Scottish Routes from Diagnosis: Context & Methodology

Table of Contents

Table of Figures/Tables

Acknowledgements

Introduction

Background

The cancer story is changing. The combination of an ageing and growing population, better diagnosis of cancer and more effective cancer treatment means that there are now unprecedented numbers of people living in the long term after a cancer diagnosis. This will only increase, as the number of people living with cancer in the UK is projected to rise from approximately 2.5 million in 2015 to 4 million by 2030 (Maddams et al, 2012). In many cases cancer is becoming a condition that people live with for many years; people are now twice as likely to survive at least 10 years after being diagnosed with cancer as they were at the start of the 1970s (Quaresma et al, 2014).

People living with and beyond cancer will have different intensities and complexities of need. These needs depend on the type of cancer experienced and the treatment undergone, as well as on other patient, psychosocial and cancer characteristics. These needs will fluctuate over time. The need to better understand Scotland's cancer population and the services and support they require was central to the Scottish Government's *Beating Cancer: Ambition and Action* (2016), which called for Scotland's cancer treatments and services to be rooted in evidence. Effective analysis of existing routinely collected cancer-related data is a contributory means of *"embed[ding] research in the ethos of our healthcare services"*. To this end, the Macmillan-Information Services Division[1] (ISD) analytical partnership set out to investigate variations in cancer pathways in the Scottish Routes from Diagnosis (SRfD) project.

What is Scottish Routes from Diagnosis?

Scottish Routes from Diagnosis (SRfD) focuses on improving the understanding of post-diagnosis pathways for people living with cancer and the services needed to support them.

It is a project that links and analyses routinely collected data with an aim to quantitatively describe the survivorship experiences of people living with cancer in Scotland, both across and within cancer types. It is a powerful and robust approach based on an adapted framework of the RfD in England.

Aim of the project

The aim of the project is to investigate the survivorship experiences of residents of Scotland diagnosed with breast, colorectal, lung or prostate cancer in 2007 and in 2012.

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[1] Part of NHS National Services Scotland

This aim was sought through the following objectives:

1. Create meaningful survivorship outcome groups for people diagnosed with cancer in Scotland, which can be applied to allow comparison of cancer experiences across and within different cancer types.
2. Provide a detailed description of survivorship for the four most commonly diagnosed cancers in Scotland by:
    o Investigating patient, tumour and treatment characteristics by cancer type and survivorship outcome group.
    o Providing insights into the role of comorbidities (pre and post diagnosis) in survivorship.
    o Exploring end of life experience and cause of death.
    o Exploring the role and variation of unscheduled care and other inpatient stays in cancer diagnosis and in the post-diagnosis period.
    o Examining the frequency and time interval of metastatic disease, previous and subsequent diagnoses of cancer.
3. Present the results of the above analyses in a clear way that helps to identify relationships and further the understanding of how patient characteristics and health events influence the diversity of outcomes within and between cancer types.

This first SRfD publication focuses on the first objective with a detailed description of the methodology undertaken, and is published alongside details of the cohort characteristics. Subsequent publications will focus on each of the other areas of interest described in Objective 2 and will be published at a later date.

Why is this important?
Cancer is not just one disease which can be treated in one specific way; there are over 200 different types of cancer that each present in different ways and have their own treatment methods. As such, people's experiences of cancer can vary enormously.

Even within a specific cancer type, there may be a wide diversity in people's experiences. This can be related to a variety of factors, for example: the sub-type of cancer; a person's general state of health at time of diagnosis; a person's social network of support; or the stage of cancer when diagnosed. As a result, the survivorship outcome groups developed as part of this project seek to provide insight into not only how people's experiences vary across different cancers, but also how they vary within cancer types. It is hoped this will provide insight into future cancer service planning and cancer research.

Methodology

Which cancers were investigated (and why)?

The cancer types chosen for SRfD were:

- **Female breast cancer (ICD-10 C50) – referred to as 'Breast cancer'**

- **Colorectal cancer (ICD-10 C18-C20)**

- **Trachea, bronchus & lung cancer (ICD-10 C33-C34) – referred to as 'Lung cancer'**

- **Prostate cancer (ICD-10 C61)**

These four cancer types are the most common in Scotland, amounting to over half of all cancers (54%) diagnosed in Scotland in 2017 (ISD, 2019). The large numbers of cases involved provide the basis for relatively detailed analysis.

This cohort represents two sex-specific cancers (breast and prostate) as well as cancers which typically have different aetiologies, or set of causes. Furthermore, these cancers generally have different prognoses, with breast and prostate cancers typically having relatively high survival over time and lung cancer having lower survival over time (see Figure 2.1).

The inclusion of rarer cancers was considered, but was limited by the RfD model requirements (i.e. extensive analysis of detailed sub populations within the cancer types) and the statistical disclosure protocol.

How was this done?

Following approval of the SRfD project by the Public Benefit and Privacy Panel[2] (PBPP), a national extract was taken from the Scottish Cancer Registry (SMR06) that included all people diagnosed with breast, colorectal, lung or prostate cancer in 2007 and in 2012.

The following data inclusion and exclusion criteria were applied to this extract:

- People who did not have a valid unique patient identifier (UPI) were excluded. This identifier is called the Community Health Index (CHI) number and without it a person's health records cannot be linked.

- People aged <15 and >99 years at the time of diagnosis were excluded.

- Cases where the death certificate was the only notification of cancer to the Cancer Registry (DCO cases) were excluded.

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[2] Public Benefit and Privacy Panel for Health and Social Care, https://www.informationgovernance.scot.nhs.uk/pbpphsc/

- People were excluded if they were recorded as having moved out of Scotland or if they were *presumed* deceased (people aged over 110) on their cancer registration record. Those who were known to be deceased, based on death registrations, were included.

- Where a person had more than one cancer diagnosis of the same type in a given year, only the first cancer diagnosis was included for analysis; this is referred to as a person's 'index cancer'. People can appear in more than one cancer cohort per year; but only once in each cohort. For example, a woman can be in the 2007 breast cohort and the 2007 colorectal cohort, or the 2007 breast cohort and the 2012 breast cohort, but if she had two breast tumours in 2007 she will only appear in the 2007 breast cohort once based on the first breast cancer in that year.

- People with a cancer diagnosis prior to their index diagnosis were included, but were flagged for identification and additional analysis within a future chapter.

Following the application of the above inclusion/exclusion criteria, the following numbers of people/index cancers were included for analysis in the cohorts:

Table 1.0: Number of people diagnosed with cancer following inclusion/exclusion criteria, by diagnosis year and cancer type

Cancer Type	Diagnosis year	
	2007	2012
Breast Cancer	4,020	4,468
Colorectal Cancer	3,618	3,825
Lung Cancer	4,884	5,182
Prostate Cancer	2,760	3,107

While numbers for all these cancer types increased between 2007 and 2012, changes in the Scottish population (both the total population and the age composition) mean that incidence rates of these cancers have not increased over time. For example, both lung and colorectal cancer showed indications of a fall in European age standardised rates (EASR) over this time period, and this has decreased further in the years since. Prostate cancer has shown very little change in EASRs either between 2007 and 2012 or in the period since. Breast cancer showed some suggestion of an increase in EASRs between 2007 and 2012, this has since fallen (ISD, 2019).

Approval obtained from PBPP also permitted data linkage of various relevant NHS administrative datasets to the Scottish Cancer Registry extract and to National Records of Scotland mortality data (please see the notes box on page 11 for further details of the various datasets used in this analysis).

People included in the 2007 cohorts were followed-up for 10 years; those in the 2012 cohorts were followed-up for 5 years. By looking at two follow-up periods, it was possible to look at longer term outcomes alongside more contemporary patient experiences. For the 2012 cohorts it was also possible to include data from more recently developed datasets (e.g. the Unscheduled Care dataset). The data used in this study relate to the most recently available years of cancer registration and the most up-to-date death information available at time of data extraction (i.e. 2007 and 2012 cancer registrations were followed up to the end of 2017).

