Estimating the calculation of complete cancer prevalence for the United Kingdom 1948-2013

Short Title: UK Complete Cancer Prevalence 1948-2013

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Abstract

Objective

To calculate the complete person prevalence of cancer in the UK using an index date of December 31st 2013 to aid in the understanding of the current cancer population.

Materials and Methods

Data on all diagnoses of malignant neoplasms (International Classification of Diseases [ICD]-10 C00-C97, excluding non-melanoma skin cancer [C44]) were obtained from the cancer registries of England and Wales, Scotland and Northern Ireland. Data availability differed across the nations at the time of analysis. We calculated person prevalence rather and as such, only the first cancer diagnosis was considered. A negative binomial regression model with a log link function was constructed for each cancer site, sex, age group at diagnosis (0-39, 40-69 and 70+) and nation of residence to estimate the number of people diagnosed with cancer who were still alive at the index date and who may have been diagnosed with cancer prior to cancer registration began.

Results

We estimated 2,273,156 were people living after a cancer diagnosis in the UK at the end of 2013, with 82% of them in England. Overall, the distribution of the prevalence population by time since diagnosis differed between cancer sites. For lung cancer, 66% were diagnosed in the last five years compared to 50%, 43% and 33% for prostate, colorectal and female breast cancer respectively. About 40% (N = 902,116) of the total UK prevalence population were within five years of diagnosis at the end of 2013.

Conclusions

We used cancer registration data from the four UK nations to enumerate the cancer population. Our detailed findings about the number of the population of people living after a cancer diagnosis can be

used to estimate the magnitude of the burden of cancer and inform healthcare and social care services across the UK of the resources needed to support better care.

Introduction

Understanding the cancer population is becoming an increasingly important aspect for national health systems as they attempt to tackle the growing cancer burden. Knowing the size of the cancer population helps health care systems meet current and future cancer patient needs now.[1] Evidence shows that cancer incidence in the United Kingdom (UK) is increasing [2], whilst survival for most cancers is also improving [3], leading to the assumption that the number of people living after a cancer diagnosis (termed cancer prevalence) is increasing. [4] Calculating cancer prevalence estimates the total number of people living with after a cancer diagnosis and may also provide a concept of how these patients should be classified: while cancer is often described as a single disease, each cancer site varies considerably in terms of survival, treatment and management, subgroups can help us better understand and address the needs of specific categories of cancer survivors [5]. Cancer prevalence can aid in this categorisation process as it allows a better understanding of the proportion of cancer survivors by different cancer site and the distribution of the cancer population by time since diagnosis.

Calculating cancer prevalence is not a novel idea [4, 6], but it is a very important one and one which can be addressed in different ways. These include selecting a point in time (index date) and calculating the number of people living with a cancer diagnosis (person prevalence) or alternatively the number of cancers diagnosed (tumour prevalence which considers people with more than one cancer). The United Kingdom and Ireland Association of Cancer Registries (UKIACR) has published guidelines for the calculation of cancer prevalence; we follow these standards to allow consistent comparisons between nations now and in the future. [7]

This study aims to estimate the complete person prevalence of cancer in the UK using an index date of December 31st 2013 to understand the current number of people living after a cancer diagnosis. The calculated prevalence includes an estimate for the population whose cancer diagnoses would have pre-dated the registries. [4]

Materials and Methods

Data

Data on all diagnoses of malignant neoplasms (International Classification of Diseases [ICD]-10 C00-C97, excluding non-melanoma skin cancer [C44]) of residents in England and Wales, Scotland and Northern Ireland at time of diagnosis who were still alive on 31st December 2013 were obtained from the cancer registry in each nation. Each record included details on year of diagnosis, age at diagnosis, sex, cancer site (ICD-10) and vital status.

Registrations for non-melanoma skin cancer (ICD-10 C44) were excluded as they are likely to be less complete and less accurate than those for other cancer sites. There is also a propensity for multiple non-melanoma skin cancers to occur in one individual, and cancer registries across the world adopt different practices in recording these, with some not recording them at all. Therefore, the category "all cancers combined" often omits these cancers in the interest of enhancing the validity of international comparisons of cancer incidence and statistics. [8]

Data availability differed across the nations at the time of analysis. For England and Scotland, data were available for the period of diagnosis 1971-2013 (43 years), 1985-2013 for Wales (29 years) and 1993-2013 (21 years) for Northern Ireland. These differences were due to when each registry was set up and the duration that each nation has been collecting information on cancer diagnoses. At the time of analysis, cancer registration data were available up to 31st December 2013 for all nations and therefore this was chosen as the index date.

