Scottish Routes from Diagnosis: Chapters One and Two: Summary

Background

The cancer story is changing. The combination of an ageing and growing population, better diagnosis of cancer and more effective cancer treatments means that there are now unprecedented numbers of people living longer after a cancer diagnosis. 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* (SG (2016)), which called for Scotland's cancer treatments and services to be rooted in evidence.

To this end, Macmillan and Information Services Division (ISD) of NHS National Services Scotland, are working in partnership to investigate variations in cancer pathways in the Scottish Routes from Diagnosis (SRfD) project.

Aim and Methods

The aim of SRfD is to investigate survivorship experiences and improve understanding of post-diagnosis pathways for people living with cancer and the services needed to support them. The project does this by linking and analysing routinely collected data for residents of Scotland diagnosed with female breast, colorectal, lung and prostate cancer. It focuses on people diagnosed with cancer in 2007 and in 2012, followed up for 10 and five years respectively.

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.

The two follow up periods studied allow the project to look at longer term outcomes alongside more recent patient experiences.

Table 1: Number of people diagnosed with cancer following inclusion/exclusion criteria, by diagnosis year and cancer type

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

The data presented in Chapter One and Chapter Two primarily relates to people diagnosed in 2012, unless otherwise specified; however, results for both 2012 and 2007 are available in the relevant appendices. Throughout this analysis, breast cancer refers to female breast cancer and lung cancer refers to trachea, bronchus and lung cancer.

Following approval of the SRfD project by the Public Benefits and Privacy Panel[1] (PBPP), an extract was taken from the Scottish Cancer Registry (SMR06) and linked to various relevant NHS administrative datasets. These data were also linked to National Records of Scotland mortality data.

SRfD Outcome Groups

A central objective of SRfD is to capture the various survivorship outcome pathways for people diagnosed with cancer. To meet this objective, 'Outcome Groups' (OGs) were developed in collaboration with a Clinical Advisory Group (CAG) and used to provide insight into how people's experiences vary both across and within different cancers types.

Experiences of survivorship are categorised and captured within the following four Outcome Groups:

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

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

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

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

*where changes in acute healthcare needs were identified by comparing each persons' acute hospital bed day rate post-diagnosis to their rate pre-diagnosis.

**These experiences are continued but not necessarily continuous over the five years following diagnosis and may include new cancer events and treatment as well as evidence of cancer treatment activity or death due to cancer.

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[1] https://www.informationgovernance.scot.nhs.uk/pbpphsc/

Survivorship Experience

Chapter One shows how the type of cancer people are diagnosed with affects their survivorship experiences.

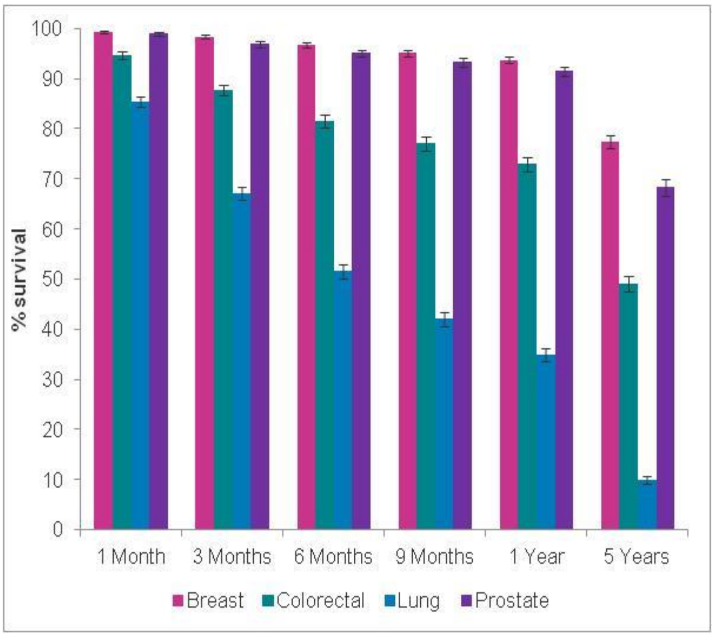

Figure 1: Survival by cancer site, all OG combined: 2012

For example, around a third (35%) of people diagnosed with **lung** cancer in 2012 survived beyond a year, compared to 73% of people diagnosed with **colorectal cancer**, 92% of men diagnosed with **prostate** cancer and 94% of women diagnosed with **breast cancer**. Five years after diagnosis, the difference in survival rates among people with these four cancer types was even greater. Among people diagnosed with lung cancer in 2012, only 10% were alive five years later; this compares to 49% of people diagnosed with colorectal cancer, 68% of men diagnosed with prostate cancer, and 78% of women diagnosed with breast cancer.