Note that the data presented in this report primarily relate to people diagnosed in 2012 unless otherwise specified. However, results for both 2012 and 2007 are available in Appendix B.

Details of the data flow and the numbers of records linked for analysis, for the 2007 and 2012 cohorts, are presented in Figure 1.0 and Figure 1.1.
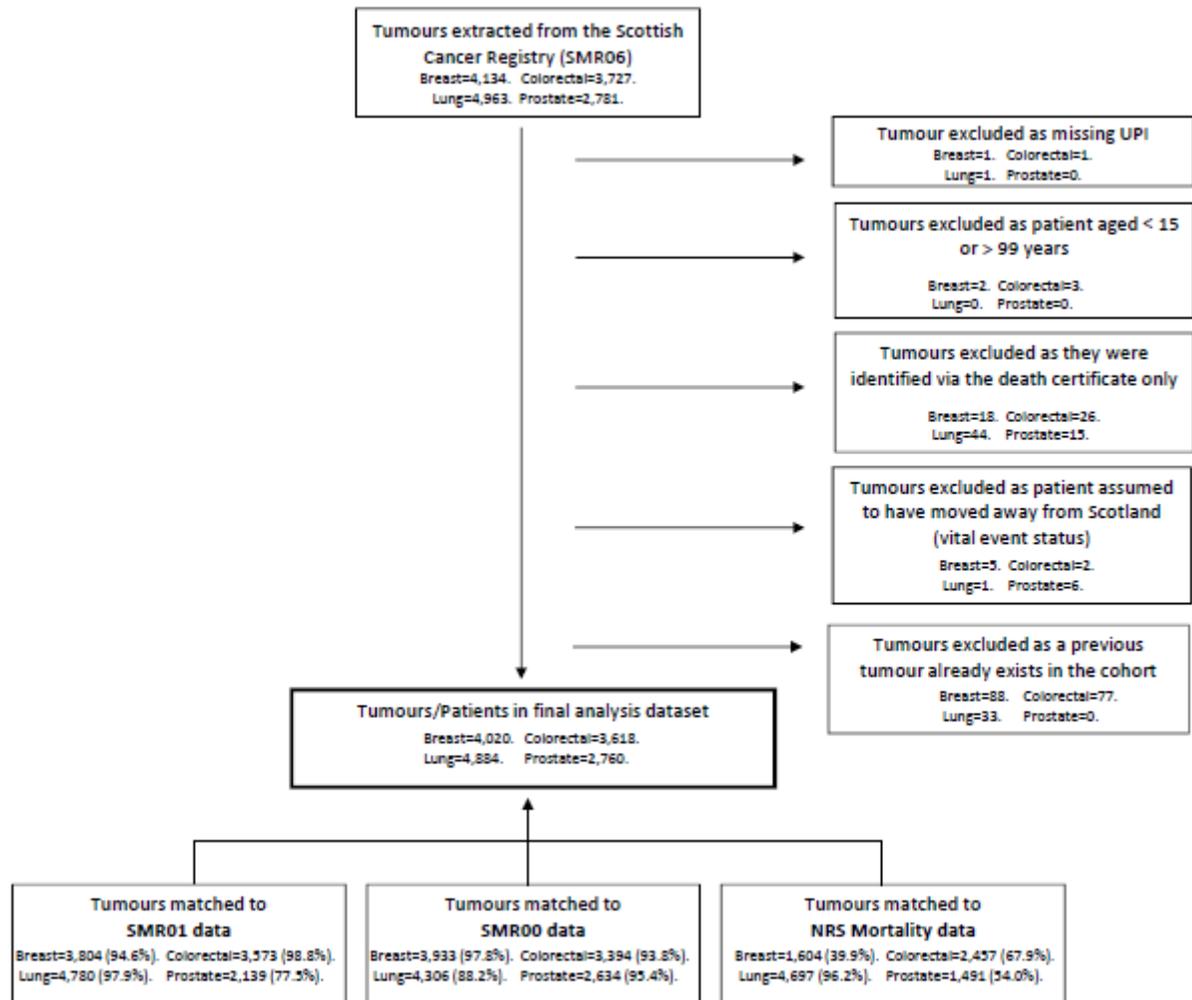
Figure 1.0: Data flow and linkage numbers: 2007

Tumours extracted from Scottish
Cancer Registry (SMR06)
Breast=4,630. Colorectal=3,916.
Lung=5,288. Prostate=3,120.

Tumour excluded as missing UPI
Breast=0. Colorectal=0.
Lung=0. Prostate=0.

Tumours excluded as patient aged < 15
or > 99 years
Breast=5. Colorectal=3.
Lung=1. Prostate=0.

Tumours excluded as they were
identified via the death certificate only
Breast=4. Colorectal=12.
Lung=26. Prostate=4.

Tumours excluded as patient assumed
to have moved away from Scotland
(vital event status)
Breast=11. Colorectal=2.
Lung=4. Prostate=9.

Tumours excluded as a previous
tumour already exists in the cohort
Breast=142. Colorectal=74.
Lung=75. Prostate=0.

Tumours/Patients in final analysis dataset
Breast=4,468. Colorectal=3,825.
Lung=5,182. Prostate=3,107.

Tumours matched to
SMR01 data
Breast=4,204 (94.1%).
Colorectal=3,754 (98.1%).
Lung=5,022 (96.9%).
Prostate=2,354 (75.8%).

Tumours matched to
SMR00 data
Breast=4,383 (98.1%).
Colorectal=3,602 (94.2%).
Lung=4,660 (89.9%).
Prostate=3,042 (97.9%).

Tumours matched to
PIS data
Breast=4,468 (100%).
Colorectal=3,791 (99.1%).
Lung=5,163 (99.6%).
Prostate=3,105 (99.9%).

Tumours matched to
USC data
Breast=1,853 (41.5%).
Colorectal=1,851 (48.4%).
Lung=3,122 (60.2%).
Prostate=1,172 (37.7%).

Tumours matched to
NRS Mortality data
Breast=1,005 (22.5%).
Colorectal=1,947 (50.9%).
Lung=4,745 (91.6%).
Prostate=984 (31.7%).

Figure 1.1: Data flow and linkage numbers: 2012

There were 217 people who were included in two cohorts (i.e. people with the same cancer type in 2007 and 2012, people with two different cancer types in 2007 or 2012, or people with different cancer types in 2007 and 2012) and three people who were included in three cohorts.

While the figures shown in this report are based on national data, the results will differ from published National Statistics due to the inclusion / exclusion criteria applied in this study.

Survivorship outcome group definition development

Alongside the approval and linkage of the required data was the development of Survivorship Outcome Groups (OGs). Robust definitions of these groups are fundamental to the SRfD project and are part of the comparative framework. This being the case, a Clinical Advisory Group (CAG) was formed to critically review, advise on, and sign off the definitions of these groups, as well as to inform and advise on the implementation, interpretation and future direction of the project.

This group includes clinical representatives of all cancer types investigated as well as representatives from general practice, nursing and palliative care. It also includes representatives from different geographic areas across Scotland. The CAG first met in November 2017 to contribute their views and lend their expertise to the project.

The Macmillan-ISD Scottish Cancer Pathways Steering Group also informed the development of the SRfD framework and OGs, both prior to the formation of the CAG and as required throughout the project.

One key aspiration in the creation of the OGs was the ability to produce definitions which could be applied across the different cancer types. This meant a more general approach to the OGs was taken than would have been the case if cancer type-specific OGs had been produced. However, this

approach enabled the OGs to be compared across cancer types, as well as within cancer types, for the first time in an analysis of Scottish cancer data.

Equally important was the requirement to define enough OGs to suitably delineate the experiences and outcomes for people living with cancer (PLWC), while remaining few enough that the OGs were relatively easy to use (for example, in planning, service development, or research). There also had to be enough people within each OG to permit further meaningful interrogation of the data.

