

Segmenting the 2 million – new understanding of people living with and beyond cancer

Authors

L Irvine[1]; H McConnell[2]; S McPhail[3]; L Hounsome[4]

[1] Macmillan-NCIN Senior Data Fellow, NCIN, [2] Macmillan Cancer Support, [3] Senior Analyst, NCIN, [4] Principal Cancer Intelligence Analyst, Knowledge and Intelligence Team (South West)

Background

Research shows that two million people are currently living in the UK with a cancer diagnosis, predicted to increase to four million by 2030 (Figure 1) [1].

However, there is little granular information on this cancer survivor 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

The first stage of this work looks at people diagnosed with cancer in England between 1991 and 2010 in the National Cancer Data Repository (NCDR). We identify people alive with cancer at the end of this period (i.e. 20-year prevalence) and then explore the characteristics of this population using a combination of parameters including age, gender, locality, ethnicity, 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].

Figure 2

Number of cancer survivors in England by time since diagnosis

Based on people diagnosed with cancer in 1991-2010

Total number of survivors for the 20 year period ~ 1,500,000

Twenty-year prevalence for all malignant cancers combined (excluding non-melanoma skin cancer), number of people still alive at the end of 2010

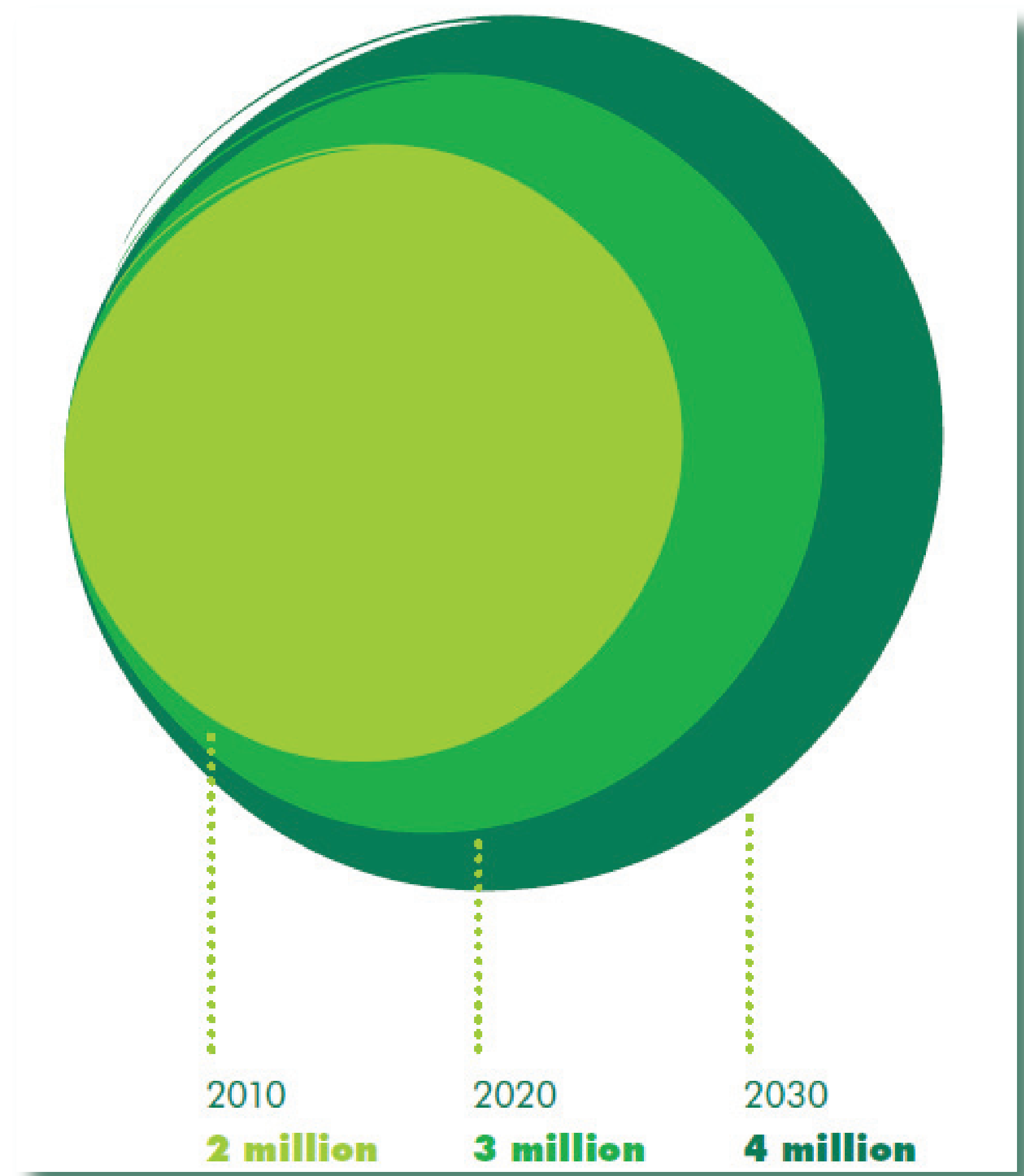
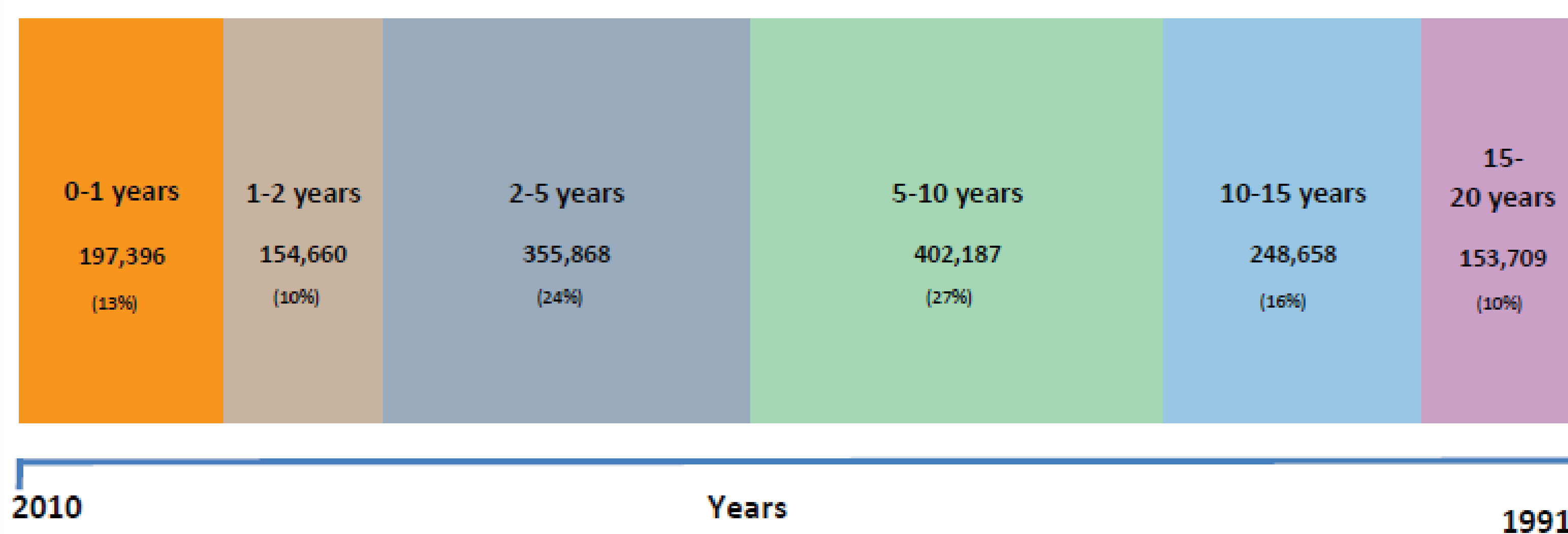