The proportion of people in each survivorship outcome group varies across the four most common cancer types in Scotland (Figure 2). Around half of those with breast or prostate cancer lived with similar (OG1) or increased (OG2) acute healthcare needs. This compares to a third of people with colorectal cancer and fewer than one in ten of those with lung cancer. For many people cancer becomes a continued presence in their lives; around 40% of people with prostate, breast or colorectal cancer were likely to be living with further cancer activity (this may be metastatic disease, new primary cancer or other cancer activity) in the years following treatment (OG3).

For OG4, or limited survival, almost 3 in 10 people diagnosed with colorectal cancer die within a year of diagnosis. However, relatively small numbers of people who are diagnosed with prostate or breast cancer die within 12 months of a diagnosis, with 8% and 6% respectively. Lung cancer survivorship is low: of those that survive beyond a year (35%), the vast majority will live with a continued presence of cancer (77%) and survival five years after diagnosis is 10%.

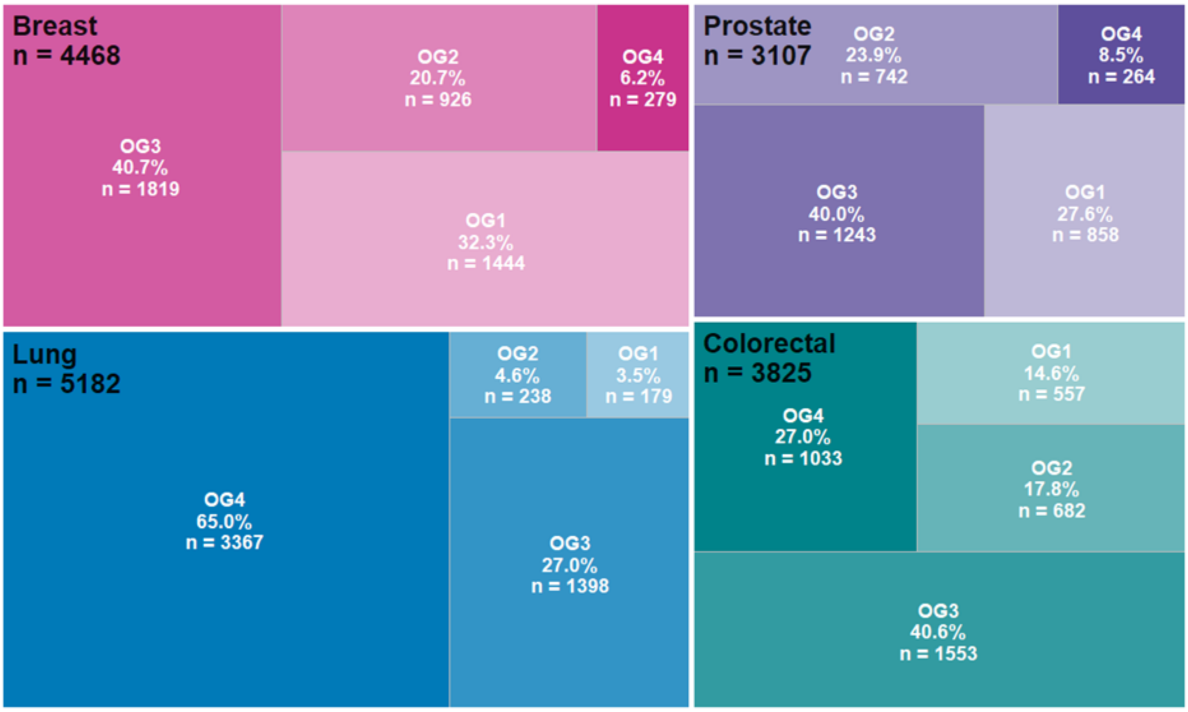

Figure 2: Proportion of cancer cohorts within survivorship groups 1-4: 2012.

Much of people's survivorship experience will also depend on other factors such as age, or at what point in its development the cancer is diagnosed. Such factors are discussed in detail in Chapter Two, the Cohort Up Close, which examines the characteristics of the cohorts, from patient characteristics to cancer factors to typical treatments.

