A new way of counting cancer prevalence to understand the prevalence of multiple primaries in the UK

Background

An estimated 2.5 million people are living with and beyond cancer in the UK, predicted to increase to 4 million by 2030. The Macmillan-NCIN UK Cancer Prevalence Project aims to provide the most granular understanding of the cancer survivorship population in the UK. Previous cancer prevalence analyses have largely been based on a person count and a ‘first diagnosis only’ method, but second and subsequent cancer diagnoses present new treatment and support needs. We aim to capture the prevalence of people diagnosed with more than one type of primary cancer within a specified 20-year period.

Methods

We used the Public Health England National Cancer Data Repository to link UK cancer registrations to mortality records in order to identify people diagnosed with cancer between 1991 and 2010 and still alive on 31st December 2010.

We calculated 20-year cancer prevalence based on the first diagnosis of any cancer in the 20-year time period. We then identified second or subsequent diagnoses of a different site within the 20-year period.

Results

Breast, colorectal, prostate and lung cancers had the highest absolute numbers of second and subsequent cancer diagnoses of a different site in the 20-year period 1991–2010 (figure 1). The highest proportions of second and subsequent cancer diagnoses of a different cancer site within the 20-year period were found for lung, pancreatic, liver, uterus and stomach cancers. Overall, the lowest proportions were found for sarcoma cancer, Hodgkin lymphoma, prostate cancer and breast cancer.

There were 480,766 females living with and beyond breast cancer in 2010, with an additional 10,000 female survivors living with breast cancer as a second or subsequent cancer diagnosis, having previously been diagnosed with another type of cancer within the 20-year period. One in 24 colorectal cancer survivors, or around 9,400 people, had a previous cancer diagnosis of a different site within the 20-year period.

Conclusions and limitations

This first-stage analysis has proven useful in informing us about multiple primaries. However, the nature of the extracted dataset used for this stage of the cancer prevalence project has substantial limitations, so that we can derive only limited information about many primary cancer diagnoses. The cancer diagnoses in our analysis are based on the 20-year finite time period 1991–2010; thus not capturing pre-1991 and post-2010 diagnoses. Our dataset only counts subsequent diagnoses of different cancer sites, and not of the same cancer site. Our analysis is also only based on analysing some of the most common cancer sites.

Even with these limitations in mind, our initial findings are thought-provoking. For example, the cancer shown with the highest proportions of second or subsequent diagnoses of a different cancer site tended to be the those cancers more associated with socio-economic and lifestyle factors rather than smoking, alcohol and diet. Shared risk factors may explain some of the variation between the nations where, for example, there are higher smoking rates in Wales and Scotland and a correspondingly higher number of lung cancer cases in these nations.

Although women living with cancer are more likely to have had a previous cancer diagnosis of a different cancer site than men living with cancer within the 20-year period, this may be due to the larger number of women living and surviving specific cancer diagnoses, most notably breast cancer. Treatment effects and lifestyle or genetic factors may also contribute to these findings, but more investigation is needed about these sex-related differences.

For the next stage of the UK Cancer Prevalence Project we will investigate multiple primary tumours in more detail. This will involve further analysis of the cancer registrations data, which are based on a longer period of time (not just the 20 years). We will explore all second and subsequent cancers (not just the second and subsequent diagnoses of a different cancer site). We will also explore further the findings and the context of these data by discussing the information with experts, comparing our findings with other studies and having a deeper understanding of cancer registration practice.

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References and notes:


2. ICD-10 codes were used to identify people diagnosed with cancer between 1991 and 2010.


4. Proportions may be underestimated if cancer registration data are not complete. There may also be some degree of misclassification of cancer sites.

5. Data is not complete for the UK as a whole, but data is available for England, Scotland, Wales and Northern Ireland.

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9. Figures were presented here as approximate numbers and may differ from other reported findings. Figures which refer to the number of second or subsequent cancers have been rounded and/or approximated.

10. Caution should be taken when comparing cancer data from different countries due to differences in data sources and data collection methods. Previous studies conducted by the International Agency for Research on Cancer (IARC) found that Scottish rates of secondary primaries were similar to other (non-UK) cancer registries.

Acknowledgements

This work is part of the Macmillan Cancer Support and Public Health England’s National Cancer Intelligence Network’s Work Plan. Data is received and processed in collaboration with the Welsh Cancer Intelligence and Surveillance Unit, Health Intelligence Division, Public Health Wales, the Scottish Cancer Registry and the Northern Ireland Cancer Registry which is funded by the Public Health Agency for Northern Ireland.