Figure 1: Number of people living with a cancer diagnosis in the UK

Results

Our analysis has revealed a range of new granular data about the cancer survivorship population. For example there are around 400,000 long term survivors in England, where people are still alive more than 10 years and up to 20 years after their diagnosis (Figure 2). Our study of prevalence only includes people diagnosed between 1991-2010, so the total number of long-term survivors will be even higher.

There is little difference in the number of males and females alive with cancer in the early years after diagnosis. However there are more female survivors than male over longer periods of post diagnosis. For example there are almost twice as many women than men still alive more than 10 years and up to 20 years after their diagnosis (around 260,000 compared with 143,00) in England (Figure 3). The reasons for these differences will be explored further in the next stage of our study.

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 (22,000 people aged 0-24) as well as those of working age (575,800 aged 15-64) living with cancer in England (Figure 4). The care and support needs for these patients are likely to be very different for these patients compared to those over the age of 65.

Figure 3

Number of cancer survivors in England by time since diagnosis and sex

Based on people diagnosed with cancer in 1991-2010

Twenty-year prevalence for all malignant cancers combined (excluding non-melanoma skin cancer), number of people still alive at the end of 2010

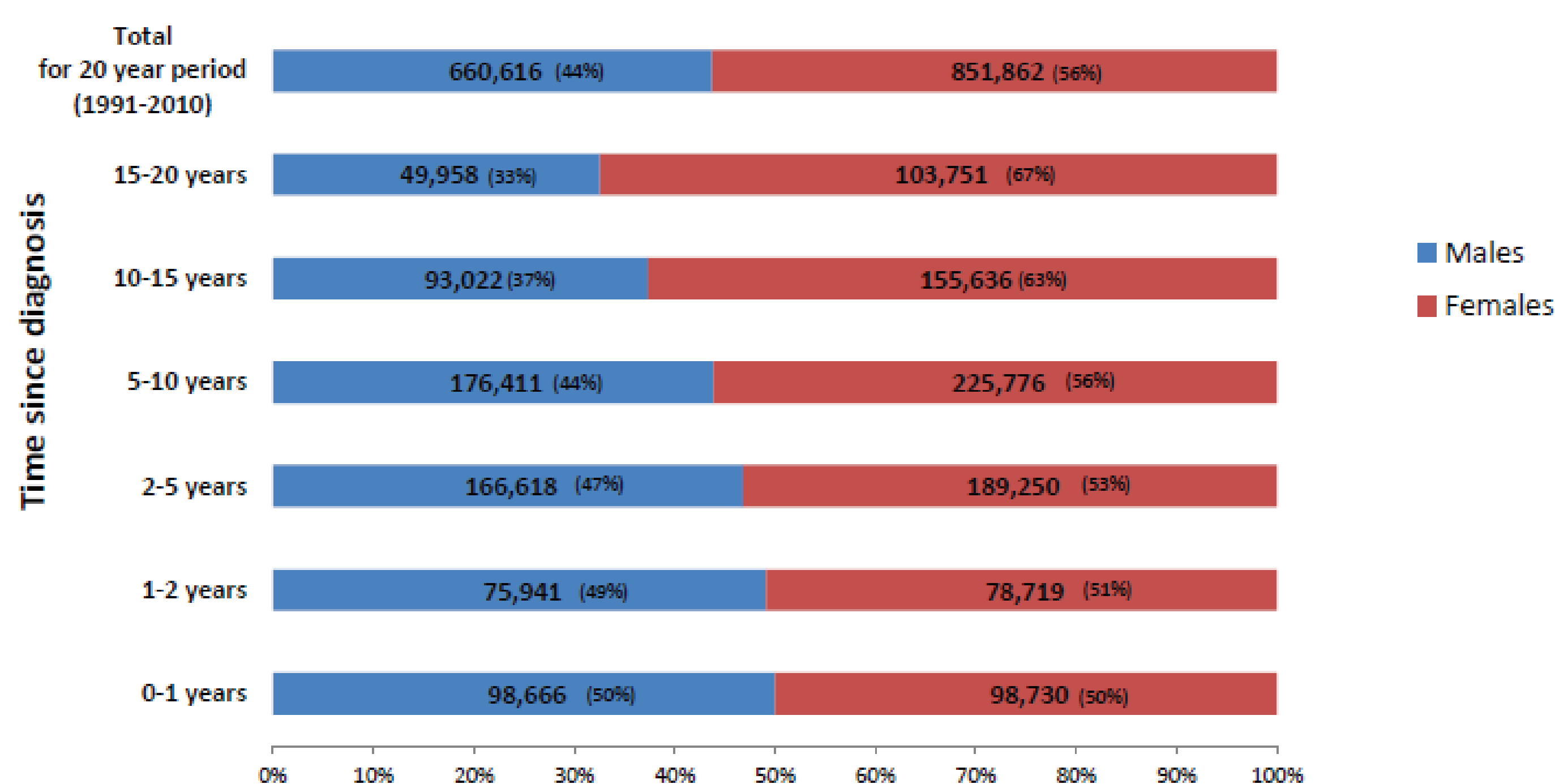
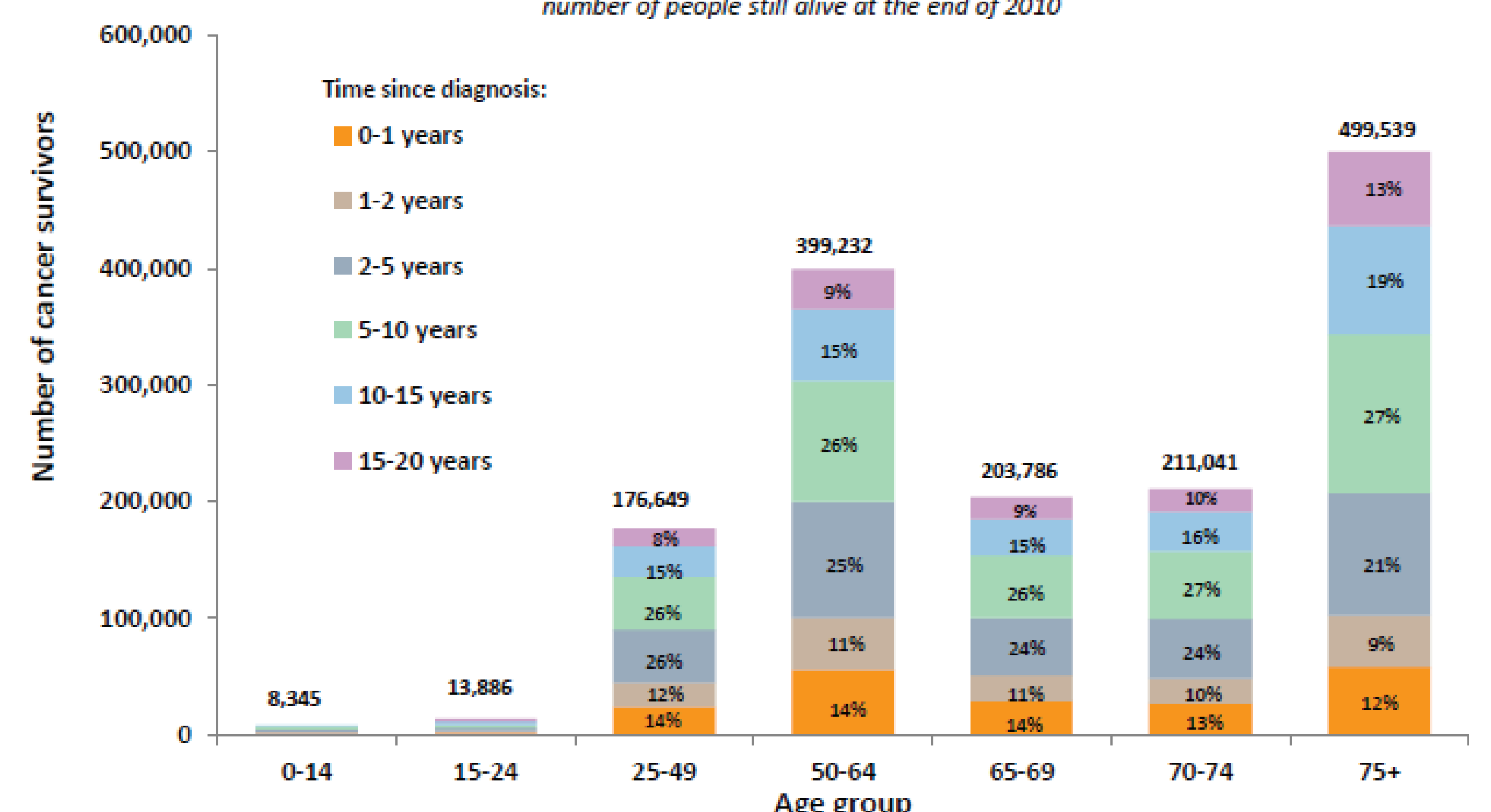