The final OG definitions were agreed and signed off by the CAG and the Director of the Scottish Cancer Registry in August 2018.

The Outcome Groups (OGs) and their definitions are:

Outcome Group 1 (OG1) – People living with similar acute healthcare needs* compared to the time before their cancer diagnosis

Anyone not in OG3 or OG4 and with similar acute healthcare bed day rates to pre-diagnosis.

Outcome Group 2 (OG2) – People living with increased acute healthcare needs* compared to the time before their cancer diagnosis

Anyone not in OG3 or OG4 and with increased acute healthcare bed day rates post-diagnosis compared to their pre-diagnosis rates

Outcome Group 3 (OG3) – People likely to be living with a continued presence of cancer after their cancer diagnosis

Anyone not in OG4 and any of the below:

- The primary cause of death mentioned any cancer, where death occurred after 12 months and within 5 years

- Advanced stage at diagnosis: Stage 3 or stage 4 for breast and lung cancer, Dukes' C or Dukes' D for colorectal cancer, Gleason sum 8-10 for prostate cancer

- Any evidence of metastatic disease (augmenting metastases information on SMR06 with SMR01 (inpatient data) hospital codes) within 5 years

- Any diagnosis of a new primary cancer on SMR06 within 5 years

- Evidence of chemotherapy or radiotherapy taking place after 12 months from diagnosis and within 5 years[†]

Outcome Group 4 (OG4) – People with limited survival (<12 months) following their cancer

- Less than 12 months survival (death within 12 months of date of cancer diagnosis)

* changes in acute healthcare needs were identified by comparing each person's bed day rate post-diagnosis to their rate pre-diagnosis. If the rate of bed days in a three year period post-diagnosis was higher than the rate of bed days in a 3 year period pre-diagnosis it was used as an indicator that the acute healthcare needs had increased post-diagnosis. A six month exclusion pre-diagnosis was used to avoid artificially inflating the rate by including any bed days leading up to the original cancer diagnosis. The first 12 months post-diagnosis were excluded to allow for the main treatment period.

	Date of diagnosis		End of follow-up (+5yrs)
-3.5yrs	**6m**	**12m**	**+4yrs**
3 years Pre-diagnosis period	Excluded period	3 years Post-diagnosis period	
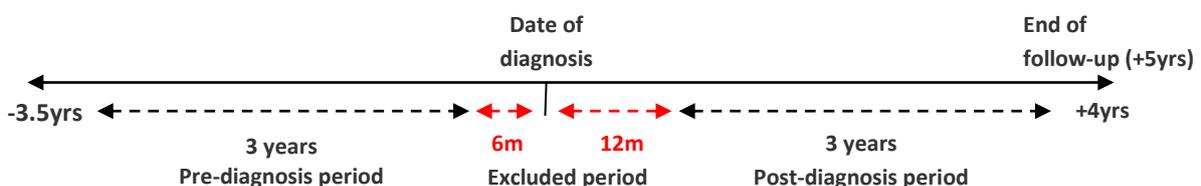
† OPCS codes: X65, Y358-Y359, Y351-Y354, Y361, Y363, Y364, Y902, X721-X724, X728-X729, X731, X738-X739

The OGs separate out people who die soon after a cancer diagnosis from people who live beyond 1 year, but who experience further cancer activity (for example, through metastatic disease, ongoing treatment beyond 12 months, or new primary cancers at a later point in time). It also seeks to differentiate between those who live in similar health after their cancer and treatment from those who experience poorer health after their cancer and treatment. It is acknowledged that throughout the period of study, people will have been aging and therefore their risk of poorer health is likely to have increased; however, this analysis aims to base groupings on lived experiences rather than trying to ascribe certain comorbidities, or worsening of comorbidities, to the cancer. There will be further investigation of specific comorbidities as part of the planned chapter on '*An investigation into the role of comorbidities in the cancer pathway'.*

Limitations

These OG definitions do not completely capture and identify the multitude of varying outcome pathways that can occur from a cancer diagnosis; however, they do meet the criteria of being both comparable across cancer types and identifying distinct groups of people sufficiently large enough to allow meaningful analysis. The OGs could be more specific and cover a more granular level of experience; however, this would limit further sub-analysis, investigation and comparability.

One of the most important limitations to acknowledge is that this project is based entirely on nationally available administrative systems; as such it is based on secondary care data only. There will be comorbidities and healthcare needs managed entirely through other routes (e.g. primary care) which are not accounted for by the OGs. Additionally, the number of days spent in hospital (bed days) are used as a proxy for need, but this may not always be an accurate reflection of actual need.

By using national data in this way, broad assumptions are being made about the types of people categorised within each OG; these assumptions may not always be accurate. For example, we hypothesise that many people in OG1 and OG2 will have had successful treatment, but this may not always be the case.

OG3 in particular is a diverse group and is intended to reflect the many different ways cancer can be an ongoing part of a person's life beyond the time of diagnosis. The broad intention of OG3 is to identify any direct cancer related activity in the 5 year period following cancer diagnosis, which can be picked up using national datasets. Consequently, OG3 is a heterogeneous group representing people with a mixture of cancer treated with a curative intent, but also people with non-curable cancers. For example, although stage 3 cancers are included in OG3, they may be treated with curative intent.

Also included in OG3 are people with second cancers, however there is no delineation regarding what the cancer type or the severity of impact the second cancer will have on a person's life. As a result, this does not mean that everyone in OG3 will have had a continuous presence of cancer for the whole period; many will have periods which are apparently cancer free before a further cancer is diagnosed or further cancer treatment activity recorded.

The OG3 definition consists of a series of indicators of further cancer activity, but this may be incomplete. Consequently, this group should be viewed as being likely to have had a continued, *but not necessarily continuous*, presence of cancer (in some form) in the five years following diagnosis.

Table 1.1 shows the number and percentage of people within OG3, defined by the subcategory (or subcategories) they are in and by cancer type.

Table 1.1: Outcome Group 3 - Breakdown of subcategories, by 2012 cohort

Indicator[1]	Breast 2012		Colorectal 2012		Lung 2012		Prostate 2012	
	N	% of OG3	N	% of OG3	N	% of OG3	N	% of OG3
Any mention on death certificate of cancer after 12 months (primary cause only) and within 5 years of diagnosis	452	25%	729	47%	1,114	80%	500	40%
Advanced stage at diagnosis	675	37%	1,030	66%	778	56%	667	54%
Any evidence of metastatic disease (augmenting metastases information on SMR06 with SMR01 hospital codes within 5 years of diagnosis)	1,376	76%	969	62%	864	62%	691	56%
Any diagnosis of a new primary cancer on SMR06 within 5 years of diagnosis	318	17%	259	17%	174	12%	195	16%
Evidence of chemotherapy or radiotherapy taking place after 1 year from diagnosis, any diagnostic/procedure[2] position (using procedure and diagnosis codes: SMR01 and SMR00) and within 5 years of diagnosis	538	30%	346	22%	276	20%	305	25%
Total people in Outcome Group 3	**1,819**		**1,553**		**1,398**		**1,243**	

1 People may have more than one indicator so the total percentage is greater than 100%
2 All procedure positions searched using the first 4 digits of each procedure code only

- Relatively small proportions of people across all four cancer types were in OG3 as a result of a new primary cancer (12-17%);
- For breast cancer, 76% of the women in OG3 had evidence of metastatic disease at some point within 5 years of diagnosis;
- For colorectal cancer, the highest proportions of the people in OG3 were as a result of evidence of metastatic disease within 5 years (62%) or advanced stage at diagnosis (66%);
- Of the people in OG3 with lung cancer, 80% were categorised due to a primary cause of lung cancer recorded on their death certificate, while 62% had evidence of metastatic disease within 5 years of diagnosis.
- For prostate cancer, 54% of the men in OG3 had an advanced stage of cancer at diagnosis and 56% had evidence of metastases within 5 years of diagnosis;

Currently there is no consistent and robust method of identifying distant recurrence in the nationally available datasets, and this is therefore a limitation of this analysis. Therefore, distant recurrence is not considered a part of OG3. A future chapter will focus on the role of multiple cancers within these cohorts; however, better data on recurrence would enable further refinement of the analysis and understanding of the impact on people's lives.

