	96.5	96	95.9	96.5	96.4	96	94.3	95.8	98.4	92.5	95	89.8
		Ranked	2	5	7	2	4	5	10	8	1	11	9	12
		2005–07	96.5	97.1	95.9	97.1	96.7	96.1	95	96.6	98	94.3	95	93.4
		Ranked	6	2	8	2	4	7	9	5	1	11	9	12
	5-year	1995–99	85.5	84.4	83.4	87.1	86	84.9	76.9	81.8	86.7	74.8	77.5	73.5
		Ranked	*4*	*6*	*7*	*1*	*3*	*5*	*10*	*8*	*2*	*11*	*9*	*12*
		2000–02	87.4	86.5	84.9	87.5	83.9	86.6	81.5	83.8	89.3	78.8	81.6	76.7
		Ranked	*3*	*5*	*6*	*2*	*7*	*4*	*10*	*8*	*1*	*11*	*9*	*12*
		2005–07	87.8	88.5	82.6	89.1	86.8	86.4	82.4	85.5	88.5	81.6	84.1	81
		Ranked	*4*	*2*	*9*	*1*	*5*	*6*	*10*	*7*	*2*	*11*	*8*	*12*
	Conditional 5-year	1995–99	89.1	88.2	87.3	89.7	89.4	88.9	82.6	85.6	88.8	82.4	83.6	82.7
		Ranked	*3*	*6*	*7*	*1*	*2*	*4*	*11*	*8*	*5*	*12*	*9*	*10*
		2000–02	90.6	90	88.5	90.6	87	90.2	86.4	87.3	90.6	85	86.3	85.1
		Ranked	*1*	*5*	*6*	*1*	*8*	*4*	*9*	*7*	*1*	*12*	*10*	*11*
		2005–07	90.9	91.2	86	91.8	89.7	89.8	86.6	88.4	90.2	86.4	88.9	86.4
		Ranked	*3*	*2*	*12*	*1*	*6*	*5*	*9*	*8*	*4*	*10*	*7*	*10*
Ovarian cancer	1-year	1995–99	70.4	70.4	69.4	74	68.9	71.9	63.4	70.4		59.8	62.8	56.6
		Ranked	3	3	6	1	7	2	8	3		10	9	11
		2000–02	72.8	68.9	71	75.3	74.1	73.1	67.9	74.3		62.6	64.9	60
		Ranked	5	7	6	1	3	4	8	2		10	9	11
		2005–07	73.3	73.7	69.7	77.6	68	75.9	70.6	75.2		65.4	63.9	60.5
		Ranked	5	4	8	1	7	2	6	3		9	10	11
	5-year	1995–99	35.9	36.4	41.4	35.1	32.7	39	31.5	37.2		32.5	39	31.5
		Ranked	6	5	1	7	8	2	10	4		9	2	10
		2000–02	39.6	34.1	34.9	37.8	37.1	39.1	33.7	40.2		34.3	37.8	33.8
		Ranked	2	9	7	4	6	3	11	1		8	4	10
		2005–07	39.9	34.2	36.9	44.1	28.8	43.2	36.1	39.7		36.4	36.5	36.3
		Ranked	3	10	5	1	11	2	9	4		7	6	8
	Conditional 5-year	1995–99	48.6	49.2	58.3	45.7	43.7	53.3	48.9	50.6		52.8	63	53.8
		Ranked	9	7	2	10	11	4	8	6		5	1	3
		2000–02	53	47	46.4	49.1	48.1	52.2	47.2	52.2		52.6	55	53.9
		Ranked	3	10	11	7	8	5	9	5		4	1	2
		2005–07	52.7	43.5	50.8	55.8	39.1	55.7	48.8	50.9		53.5	55.7	57.4
		Ranked	6	10	8	2	11	3	9	7		5	3	1