Age

Looking at the 2012 cancer cohorts by age, women diagnosed with breast cancer were, on average, younger (63) than people diagnosed with the other cancer types studied (age 70 for colorectal and prostate cancer, and 72 for lung cancer). For most cancer types studied, average age increased with increasing outcome group (i.e. the older a person is, the more likely it is that they will be in OG3 or OG4 and experience worse cancer outcomes). However, the breast cancer cohort followed a slightly different pattern, where the youngest average age was for women likely to be living with a continued presence of cancer (OG3) as well as those living with similar acute healthcare needs (OG1).

There appeared to be no difference in cancer incidence between men and women in the 2012 lung cohort. This is a change from 2007, when more lung cancers were diagnosed in men.

Deprivation

Regarding deprivation[2] in 2012, there were higher rates[3] of incidence in the prostate cancer cohort among people who lived in the least deprived areas of Scotland. By Outcome Group this was only statistically significant in those living with similar acute healthcare needs (OG1). For the lung cancer cohort incidence rates appeared around three times higher in more deprived areas compared to the least deprived (Figure 3) This trend was also fairly consistent across outcome groups. For the breast and colorectal cancer cohorts, there was no significant difference in cancer incidence according to deprivation. By outcome group there were statistically significant differences across the deprivation quintiles for breast cancer in women living with similar acute healthcare needs (OG1) where higher rates were observed in the least deprives quintiles when compared to the most deprived quintiles. There were statistically significant differences observed in Outcome Group 4 in the colorectal cancer cohort where higher rates were observed in the most deprived areas compared to the least deprived areas.

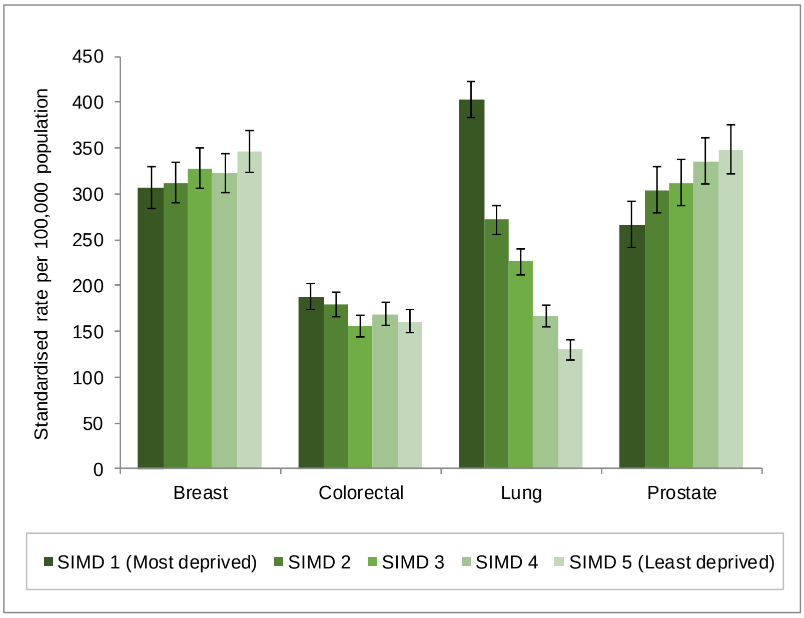

Figure 3: Standardised cancer incidence rates by deprivation (age 45 and over): 2012

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[2] Deprivation is measured using the Scottish Index of Multiple Deprivation (SIMD), which ranks areas in Scotland from most deprived (ranked 1) to least deprived (ranked 6,976). Here it is presented by population-weighted quintile where SIMD1 represents the 20% most deprived areas in Scotland and the least deprived areas is represented by SIMD5.

[3] Truncated, standardised rates per 100,000 population

Urban-rural Indicator/Living

When considering the impact of whether a person was living in an urban or rural area, only lung cancer showed a clear urban / rural contrast (once rates had been age standardised). The highest rates of lung cancer were found in urban areas, while lower rates were observed in rural areas (Figure 4).