It is recognised that there is no single definition of people's needs and this initial work is only a starting point. The way people use services – in this case, hospitals – is one way that they express their needs. This is how we have defined needs in SRfD. A strength of this analytic approach is that Scottish hospital records are of a high quality and are mostly complete. However, these records are not without their limitations as people in need may be unable to, or decide not to, seek hospital care despite needing it. Furthermore, they may seek hospital care and not receive it (unmet needs) or be treated in hospital when an alternative setting may be more appropriate. It is therefore helpful to

also consider how the provision and use of services compares between different people (comparative need) and views of experts (normative need). What people feel they need (felt need) needs to be listened to. Further work is therefore required to understand these other perspectives on need, using a range of methods, including qualitative research (Bradshaw, 1972; Stevens et al, 1998). Other factors such as self-efficacy and the role of support networks (for example), whilst vital to survivorship experience, are outside the scope of this project.

As survival from cancer improves, there is an increasing interest in measuring people's experiences. These can be assessed in a variety of ways. For example, Macmillan jointly funds the Scottish Cancer Experience Survey with the Scottish Government, which is run in partnership with ISD. A variety of measures have also been developed to record people's experiences in clinical settings – as patient reported outcome measures and as patient reported experience measures (PROMs and PREMs, respectively). As with measuring need, it is recognised that the description of experience in this work, reflected in hospital care, is one of many ways of describing the experiences of living after a diagnosis of cancer.

It is also important to note that not all of the increased need presented in this analysis can be attributed to a cancer. People are likely to experience higher rates of comorbidities as they age, regardless of cancer or its impact. This analysis seeks to understand the lived experiences of people diagnosed with cancer and therefore a decision was made not to statistically adjust results for ageing. This has the advantage of producing a clearer picture of people's real experiences, however it is acknowledged that these experiences cannot be attributed to the cancer diagnosis alone.

SRfD was designed as a descriptive analysis, enabling detailed and in-depth understanding of the four most prevalent cancers in Scotland (breast, prostate, colorectal and lung). However, the design of this study does not frame the needs or outcomes of people with cancer compared with the general Scottish population.

While these cancers make up over half of all cancers diagnosed each year in Scotland, there were almost 15,000 cancers of other types (14,872) diagnosed in 2017 (ISD, 2019) and this study does not inform on survivorship among this significant group of PLWC.

The time periods chosen for this analysis (2007 and 2012) allow for five and ten year follow-up and use the latest available data at the time of data extraction. It is possible that incidence trends, treatment methods and survival may have changed in the intervening period.

Statistical Software
The following Statistical software packages were used in this analysis:

- IBM SPSS Statistics 24
- R 3.5.1 was used to produce the treemap diagrams.
- STATA 13 was used for Kaplan-Meier estimates. Survival was calculated using Kaplan-Meier observed survival methods.

Further Information
In this report a series of terms and abbreviations are used, these can be found in Appendix A.

For more information on the Scottish Routes from Diagnosis project or for more general information on the Macmillan and ISD Scotland Scottish Cancer Pathways collaboration please see the [Macmillan](#) or [ISD websites](#).

Results

Throughout the presentation of these results, please note that 5 year post-diagnosis data refers to people diagnosed in 2012, and 10 year post-diagnosis data refers to people diagnosed in 2007.

Survivorship outcome groups

- **The outcome experiences of people diagnosed with different cancer types can be very different.**

- **Around half of people diagnosed with breast or prostate cancer in 2012 were living with increased (OG2) or similar acute healthcare needs (OG1). This compared to a third of people diagnosed with colorectal cancer and fewer than one in ten of those with lung cancer.**

- **Many people diagnosed with cancer live with a continued presence of cancer – around 40% of people diagnosed with prostate, breast or colorectal cancer in 2012 were likely to be living with a continued presence of cancer (OG3) in the 5 years after diagnosis.**

The proportion of people in each survivorship outcome group varies across the four cancer types. However, the proportion of people in each outcome group, for each cancer type, is broadly similar for people diagnosed in 2007 and 2012 (Table 2.0)

Table 2.0: Number and percentage of people in each survivorship outcome group, by year of diagnosis and cancer type

| | 2007 | | | | | | | | 2012 | | | | | | | |
| | Breast cancer | | Colorectal cancer | | Lung cancer | | Prostate cancer | | Breast cancer | | Colorectal cancer | | Lung cancer | | Prostate cancer | |
Survivorship Outcome Group	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Living with similar acute healthcare needs (OG1)	1,231	31%	451	12%	141	3%	728	26%	1,444	32%	557	15%	179	3%	858	28%
Living with increased acute healthcare needs (OG2)	865	22%	658	18%	182	4%	715	26%	926	21%	682	18%	238	5%	742	24%
Living with a continued presence of cancer (OG3)	1,614	40%	1,496	41%	1,118	23%	1,045	38%	1,819	41%	1,553	41%	1,398	27%	1,243	40%
Limited Survival (OG4)	310	8%	1,013	28%	3,443	70%	272	10%	279	6%	1,033	27%	3,367	65%	264	8%
Total	4,020		3,618		4,884		2,760		4,468		3,825		5,182		3,107	

Figure 2.0 shows the proportion of people who where diagnosed with each cancer type in 2012. It also shows how people diagnosed with each type of cancer are distributed across the four survivorship outcome groups.
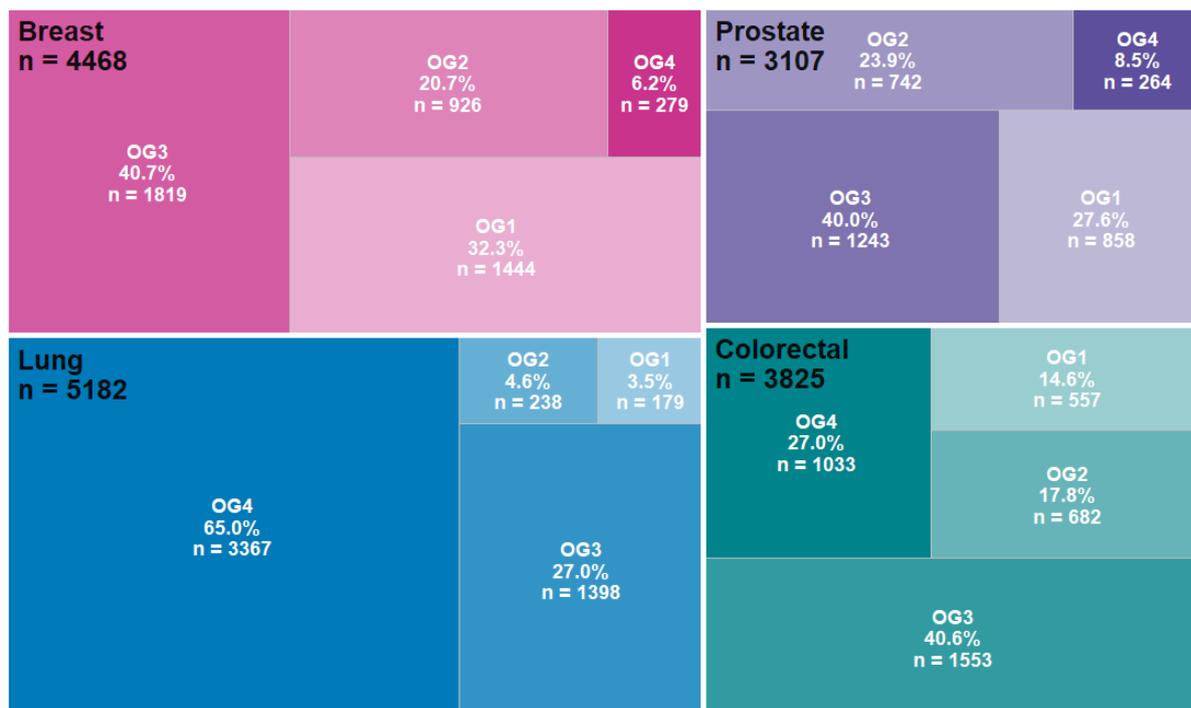
Figure 2.0: Proportion of people in each survivorship outcome group, by cancer type: 2012

This illustrates the different outcomes for each cancer. Around two thirds (65%) of people with a lung cancer diagnosis have limited survival and almost a third (27%) have a likely continued presence of cancer. This contrasts with breast and prostate cancers, where a relatively small proportion of people (6% of breast cancer and 8% of prostate cancer patients) have limited survival.

