

Scottish Routes from Diagnosis: Discussion

A central part of the SRfD framework are the Outcome Groups, which aim to capture the various experience pathways and outcomes of people living with cancer to explore variations, and potential causality and implications of outcomes. The main findings from the analysis in Chapters 1 and 2 show there is a high level of variation in **outcome experiences both between cancer types and within cancer types. People across all outcome groups and cancer types need a range of support.** The potential reasons for certain outcomes, and possible implications, are explored here.

Across the cancers studied, **30% (n=4,943) of the 2012 cohort died within a year of diagnosis (OG4 - limited survival)**. Within all cancer types investigated, people with limited survival were more commonly found to have no treatment recorded. This may be due to patient choice, the person dying before treatment begins or a lack of available beneficial treatment options. Clinical advice based on the progression of the disease, or the patient having additional complications with comorbidities may also contribute to non-treatment. Upcoming analysis will look at the intent of treatment where it occurs.

When considering all those with limited survival across cancer types, **people diagnosed with lung cancer typically experience worse outcomes and poorer survival than those with breast, prostate and colorectal cancer.** People diagnosed with lung cancer die more quickly than those with the other cancers studied; two thirds of all people diagnosed with lung cancer in 2012 had limited survival (OG4). There are several potential causes for this. Lung cancer can be aggressive and progress quickly. Diagnoses were commonly at late stage; almost half (45%) of the 2012 lung cancer cohort were diagnosed with stage 4 cancer. In addition, diagnoses tended to be made in people who were, on average, older than some of the other cohorts studied.

In addition, **between 2007 and 2012, the split of lung cancer diagnoses between males and females changed.** In 2007 slightly more than half of all lung cancer diagnoses were for men; however, by 2012 lung cancer diagnoses were evenly split between the sexes. This trend is observed elsewhere (ScotPHO, Lung Cancer: Scottish Data, 2017) and believed to be related to historical differences in the prevalence of smoking in women (Dela Cruz, et al, 2011).

For many people, cancer is a continued or repeated condition, regardless of cancer type: 27% of the lung cancer cohort, and around 40% of people diagnosed with prostate, breast or colorectal cancer from the 2012 cohort, were likely to be living with a continued presence of cancer (OG3) in the following five years. This may be because of metastatic disease, recurrence of the cancer or due to new tumours being detected, either broadly around the time of diagnosis in this study or in the years that followed diagnosis. This outcome group contains a mix of cancers diagnosed at an early and later stage, reflecting the different ways cancer may play a part in future years. People in this

group may experience a more protracted, complicated pathway, and / or experience repeated cancer events over the following five years. Such events may include receiving additional cancer diagnoses, undergoing additional treatment regimes, or living with treatable but not curable cancer. Thus, people in OG3, alongside those people living with increased acute healthcare needs (OG2), are likely to have a wide spectrum of needs and will often make repeated use of social and health care services.

People surviving more than a year after their cancer diagnosis and living with increased or similar acute healthcare needs (OG 1 and OG 2) have more early stage cancer diagnoses and often have clearer-cut treatment pathways. For example, the vast majority of people with colorectal cancer have surgery only; and those with breast cancer are most likely to have surgery, radiotherapy and hormonal therapy. People in these outcome groups also have fewer significant comorbidities as measured by acute healthcare activity.

An aspiration for those diagnosed with cancer is to have similar acute healthcare needs following treatment compared to the time before their cancer diagnosis (OG1). The work presented here suggests **considerable proportions of people with some cancer types may experience this** (i.e. 32% of women diagnosed with breast cancer and 28% of men diagnosed with prostate cancer in 2012). However, this appears to be a much rarer outcome for people diagnosed with colorectal cancer (15%) and for people diagnosed with lung cancer (3%) in 2012. Further work exploring these cancers may be useful in understanding how more people diagnosed with colorectal or lung cancer could become part of OG1.