Figure 4

Number of cancer survivors in England by attained age, and time since diagnosis for each age group (%)

Based on people diagnosed with cancer in 1991-2010

Twenty-year prevalence for all malignant cancers combined (excluding non-melanoma skin cancer), number of people still alive at the end of 2010



Conclusions

Understanding the numbers and characteristics of people living with cancer and in particular long 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 conditions [3].

Our work uses patient-level data to quantify a united picture of need across the cancer population for the whole of England, which is essential to understand the full burden of disease. The second phase of this work will collate data for the whole of the UK, and explore the results in more detail. It will also obtain or model prior to 1991 to enable segmentation of the total number of people living with cancer. We will also explore new breakdowns of the data. For example by care pathways, cancer types, UK and UK nations, new NHS and PHE localities, and age at diagnosis as well as the attained age shown here.

References

- [1] Maddams J, Utley M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010-2040. Br J Cancer 2012; 107: 1195-1202. (Scenario 1 presented here).
- [2] Maddams J, et al. Cancer prevalence in the United Kingdom: estimates for 2008. British Journal of Cancer. 2009. 101: 541-547.
- [3] Richards M, Corner J and Maher J. The National Cancer Survivorship initiative: new emerging evidence on the ongoing need of cancer survivors. Br J Cancer 2011; 105: S1-S4.

Source of data: National Cancer Data Repository (NCDR)

For more information please contact Lucy Irvine, NCIN, lucyirvine@nhs.net