Just over half of all people diagnosed with breast or prostate cancer were living with similar or increased healthcare needs (OG1 and OG2) (53% of breast cancer and 51% of prostate cancer patients), whereas a third (32%) of those diagnosed with colorectal cancer were in these outcome groups. Relatively few people diagnosed with lung cancer in 2012 were living with similar or increased acute healthcare needs (8%).

One similarity among people diagnosed with breast, colorectal or prostate cancer was the proportion who were living with a likely continued presence of cancer (around 40% for all three cancer types). This indicates that, for a large proportion of people diagnosed with these common cancers in Scotland, cancer becomes a continued presence and the initial treatment of a person's index cancer may be just one part of their overall cancer experience.

For the purposes of further analysis (both here and in other publications associated with this work) it is worth noting that there are fewer people in certain survivorship outcome groups (lung cancer OG 1 and OG2; prostate and breast cancer OG4). This limits the conclusions that can be drawn for these groups.

Survival time

In this section survival time after diagnosis is presented by cancer type and by outcome group. However, it should be noted that survival time is part of the definition used to identify people in survivorship OG4 and this should be considered in any interpretation of these findings.

It is also worth noting that this is a measure of crude survival; it includes all causes of mortality (both cancer related and non-cancer related). This means outcome groups and cohorts with older populations will have lower survival, as older people often have lower cancer survival and higher background mortality.

- **Five year cancer survival rates for the 2012 cohorts vary by cancer type, from 10% survival in people diagnosed with lung cancer, to 78% in women diagnosed with breast cancer.**

- **There were statistically significant increases in 5 year survival for the 2012 breast, colorectal and lung cancer cohorts when compared to the equivalent 2007 cohorts as a whole.**

- **Among people who were in the limited survival outcome group (OG4), people diagnosed with lung cancer died more quickly than people with other types of cancer.**

Survival curves for the 2012 cohorts are shown in Figure 2.1, indicating the differences in survival for the four cancer types over time.
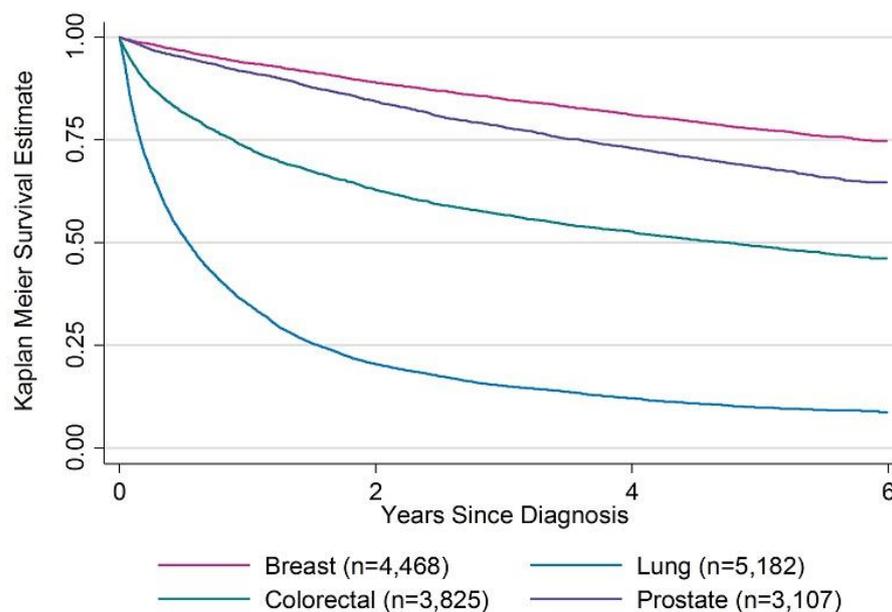

Figure 2.1: Survival curves for the 2012 cancer cohorts over time from diagnosis

Across all outcome groups, 94% of women diagnosed with **breast** cancer in 2012 were still alive 1 year post-diagnosis. Over three-quarters (78%) of this cohort were still alive five years after diagnosis.

Among people diagnosed with **colorectal** cancer in 2012, 73% were alive 1 year post-diagnosis. Around half (49%) of this cohort were still alive 5 years post-diagnosis.

Approximately half (52%) of the **lung** cancer cohort diagnosed in 2012 was still alive 6 months post-diagnosis; after 1 year this reduced to around a third (35%). Only 10% of people diagnosed with lung cancer in 2012 were alive 5 years post-diagnosis.

Survival after **prostate** cancer was relatively high, with 92% of those diagnosed in 2012 being surviving 1 year after diagnosis. Five years after diagnosis, 68% of these men were still alive.
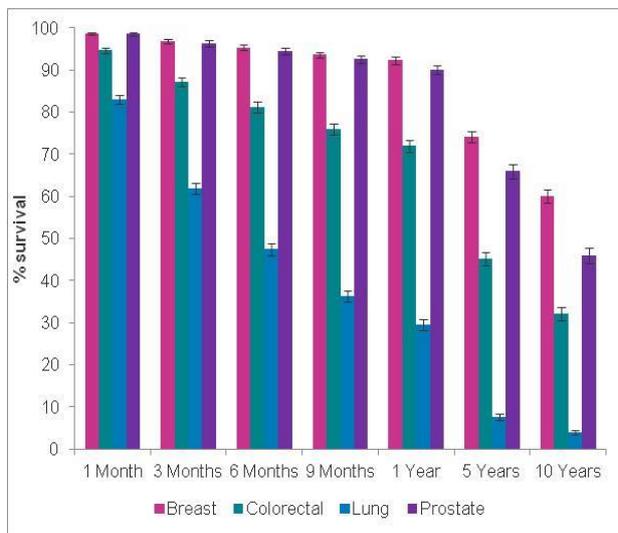

Figure 2.2: Survival by cancer site, all OG combined: 2007
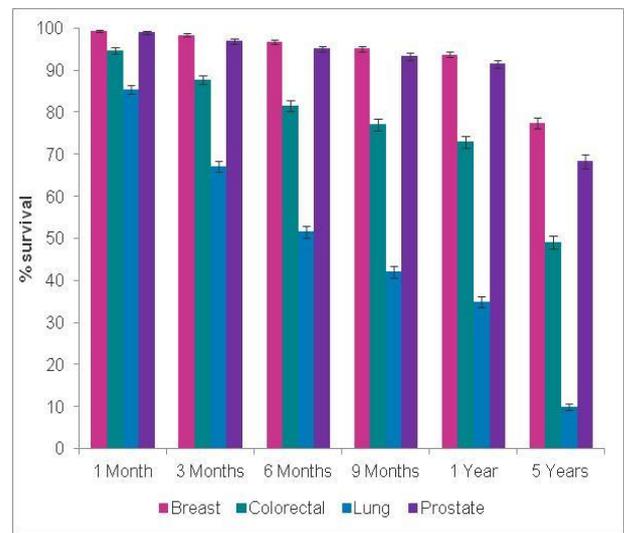
Figure 2.3: Survival by cancer site, all OG combined: 2012

As with the 2012 cohort, there was a large amount of variation in survival amongst the 2007 cohort depending on cancer type. However, between 2007 and 2012 there was a statistically significant increase in 5 year survival for lung (from 8% to 10%), breast (from 74% to 78%) and colorectal (from 45% to 49%) cancer. Prostate cancer survival rates also increased over this time period (from 66% to 68%) but were not considered statistically significant.