Between 2007 and 2012, there was a **statistically significant increase in five year survival for lung, breast and colorectal cancer cohorts**; prostate cancer survival rates also increased over this time period, but this increase was not statistically significant. The differences in survival may be influenced by diagnosis at an earlier stage and by improvements in treatment modalities including surgery, systemic anti-cancer therapy (SACT), radiotherapy and hormonal therapy. There was an increase in screen-detected cancers (breast and colorectal) from 2007 to 2012, with the roll-out of national screening for colorectal cancer from 2007 (ISD Scotland, Scottish Bowel Screening Programme; ISD Scotland, Breast Screening 3 year percentage) likely to be an influencing factor. Screen-detected cancer made up a significant proportion of colorectal (18%) and breast (32%) cancers. This increase in screen detected cancers is a positive step in catching cancer earlier.

In some cancers, **there is a relationship between deprivation and cancer incidence**; for example, the age standardised rate of lung cancer incidence in 2012 was around three times higher in the most deprived communities compared to the least deprived areas. This general trend is also applied within the outcome groups. The trend in incidence by deprivation is consistent with other publications and likely to be related to socio-economic differences in smoking prevalence, where more deprived communities tend to have higher rates of smoking (ScotPHO, Tobacco use: adult smoking in Scotland). In developed countries such as Scotland, tobacco smoking is estimated to account for 80-90% of lung cancer cases (ScotPHO, Lung cancer: key points). In contrast, age standardised rates of prostate cancer were higher in the least deprived areas compared to the most deprived (1.3 times higher); this corresponds to other publications and may be related to lower

levels of PSA testing in deprived communities. There is also a relationship between deprivation and screening uptake which will influence the number (and stage) of cancers detected (ISD, 2019).

The Outcome Groups also presented **variance in type of treatment across cancers**. Treatments that aim to cure, for example surgery, tend to be the least intensive. Treatment options for people with treatable but not curable cancer are often very intensive; the intent of these treatments is to modify the disease, prolong life or to deliver palliative care. The proportion of people living with cancer in 2012 who had no treatment recorded differed by cancer type, from 2% of women diagnosed with breast cancer to 43% of people diagnosed with lung cancer. For prostate cancer, 23% had no recorded treatment.¹ However, due to programmes such as Active Surveillance and Watch and Wait, a proportion of men diagnosed with prostate cancer may be given treatment in later years. An additional factor to consider is shifting practices by clinicians, with a trend for more intensive treatment 'up front' for men diagnosed with advanced prostate cancer.

Treatment decisions will be dependent on disease, person and choice. Different cancer types typically demand different treatment approaches: for example, hormonal therapy will be used for most men with advanced stages of prostate cancer but has no role in the treatment of lung or colorectal cancer. In breast cancer, hormonal therapies will typically be guided by molecular features of the individual cancer. Stage of cancer 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. Patient factors will also influence choice of treatment, with treatments sometimes being excluded due to comorbidity.

Impact on Service Development and Recommendations

The often severe needs that can accompany patients with limited survival (OG4) highlights **the great need for palliative care for people who may be at risk of experiencing a rapid death following a cancer diagnosis**. Access to palliative care relies on continued improvements within the integration of services and early coordination of care. In 2015, the Scottish Government provided a blueprint for palliative and end of life care with the *Strategic Framework for Action on Palliative and End of Life Care* (2015). Among the aims and commitments, the *Framework* recognised the importance of identifying people who may benefit from palliative and end of life care. The evidence presented here further highlights the importance for integrated social and health care to identify patients with limited survival earlier. In doing so, it could reduce unnecessary investigations and help balance the needs for anticancer treatment alongside palliative and supportive care. It would also enable people to access palliative care earlier, and potentially experience better end of life care.

Identifying patients with limited survival earlier and then providing care also requires end of life services to have the capacity and workforce needed to support these populations. This includes palliative care specialists such as specialist nurses who can support people with complex needs as well as the community workforce who can provide generalist health and social care at end of life.

¹ Treatment details are recorded for any related cancer treatment at time of cancer registration. As such this will include treatment recorded within at least the first 6 months after diagnosis and is limited to no more than 2 years after diagnosis.

One potential tool to help identify patients could be the development and utilisation of machine learning technology to produce clinical algorithms to more efficiently identify and direct people to palliative care. Recent work in this area shows the capabilities of such algorithms, which can accurately predict the traits and potential needs of people based on collected health and social care data, and provide person-centered recommendations. Technology such as this can guide service provision by forecasting demand based on actual or hypothesized data (Kang; et al, 2018).

