

Scottish Routes from Diagnosis: Mortality and End of life care

Summary

Acknowledgements

The analysis presented in this report uses data shared by patients and collected by the NHS as part of their care and support.

Thank you to the Macmillan-ISD Steering Group and to the Scottish Routes from Diagnosis Clinical Advisory Group for clinical and research support and advice in relation to the Scottish Routes from Diagnosis project.

Background

Scottish Routes from Diagnosis (SRfD) was a collaborative project between Public Health Scotland (formerly ISD) and Macmillan, which investigated survivorship outcomes and experiences of residents of Scotland with the four most common types of cancer found in Scotland: breast, prostate, colorectal and lung, using national datasets from 2007 and 2012.

The project developed survivorship Outcome Groups (OGs), which capture the survivorship experiences in four different groups and allows comparisons across (as well as within) cancer types. Reporting patient factors, pathways, and outcomes using these outcome groups allows for investigation into the very different experiences people can have following a cancer diagnosis, both within a particular cancer type and across different types.

For a full explanation of the Outcome Groups and methodology of SRfD, please refer to the initial [context and methodology publication](#).

Please note that this publication is based on data relating to cancer prior to the COVID-19 pandemic. Consequently, caution may be required in generalising these results to later time periods.

Mortality and end of life care analysis

This report presents a summary of the key findings only and focuses on the 2012 cohorts; for all analysis, definitions and context please refer to the full Mortality and End of Life Care report.

Mortality and end of life care – Summary of key findings

Review of five-year survival

- The **breast** cohort had the highest overall five-year survival rate at 78%. For those living with a continued presence of cancer (OG3) the survival rate was 70%.
- The **lung** cohort had the lowest overall five-year survival rate at 10%. Around half of the cohort survived for six months or less.
- The overall five-year survival rate for the **prostate** cohort was 68%; for those in OG3 it was 51%.
- Around half (49%) of the **colorectal** cohort were still alive five years after diagnosis.
- Survival rates were better for the 2012 cohorts compared to the 2007 cohorts.

Treatment intent

- Three-quarters of the **breast** cohort had a curative therapy objective at diagnosis; and, of those where treatment intent was non-curative only 11% did not receive treatment.
- Around 60% of the **colorectal** cohort had a curative aim. This proportion was lower in older age groups; and, for those with non-curative intent older age groups were also less likely to receive treatment. Almost everyone diagnosed at Dukes' stage A, B or C received treatment; of those diagnosed at Dukes' stage D less than 10% had a curative therapy objective.
- The majority of the **lung** cohort were diagnosed at an advanced stage and it was also the oldest cohort at diagnosis resulting in a low proportion with curative treatment intent (18%) and almost half the cohort (43%) receiving no treatment.
- In the **prostate** cohort around 40% had a curative aim and it is assumed that this is relatively low because watchful wait and active surveillance are classified as non-curative therapies. The proportion not receiving treatment is impacted by the omission of watchful wait and active surveillance from the treatments analysed.

Cause of death

- The main cause of death across all cohorts is cancer although this proportion is lower in the **breast** and **prostate** cohorts where people are surviving longer after their initial cancer diagnosis into older age where they are dying from other causes.
- In the **lung** cohort there were around 4,700 deaths with 87% of these deaths having a primary cause of death of lung cancer (other cancers accounted for 4% of deaths).
- There were around 1,900 deaths in the **colorectal** cohort where 70% had a primary cause of colorectal cancer and 14% were caused by other cancers.
- In the **prostate** cohort there were just under 1,000 deaths and 56% had a main cause of prostate cancer, other cancers accounted for 15% of deaths and heart disease a further 9%.
- There were around 1,000 deaths in the **breast** cohort with 53% due to breast cancer and 11% due to other cancers. Dementia as a main cause of death has increased in this cohort as women survive longer into older age, accounting for 10% of those that died aged 75 or over (and 6% of all deaths).