Survival rates 10 years post-diagnosis vary between these cancer cohorts from 4% of people diagnosed with lung cancer, 32% of people with colorectal cancer, 46% of men with prostate cancer and 60% of women diagnosed with breast cancer (Figure 2.2).

Survival by outcome group

People with Limited Survival (OG4)
As shown previously, the number and proportion of people diagnosed in 2012 who died within a year of their cancer diagnosis (OG4) differed by cancer type.   Among these people who died within the first year, survival rates across that first year also varied by cancer type (Figure 2.4 and Figure 2.5).
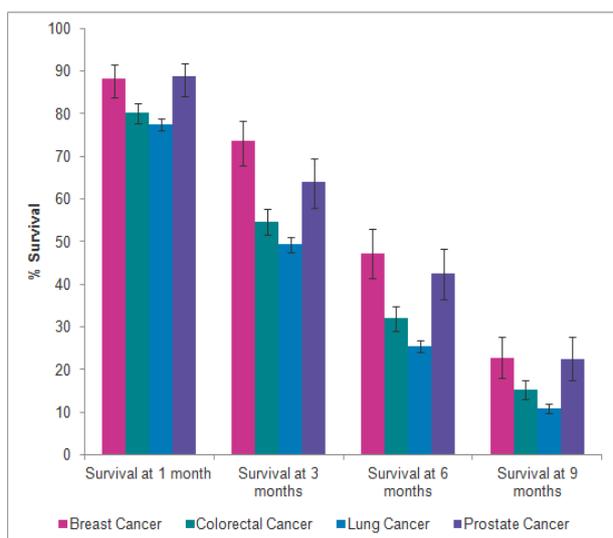
Figure 2.4: Survival time after diagnosis by cancer type for people in OG4 (limited survival): 2012
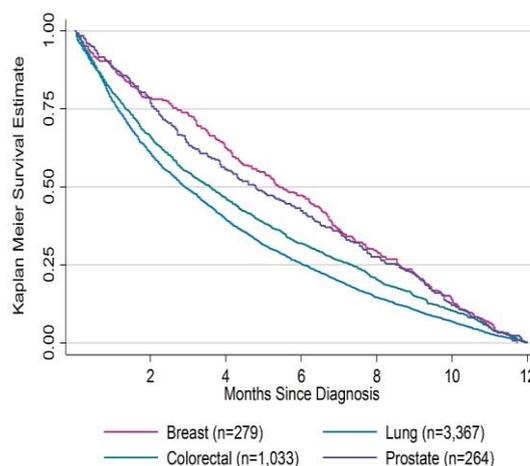
Figure 2.5: Observed survival time by cancer type for people in OG4 (limited survival): 2012

- Of the 279 women who died within a year of a **breast** cancer diagnosis, 88% were alive 1 month later, 73% were alive at 3 months, 47% at 6 months after diagnosis and 23% at 9 months.

- Of the 1,033 people who died within a year of a **colorectal** cancer diagnosis, 80% were alive 1 month after diagnosis, 55% at 3 months, 32% at 6 months after diagnosis and 15% at 9 months.

- Of the 3,367 people who died within a year of a **lung** cancer diagnosis, 78% were alive at 1 month, 49% at 3 months, 25% at 6 months after diagnosis and 11% at 9 months.

- Of the 264 men who died within a year of a **prostate** cancer diagnosis, 89% were alive 1 month later, 64% were alive at 3 months, 42% at 6 months after diagnosis and 22% at 9 months.

People with similar or increased acute healthcare needs (OG1 / OG2) and people likely to be living with a continued presence of cancer (OG3)

Due to outcome group definitions, it should be noted that 1 year survival among people in OGs1-3 was 100%.

In 2012, of the 4,468 women diagnosed with **breast** cancer, 1,444 were categorised as living with similar acute healthcare needs, of which 97% were alive 5 years after diagnosis. There were 926 women living with increased acute healthcare needs, 85% of whom were alive at 5 years and 1,819 women likely to be living with a continued presence of cancer, 70% of whom were alive 5 years after the original cancer diagnosis (Figure 2.6 below).

In 2012, of the 3,825 people diagnosed with **colorectal** cancer in, 557 were living with similar acute healthcare needs, 98% of whom were alive 5 years after diagnosis. There were 682 PLWC with increased acute healthcare needs, 84% of whom were alive 5 years after diagnosis and 1,553 PLWC likely to be living with a continued presence of cancer, 49% of whom were alive 5 years after the original cancer diagnosis.

Of the 5,182 people diagnosed with **lung** cancer in 2012, the numbers living with similar acute healthcare needs were fairly small (n=179), so caution should be taken with the survival rates. Of these 179 people, 88% of these people were alive 5 years later. There were 238 PLWC with increased acute healthcare needs, 58% of whom were alive 5 years after diagnosis and 1,398 PLWC likely to be living with a continued presence of cancer, 15% of whom were alive 5 years after the original cancer diagnosis.

In 2012 of the 3,107 men diagnosed with **prostate** cancer, 858 were living with similar acute healthcare needs, 98% of whom were alive 5 years after diagnosis. There were 742 men with increased acute healthcare needs, 88% of whom were alive 5 years after diagnosis and 1,243 men likely to be living with a continued presence of cancer, 51% of whom were alive 5 years after the original cancer diagnosis.
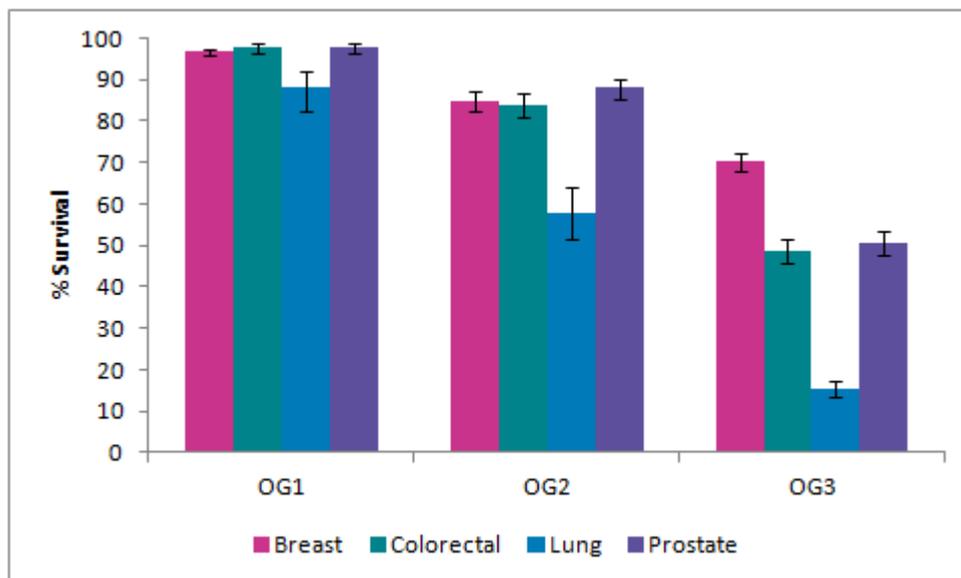
Figure 2.6: Five year survival by cancer type for people in OGs1-3: 2012

For people likely to be living with a continued presence of cancer (OG3) after diagnosis in 2012, 5 year survival varied from 15% for the lung cancer cohort to 70% for the breast cancer cohort.