Research shows that some people living with cancer can experience a gap in their care and support during and after treatment in the acute setting. The 2018 Scottish Cancer Patient Experience Survey reported that some people felt they did not receive enough care and support during treatment: almost 24% felt they were given care and support to some extent, with 17% of people stating they were not given enough care and support from health and social services (Scottish Government, 2018, p9). After treatment finished, 22% of people felt they were not given enough care and support and 28% reported receiving care to some extent after treatment (Scottish Government, 2018, p.9) In addition, around 40% of people reported not receiving information on financial help or benefits (Scottish Government, 2018, p.9) 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 once they leave acute care. Increased support may be needed to address a complex array of clinical, social, emotional and financial needs, as well as work support.** Examples of increased clinical support include: early access to early palliative care; support with the uncertainty caused by cancers that are more difficult to cure or cannot be cured; chronic illness management; rapid re-entry into the system and fast diagnostics to identify second cancers and recurrence. In some cases, increased support will be required for managing comorbidities. In other cases, cancer or its treatment may result in increased visits to hospital, which might present further challenges due to transportation requirements.

In addition to clinical needs, people with a cancer diagnosis often face complex non-clinical needs such as financial, emotional and social needs. The delivery of Holistic Needs Assessments (HNAs) is an important tool to ensure care is person-centred and multivariate needs are addressed appropriately. The HNA helps manage needs, concerns and improves patient experiences as they navigate their cancer journey from diagnosis, treatment and beyond. Evidence suggests that receiving tailored support through the utilisation of an HNA and signposting to support services can significantly reduce a patient's level of concern (Snowden, 2018).

At a system and community level, significant work has been done to address patients with a coordinated and person-centred response. The partnership programme between the Scottish Government and Macmillan Cancer Support, *Transforming Care after Treatment* (TCAT), ran from 2013-2019 and established best practices and models of care for improving the delivery of integrated health and social care for people affected by a cancer diagnosis and its treatment (Macmillan Cancer Support). Similarly, the Macmillan-funded community-based service offered by Glasgow City Council, *Improving the Cancer Journey* (ICJ), has been delivering personalised and tailored support to anyone affected by a cancer diagnosis in Glasgow since 2014 (Macmillan Cancer Support). Both programmes provide exemplary models of delivery for health and social care from diagnosis, treatment and beyond, and learnings from TCAT and ICJ were written into the Scottish Government's 2016 cancer strategy, *'Beating Cancer: Ambition and Action'* (Scottish Government, p8). Furthermore, the landscape of social and health care in Scotland changed in 2016 with

legislation that brought health and social care together into a single, integrated system with 31 representative integration authorities (Scottish Government, Health and Social Care Integration). For cancer care, this reform work laid further foundations to improve the coordination and navigation of people following diagnosis and treatment. In 2019, work progressed further with the launch of the Transforming Cancer Care (TCC) partnership programme between Scottish Government and Macmillan, which will offer every newly diagnosed cancer patient in Scotland a support worker who will carry out an assessment to understand their needs, before referring them to support (Scottish Government, 2019).

The continued investment and drive for this on-going integrated work is vital because good coordination and navigation of care is important to anyone diagnosed with cancer, no matter the age, stage of cancer at diagnosis, or type of disease. **The results of SRfD show that a majority of people will find that cancer has a long-term impact on their use of acute services and their health.**

Conclusion

The evidence presented here 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, and that experiences of cancer may vary significantly even among people diagnosed with the same cancer type. Care and support must be integrated, coordinated, person-centred and tailored to meet a variety of needs. Whether people have a short or longer lifespan with their cancer, whether they are in complete remission 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 previously understood.

The results of this work also indicate the volume of people who die within 1 month, under 3 months or less than 1 year from diagnosis. This can influence planning and provision around palliative and end of life care to ensure everyone has a tailored support package which reflects their individual needs and maximises their feelings of health and wellbeing during the end of their life.

Further upcoming chapters will also analyse mortality and end of life; comorbidities; multiple cancers and metastatic disease and the role of planned and unplanned hospital activity in further detail. These will all complement the work presented here and together will aid in progressing the knowledge around people living with cancer and their experiences of cancer in Scotland.

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