Place of death

- Only a small proportion of non-cancer deaths took place in a hospice or specialist palliative care unit.
- The focus of this analysis was on deaths from cancer with the **lung** (4,257) and **colorectal** (1,636) cohorts having the highest number of cancer deaths. The **breast** and **prostate** cohorts had 642 and 694 deaths from cancer respectively.
- Across all cohorts around one-third of deaths from cancer occurred in large or acute hospitals and this proportion is slightly higher in the **lung** cohort (36%).
- Around 11% of deaths from cancer in the **breast** and **prostate** cohorts took place in care homes, reflecting the older ages of those that died in these cohorts. Almost a third (29%) of deaths from other (non-cancer) causes in the **breast** cohort took place in care homes.
- In the **colorectal** and **lung** cohorts, for people living in the most deprived SIMD quintile, 41% of deaths from cancer took place in a large or acute hospital whereas the equivalent proportion for those living in the least deprived SIMD quintile was 33% for the **lung** cohort and 29% for the **colorectal** cohort.
- Across all cohorts, the proportion of deaths that occurred in a small or community hospital was higher for small towns and rural areas (especially remote areas); this proportion was lowest for urban areas where the proportion dying in a large or acute hospital was highest.

- Multinomial regression was used to examine the relationship between place of death with respect to SIMD quintile and urban-rural category for deaths from cancer (while also controlling for age at diagnosis and survival time).
 - In the **colorectal** cohort people in the least deprived areas were 2.2 times more likely (than the most deprived areas) to die in a hospice or specialist palliative care unit (compared to a large or acute hospital); in the **lung** cohort this was 1.7 times more likely.
 - Across all cohorts, people living in rural areas and small towns were much more likely to die in a small or community hospital (compared to a large or acute hospital) reflecting the geographical location of many of these hospitals. The effect was greater in remote areas.

Opioid prescribing in the community

- Across all cohorts, the proportion of people prescribed an opioid in the community prior to a death from cancer increased with proximity to death. In the 15-18 months prior to death this proportion was between 17% and 27%; in the last three months before death it was between 59% and 69%. The proportions were slightly lower in the **colorectal** cohort.
- Analysis of opioid prescribing in the three months before a death from cancer in a private home with respect to deprivation, survival time and rurality suggests:
 - Equitable access, with the possible exception of rurality for the **lung** cohort where the proportion was lower in urban areas (84%) than rural areas (90%).
 - Shorter survival time may impact opioid prescribing in the **lung** cohort where the proportion for those surviving less than three months (78%) was lower than those surviving longer than three months (89%).

Acute admissions in last year of life

- For deaths from cancer, 10% of the **breast** cohort had no admissions (or day cases) in their last year of life (post-diagnosis) and this proportion was lower for the **colorectal** (5%), **lung** (6%) and **prostate** (8%) cohorts.
- Those women in the **breast** cohort that had at least one admission in the twelve months prior to death spent on average around 12% of their last months as an inpatient in an acute hospital (including geriatric long stay and hospice admissions). This proportion rises to around 17% for the **lung** cohort; and, the majority of this time was for stays that began with a non-elective (emergency or urgent) admission. More detailed analysis of hospital activity in the last months of life is recommended, especially relating to emergency admissions and for those with lengthy stays ending with a death in hospital.
- The proportion of time spent in hospital increased as survival time decreased for all cohorts. For **breast** and **prostate** cohorts for those surviving six months or less this was around 38% of this time falling to around 10% for those that lived for more than one year. For the **lung** and **colorectal** cohorts those surviving one month or less spent on average around three-quarters of this time in hospital, with this proportion falling to around 11% for those surviving more than one year.

Further Information

Further information on the Scottish Routes from Diagnosis project, or other work resulting from our partnership, can be found on the [Macmillan](#) or the [Public Health Scotland](#) websites or by contacting us at phs.macmillan@phs.scot or HealthData@macmillan.org.uk.