For people living with similar or increased acute healthcare needs (OG1 and OG2) there was little difference in 5 year survival across colorectal (OG1 98%; OG2 84%), breast (OG1 97%; OG2 85%) and prostate (OG1 98%; OG2 88%) cancers, with lung cancer being lower in each case (OG1 88%; OG2 58%).
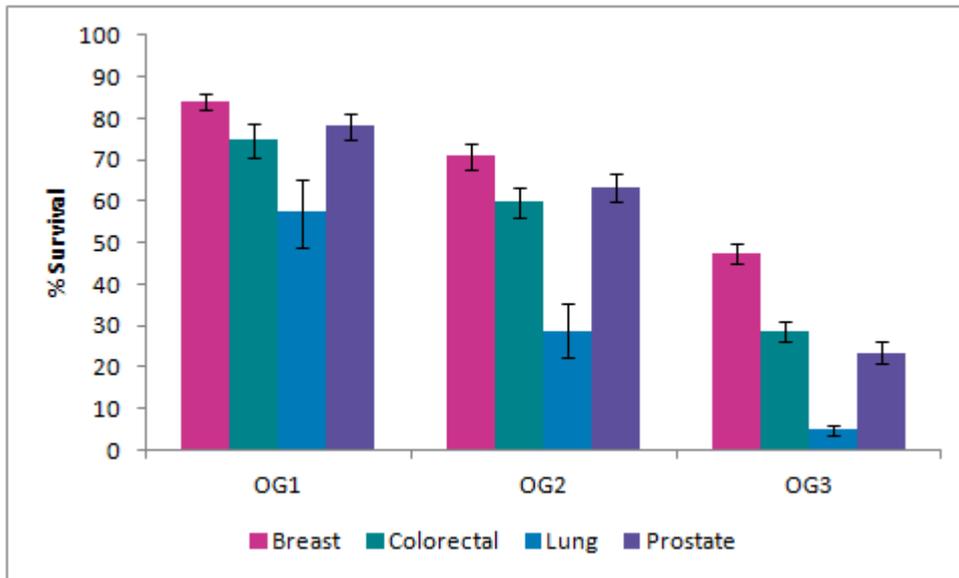
Figure 2.7: Ten year survival by cancer type for people in OGs1-3: 2007

Focussing on people diagnosed with cancer in 2007, the number likely to be living with a continued presence of cancer (OG3) was as follows:

- 1,614 women with breast cancer (of whom 47% were alive 10 years after diagnosis);
- 1,496 people with colorectal cancer (of whom 29% were alive 10 years after diagnosis);
- 1,118 people with lung cancer (of whom 5% were alive 10 years after diagnosis);
- and 1,045 men with prostate cancer (23% of whom were alive 10 years after diagnosis)

The number of people living with increased acute healthcare needs (OG2) was:

- 865 women with breast cancer (of whom 71% were alive 10 years after diagnosis);
- 658 people with colorectal cancer (of whom 60% were alive 10 years after diagnosis);
- 182 people with lung cancer (of whom 29% were alive 10 years after diagnosis);
- and 715 men with prostate cancer (63% of whom were alive 10 years after diagnosis)

The number of people living with similar acute healthcare needs (OG1) was:

- 1,231 women with breast cancer (of whom 84% were alive 10 years after diagnosis);
- 451 people with colorectal cancer (of whom 75% were alive 10 years after diagnosis);
- 141 people with lung cancer (of whom 57% were alive 10 years after diagnosis);
- and 728 men with prostate cancer (78% of whom were alive 10 years after diagnosis)

Some caution should be applied with some of these results due to small numbers.

Discussion on the results from Chapters 1 & 2 can be found at www.macmillan.org.uk/SRFD .

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Appendix A: Terms and Abbreviations

Term	Definition
95% CI	95% confidence interval.
Aetiology	The factors which cause or predispose the development of a particular condition.
Acute healthcare	Healthcare for a specific time-defined illness or condition.
Breast cancer	Female only invasive breast cancer (ICD-10 C50).
Cancer type	The site/type of the (primary) cancer, regardless of year.
CAG	Clinical Advisory Group.
Charlson Score	A method of assessing comorbidity through prior hospital records, scoring these based on the reason for the hospital admission. The Charlson score is a validated tool used by healthcare professionals to predict risk of death and the burden of a disease. Starting at zero, a patient's score can increase because of the severity of their illness or illnesses, or because the number of conditions they have increases.
Cohort	When referring to the year of index cancer diagnosis and cancer type combination (e.g. breast cancer 2007 cohort).
Clinical Presentation	One categorisation of how a cancer was first detected. Unless there is evidence to the contrary (e.g. screening or incidental finding), or there is real doubt (not known), it can be implied to be clinical presentation.
Colorectal Cancer	Colorectal cancer (ICD-10 C18-C20).
Confidence Interval (CI)	An estimated range of possible outcomes of a measurement, which gives an idea of uncertainty around that measurement. Here a 95% confidence interval is used which means that if the same measurement was repeated many times, 95% of values would fall within the defined range. This means there is a 5% chance that the true value will fall outside the defined range.
Crude rate	Calculated by dividing the total number of events in a given time period by the total number of persons in the population and then multiplying by 100,000. This allows for comparison between areas by providing a rate per 100,000 population. Crude rates do not take into account any differences in demographics between areas.
DCE	Detect Cancer Early Programme
Diagnosis year	Year in which the index cancer was diagnosed (either 2007 or 2012 here).
Dukes' Stage	Staging of colorectal cancer from A (tumour limited to muscularis propria (muscle coat), regional lymph nodes negative) to D (distant metastases).
EASR	European age standardised rate (see 'standardised rate' for more detail).
Episode	A measure of hospital activity encompassing the time a person spends within a particular hospital speciality. This may be as an inpatient, daycase or outpatient. Each episode is initiated by a referral (including re-referral) or admission and is ended by a discharge.
Gleason Score	Prostate cancer grading system, used to ascertain the

	aggressiveness of a cancer. Higher scores suggest a cancer which will grow or spread more rapidly.
Grade	A measure of how quickly a cancer may grow or spread, determined through examination of cancer cells.
ICD-10	World Health Organisation's International Statistical Classification of Diseases and Related Health Problems.
Incidental Finding	One categorisation of how a cancer was first detected. If a patient presents with a minor/major issue and is found to have a tumour/neoplasm which is not linked in any way to this issue, the tumour/neoplasm is recorded as an incidental finding.
Index cancer	The cancer/tumour which has been included in one of the cohorts for this study using the detailed selection criteria. A person may have experienced other cancers before or after this one (of the same or a different type), but this is the tumour which is included in the analysis.
ISD	Information Services Division, part of NHS National Services Scotland.
Kaplan-Meier	Kaplan-Meier is a method of estimating survival over time, measuring the proportions of time people live following a diagnosis.
Lung cancer	Trachea, bronchus & lung cancer (ICD-10 C33-34).
Metastasis	When cancer cells spread from the primary site (where the cancer started) to other parts of the body through the blood or lymphatic system. These cancers cells may grow into a tumour in another part of the body, this is referred to as a metastasis (or secondary cancer).
Morphology	This is the morphological type of the tumour as determined by a pathologist either on the basis of histology or cytology. The Scottish Cancer Registry currently records tumour type according to the International Classification of Diseases for Oncology or ICDO.
NCA	North Cancer Alliance (NHS Grampian, NHS Highland, NHS Tayside, NHS Orkney, NHS Shetland and NHS Western Isles).
OG(s)	Survivorship Outcome Group(s).
OG1	People living with similar acute healthcare needs compared to the time before their cancer diagnosis.
OG2	People living with increased acute healthcare needs compared to the time before their cancer diagnosis.
OG3	People likely to be living with a continued presence of cancer after their cancer diagnosis.
OG4	People with limited survival (<12 months) following their cancer diagnosis.
PLWC	People living with cancer.
Prostate Cancer	Male prostate cancer (ICD-10 C34).
PSA Test	The prostate specific antigen (PSA) test is a blood test which can contribute towards a diagnosis of prostate cancer.
Recurrence	When the same cancer returns after treatment. This can be local (in the same area of the body as the original cancer) or distant (in a different area of the body).
SACT	Systemic anti-cancer therapy.