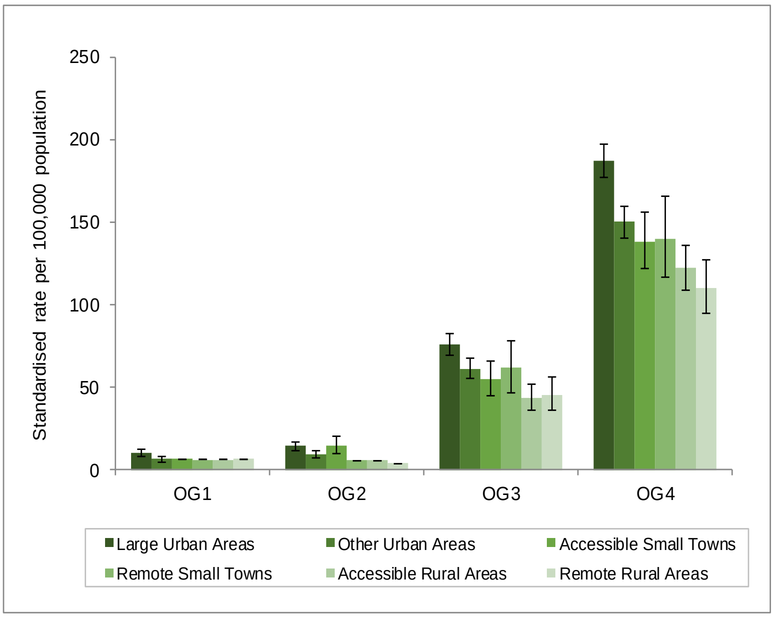

Figure 4: Standardised lung cancer incidence rates by urban-rural index (age 45 and over): 2012

Method of cancer detection

The method of cancer detection varies across cancer types. Over 90% of both lung and prostate cancers in 2012 were detected through clinical presentation, compared to 64% of breast cancers and 79% of colorectal cancers.

For cancer types with national screening programmes (colorectal and breast), screen detected cancers made up a substantial proportion of all cancer detected (18% for colorectal; 32% for breast).

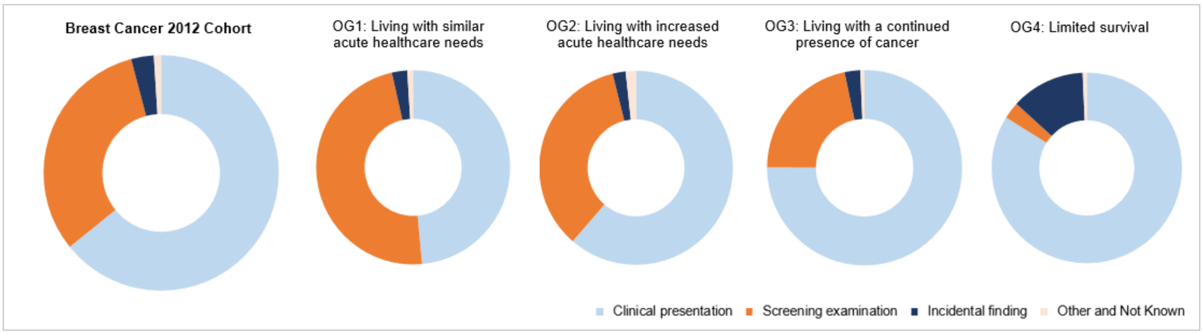

Figure 5: Female breast cancer 2012: Method of Detection by outcome group

In 2012, for colorectal cancer, 18% of diagnoses were detected through screening. This varied by outcome group; for OG1 and OG2, nearly a third of people diagnosed were detected through screening (29% of OG1; 28% of OG2); for people living with a continued presence of cancer (OG3), 20% were detected through screening; only a very small proportion (3%) of people with limited survival (OG4) were detected through screening (Figure 6).

