

SEGMENTING THE 2 MILLION

New understanding of people living with cancer

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Research shows that two million people are currently living in the UK with a cancer diagnosis, predicted to increase to four million by 2030¹. However, there is little granular information on this cancer survivorship population. As part of a joint programme, Macmillan and NCIN are using patient-level national cancer datasets to describe the cancer prevalence population in detail, including their characteristics and needs.

Methods

This work looks at people diagnosed with cancer in the UK between 1991 and 2010 using the National Cancer Data Repository (NCDR). We identified people alive with cancer at the end of this period (i.e. ~20-year prevalence*) and then explored the characteristics of this population using a combination of parameters including age, gender, deprivation and time since diagnosis. Earlier research suggests that 20-year prevalence accounts for the majority of all people living with cancer (~82% in 2008)².

Results

Our analysis has revealed a range of new granular data about the cancer survivorship population. Overall there were 1.8 million people living with cancer up to 20 years after diagnosis in the UK. Of the 1.8 million, nearly a million have survived for more than five years, with over 480,000 of these surviving 10 years or more (Figure 1). This study of prevalence only includes people diagnosed between 1991 and 2010, so the total number of long-term survivors will be even higher.

Figure 1

Twenty-year prevalence* by time since diagnosis and sex in the UK, at the end of 2010[#]

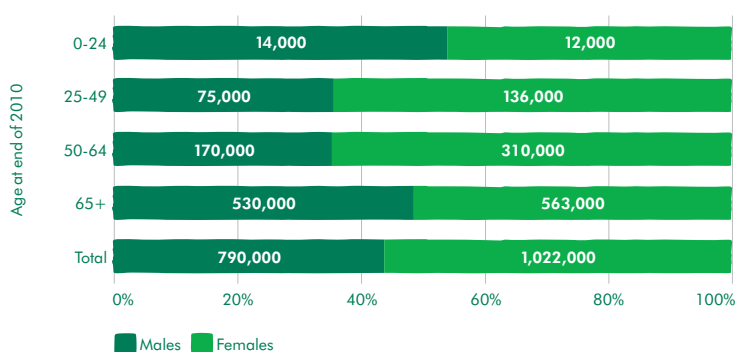


There is little difference in the number of males and females alive with cancer in the early years after diagnosis - of people still alive up to two years after diagnosis, 49% (around 208,000) are men compared to 51% (around 213,000) women. However, women account for 65% of people still alive 10-20 years after diagnosis (around 311,000 compared with 171,000 men)[#].

The majority of cancer survivors are older people. This may be expected given that cancer is generally a disease of old age. However, there is also a sizeable number of children and young people living with cancer. For those aged 25-64 nearly two-thirds are women (Figure 2). A number of reasons may explain these differences, they could relate to differences in life expectancy and incidence of cancer types between the sexes. The reasons will be explored further in the next stages of this study.

Figure 2

Twenty-year prevalence* by attained age and sex in the UK, at the end of 2010

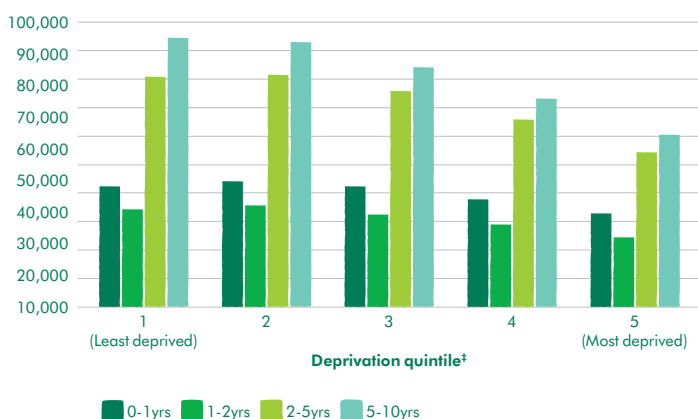


Deprivation (England only)

There were 1.1 million people in England diagnosed with cancer in the ten year period 2001-2010 and still alive at the end of 2010. Of these, 250,000 people are from the least deprived quintile, compared with 170,000 from the most deprived quintile[‡]. Overall 23% of people are from the least deprived quintile and 15% from the most deprived – this pattern persists across all time periods studied after diagnosis (Figure 3). Additional analysis shows that of all those people diagnosed with cancer between 2001-2005 (corresponding to those in the 5-10 years since diagnosis category) those in the least deprived quintile were more likely to have survived – with 40% still alive at the end of 2010, compared to 27% for the most deprived quintile. The reasons for these differences will be explored further in the next stages of our study.

Figure 3

Ten-year prevalence by deprivation quintile and time since diagnosis, England, at the end of 2010*



Conclusions

Understanding the numbers and characteristics of people living with cancer and, in particular longer-term survivors, is increasingly important for the delivery of personalised care. There is also increasing evidence that cancer survivors may not be living well: they are more likely than the general population to report poor health and wellbeing, higher use of hospital services and increases in other health conditions³.

Our work uses patient-level data to quantify a united picture of need across the cancer population for the whole of the UK in more detail than ever before, which is essential to understand the full burden of disease. The study looks at people living with cancer by different characteristics and gives us a more detailed understanding of their care and support needs. The next phase of this work will look at ethnicity (in England), cancer type, care pathway and localities across the UK. We will then add in or model data prior to 1991 to enable segmentation of the total number of people living with cancer.

Data notes

* Where data for Northern Ireland are included only 18-year prevalence is shown. Includes all malignant cancers combined excluding non-melanoma skin cancer (NMSC) (ICD-10 C00-97 excluding C44). Only the first diagnosed tumour (excluding NMSC) in each patient was included in the analysis. Anyone who died, left the country in the period or were aged over 99 at diagnosis or over 105 at the end of 2010, were excluded. Figures may not agree with those published elsewhere due to slight differences in methodologies, periods of observation, datasets, and rounding.

Numbers may not sum due to rounding.

‡ Deprivation quintiles are population-based quintiles of the Index of Multiple Deprivation (Department of Communities and Local Government). The deprivation analysis is based on 2001-2010 only.

Source data

Diagnosed cancers extracted from the National Cancer Data Repository (NCDR); National Cancer Registration Service (NCRS) and National Cancer Intelligence Network (NCIN), accessed June 2013.

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