SCAN	South-East Cancer Network (NHS Fife, NHS Lothian, NHS Borders, NHS Dumfries & Galloway).
Screen-detected	One categorisation of how a cancer was first detected. Screen-detected is where a person has been directed from a routine cervical smear/mammogram/bowel screening test in the absence of symptoms.
SIMD	Scottish Index of Multiple Deprivation (SIMD1=most deprived quintile, SIMD5=least deprived quintile).
SMR00	Scottish Outpatient dataset.
SMR01	Scottish Inpatient and daycase dataset.
SMR06	Scottish Cancer Registry dataset.
SRfD	Scottish Routes from Diagnosis.
Standardised rate	Truncated age-sex-standardised rates (EASRs) are used here. These are calculated by taking the crude rate for each age and sex group and multiplying this by the population in each age (and sex) group in the European Standard Population. It is a theoretical measure which allows for comparison across areas where the age or sex breakdown of the populations may differ (so for example when comparing an area with a higher proportion of older people to one with a younger population). This allows valid comparisons to be made between geographical areas and through time. The rates here are truncated to include only the ages of interest (for example excluding younger populations).
Stage	Stage is an assessment of how far a tumour has spread and typically involves an assessment of local size of the tumour, how far it has grown through local tissues and distant spread of disease with metastases to lymph nodes or other organs.
Statistically significant	Statistical testing suggests the result is not just due to random variation.
TNM	TNM is the international staging classification recommended by International Agency for Research on Cancer (IARC) and used for staging at most tumour sites. The TNM system is separated into 3 parts: T (Tumour) - The extent of and the size of the primary tumour, N (Node) - Whether or not the tumour has spread to the regional lymph nodes (the group of lymph glands to which tissue fluid in the area of the tumour first "drains") and M (Metastasis) - The presence or otherwise of distant metastasis.
WoSCAN	West of Scotland Cancer Network (NHS Ayrshire & Arran, NHS Forth Valley, NHS Greater Glasgow & Clyde, NHS Lanarkshire).

Appendix B: Kaplan-Meier Observed Survival Estimates

For each cohort as a whole:

Cohort	1 Month Estimate	1 Month 95% CI	3 Months Estimate	3 Months 95% CI	6 Months Estimate	6 Months 95% CI	9 Months Estimate	9 Months 95% CI	1 Year Estimate	1 Year 95% CI	5 Years Estimate	5 Years 95% CI	10 Years Estimate	10 Years 95% CI
Breast 2007	98.7	98.3 - 99	96.8	96.2 - 97.3	95.4	94.7 - 96	93.6	92.8 - 94.3	92.3	91.4 - 93.1	74.2	72.8 - 75.5	60.0	58.5 - 61.5
Breast 2012	99.3	99 - 99.5	98.3	97.9 - 98.7	96.7	96.1 - 97.2	95.2	94.5 - 95.8	93.8	93 - 94.4	77.5	76.3 - 78.7	-	-
Lung 2007	83.0	81.9 - 84	61.9	60.5 - 63.2	47.5	46.1 - 48.9	36.4	35 - 37.7	29.5	28.2 - 30.8	7.5	6.8 - 8.3	3.8	3.3 - 4.4
Lung 2012	85.4	84.5 - 86.4	67.0	65.7 - 68.3	51.5	50.2 - 52.9	42.0	40.7 - 43.4	35.0	33.7 - 36.3	9.9	9.1 - 10.7	-	-
Colorectal 2007	94.7	93.9 - 95.4	87.2	86 - 88.2	81.3	80 - 82.5	76.0	74.5 - 77.3	72.0	70.5 - 73.4	45.2	43.6 - 46.8	32.1	30.5 - 33.6
Colorectal 2012	94.7	93.9 - 95.3	87.8	86.7 - 88.8	81.6	80.4 - 82.8	77.1	75.7 - 78.4	73.0	71.6 - 74.4	49.1	47.5 - 50.7	-	-
Prostate 2007	98.7	98.2 - 99	96.3	95.6 - 97	94.6	93.7 - 95.4	92.5	91.5 - 93.5	90.1	89 - 91.2	66.0	64.2 - 67.7	45.9	44.1 - 47.8
Prostate 2012	99.0	98.6 - 99.3	96.9	96.3 - 97.5	95.1	94.3 - 95.8	93.4	92.5 - 94.2	91.5	90.5 - 92.4	68.3	66.6 - 69.9	-	-

By survivorship outcome group:

Cohort	OG1 5 Years Estimate	OG1 5 Years 95% CI	OG1 10 Years Estimate	OG1 10 Years 95% CI	OG2 5 Years Estimate	OG2 5 Years 95% CI	OG2 10 Years Estimate	OG2 10 Years 95% CI	OG3 5 Years Estimate	OG3 5 Years 95% CI	OG3 10 Years Estimate	OG3 10 Years 95% CI	OG4 1 Month Estimate	OG4 1 Month 95% CI	OG4 3 Months Estimate	OG4 3 Months 95% CI	OG4 6 Months Estimate	OG4 6 Months 95% CI	OG4 9 Months Estimate	OG4 9 Months 95% CI
	OG1: living with similar acute healthcare needs				OG2: living with increased acute healthcare needs				OG3: living with a continued presence of cancer				OG4: limited survival							
Breast 2007	96.8	95.7 - 97.7	84.1	81.9 - 86	86.7	84.3 - 88.8	71.0	67.8 - 73.9	64.4	62 - 66.7	47.4	44.9 - 49.8	83.2	78.6 - 86.9	58.4	52.7 - 63.6	40.0	34.5 - 45.4	17.1	13.1 - 21.5
Breast 2012	96.8	95.7 - 97.5	-	-	85.0	82.5 - 87.1	-	-	70.3	68.2 - 72.4	-	-	88.2	83.8 - 91.4	73.5	67.9 - 78.3	47.3	41.4 - 53	22.6	17.9 - 27.6
Lung 2007	92.2	86.4 - 95.6	57.5	48.9 - 65.1	58.8	51.3 - 65.5	28.6	22.2 - 35.2	11.7	9.9 - 13.7	4.8	3.7 - 6.2	75.9	74.4 - 77.3	45.9	44.2 - 47.5	25.5	24 - 26.9	9.7	8.8 - 10.7
Lung 2012	88.3	82.6 - 92.2	-	-	58.0	51.4 - 64	-	-	15.5	13.6 - 17.4	-	-	77.6	76.2 - 79	49.3	47.6 - 50.9	25.4	24 - 26.9	10.8	9.7 - 11.8
Colorectal 2007	95.6	93.2 - 97.1	74.9	70.7 - 78.7	84.7	81.7 - 87.2	59.9	56 - 63.5	43.3	40.7 - 45.7	28.6	26.3 - 30.9	81.0	78.4 - 83.2	54.2	51.1 - 57.2	33.1	30.2 - 36	14.1	12.1 - 16.3
Colorectal 2012	98.0	96.5 - 98.9	-	-	84.0	81 - 86.6	-	-	48.9	46.4 - 51.3	-	-	80.3	77.7 - 82.6	54.7	51.6 - 57.7	32.0	29.1 - 34.8	15.2	13.1 - 17.5
Prostate 2007	97.3	95.8 - 98.2	78.3	75.1 - 81.1	87.1	84.5 - 89.4	63.4	59.7 - 66.8	46.9	43.8 - 49.9	23.4	20.9 - 26.1	86.4	81.7 - 90	62.9	56.8 - 68.3	45.2	39.2 - 51	24.3	19.4 - 29.5
Prostate 2012	97.8	96.6 - 98.6	-	-	88.0	85.4 - 90.1	-	-	50.7	47.9 - 53.4	-	-	88.6	84.2 - 91.9	64.0	57.9 - 69.5	42.4	36.4 - 48.3	22.4	17.5 - 27.5