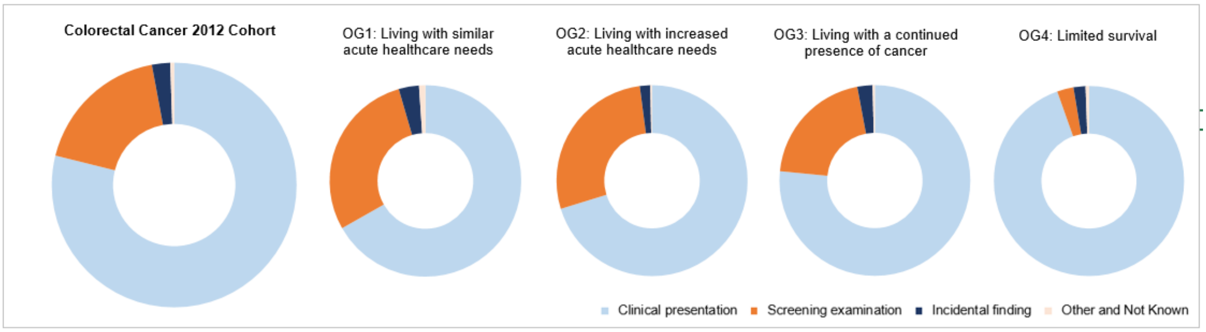

Figure 6: Colorectal cancer 2012: Method of Detection by outcome group

Tumour stage

The tumour stage at diagnosis varies across cancer type and Outcome Groups. A high proportion of breast cancers in 2012 were detected at early stage (73% were stage 1 or 2), compared to lung cancer where almost half (45%) were diagnosed at stage 4.

Treatment

Different cancer types typically require different treatment approaches. Stage of cancer at diagnosis will also impact on treatment decisions, with an emphasis on local therapy (surgery and radiotherapy) for early stage disease and systemic therapies in more advanced stages of the disease. For the 2012 cohorts, the most common treatments were dependent on cancer type, but tended to be similar for those living with similar or increased acute healthcare needs (OG1 and OG2). Treatments were more mixed (where recorded) for those living with a continued presence of cancer and for those with limited survival (OG3 and OG4).

Patient characteristics will also influence choice of treatment, with many treatments being excluded due to factors such as comorbidities; this is the subject of an upcoming analysis for SRfD. The proportion of people living with cancer (PLWC) who had no treatment recorded differed by cancer type. However, across all cancer types investigated, PLWC with limited survival (OG4) were more commonly found to have no treatment recorded:

- Breast cancer: 23% of the 279 people in OG4 recorded no treatment
- Colorectal cancer: 54% of the 1,033 people in OG4 recorded no treatment
- Prostate cancer: 33% of the 264 people in OG4 recorded no treatment
- Lung cancer: 57% of the 3,367 people in OG4 recorded no treatment

Recommendations

Cancer is not just one disease which can be treated in one specific way. Even within specific cancer types, people's experiences of cancer can vary enormously. Scottish Routes from Diagnosis was developed to explore the different experience pathways of people diagnosed with cancer using national administrative datasets. Outcome Groups 1-4 were developed to capture the different experience and intensities of need within and across the cancer types. It is hoped that SRfD will provide further insight into future cancer service planning and cancer research.

The evidence presented here shows that a majority of people will live with cancer as a long-term condition**.** It also demonstrates that there is no "one size fits all" approach to address the variety, complexity and breadth of the needs of people living with and beyond cancer. It also shows that experiences of cancer may vary significantly even within the same cancer type. Whether people have a short or longer lifespan with their cancer, whether they are cured or have cancer as a long-term condition, this work highlights the fact that a much lower proportion of people return to the life they had pre-diagnosis than was previously understood.

The serious and often severe needs that can accompany patients with limited survival (OG4), and the worse outcomes for the lung cancer cohort, highlights the great need for palliative care for people who may be at risk of experiencing a rapid death following diagnoses. This study provides compelling evidence to continue to improve the integration of services and early coordination of care.

While anyone with a cancer diagnosis can experience difficulties, people in OG2 and OG3 may need more pronounced support for the consequences of cancer or its treatment; this may include a complex array of social, emotional and physical needs as well as support in the workplace.

Good coordination and navigation of care will be important to those with elevated acute needs following cancer**.** Delivery of integrated and patient-led holistic services should include the offer and/or use of a Holistic Needs Assessment (HNA) or care plan as an intervention to help manage needs and concerns and improve patient experiences as they navigate their cancer journey.

While these reports provide an overview of survivorship experiences by patient characteristics, tumour factors and treatment, more detailed investigation of some of these aspects is required to understand them more fully.

Further planned reports will focus in more detail on specific aspects of survivorship experiences after cancer diagnosis; it is therefore important to understand the different demographics, cancer factors and any cancer type specific issues prior to the publication of these reports. Key aspects of survivorship experience such as comorbidity, hospital admissions, cause and place of death, and multiple cancers are investigated in further detail and are planned to be published at a later date.

For more information, please visit www.macmillan.org.uk/SRFD.