The study was exempt from gaining individual consent to participate, having obtained Section 251 approval from the UK Patient Information Advisory Group (PIAG) (now the Confidentiality Advisory

Group, CAG), under Section 251 of the ct 2006 [PIAG 03(a)/2001]. Ethical approval was therefore not required.

Limited duration observed cancer prevalence

Patients over 99 years of age at diagnosis, patients who were over the age of 104 on 31st December 2013 and patients who had left the nation in which they were diagnosed between their diagnosis and the 31st December 2013 were excluded from the analysis. This was in-line with the methodology used by Maddams et al. [4]

As the purpose of this work was to estimate the number of people living following a cancer diagnosis, it was decided to calculate person prevalence rather than tumour prevalence. Therefore, the study only included the first cancer diagnosis in patients diagnosed with cancer during the time period.

Data were grouped by nation and cancer site, sex and age at diagnosis. Cancer sites were grouped as follows:

1 - female breast (ICD-10 C50); 2 - prostate (ICD-10 C61); 3 - colorectal (ICD-10 C18-C21); 4 - lung (ICD-10 C33-C34); 5 - and all other cancers including male breast cancer patients (ICD-10 C00-C97 excluding C44 and 1-4). Data were also split into three age groups based on the patient's age at diagnosis: 0-39 years, 40-69 years and 70 years and over.

Observed cancer prevalence was then calculated for each of the groups described above to determine the count of people living after their cancer diagnosis that were diagnosed between when the registry was established up till the index date. This involved counting the number of people who had been diagnosed in each nation using the available data and who were alive on 31st December 2013. Observed cancer prevalence was subsequently used to estimate complete cancer prevalence. Calculation of the age of the population at the end of 2013 in complete prevalence was not possible. However, we have included for reference observed cancer prevalence counts by age at index date for patients diagnosed in England.

Estimation of complete cancer prevalence

Complete cancer prevalence is an estimate of the total number of people who are living after a cancer diagnosis at the index date regardless of their diagnosis date. This is therefore the addition of observed cancer prevalence and modelled cancer prevalence (estimate of the number of people diagnosed with cancer who were still alive at the index date and who may have been diagnosed with cancer before cancer registration started). At the time of analysis, cancer registration data were available up to 31st December 2013 (index date).

Statistical analysis

A method similar to that of Maddams et al [4] was used to calculate complete cancer prevalence. A negative binomial regression model with a log link function was constructed for each cancer site, sex, age group at diagnosis (0-39, 40-69 and 70+) and nation of residence to estimate the number of people diagnosed with cancer who were still alive at the index date and who may have been diagnosed with cancer before cancer registration started.

Observed cancer prevalence at the index date (31st December 2013) was used as the response variable, with the year of diagnosis as the predictor variable. The log of the nation population for that year of diagnosis was used as an offset in the model.

When constructing the regression model for each age group, the inclusion criteria had to be maintained with regard to age of diagnosis and age at index date for the newly modelled patients. Figure 1 shows the source of complete cancer prevalence data for each nation. The number of years of data modelled was restricted back to 1948 as this was the earliest date where patients diagnosed with cancer could still meet the age eligibility criteria of being younger than 105 years on 31st December 2013.

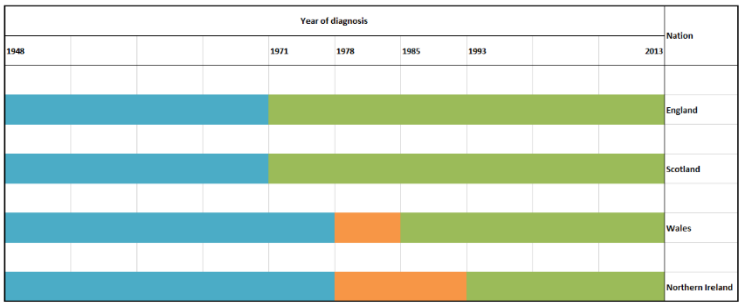

Figure 1: Source of data by nation, period of diagnosis and type

Green – observed data for all age groups
Orange – modelled data for 0-39 and 40-69 age groups (no data available for 70+ age group)
Blue – modelled data for 0-39 age group (no data available for 40-69 and 70+ age groups)

As the modelling of data estimated patients who were diagnosed with cancer at least 20 years ago, patients who were within five years of their diagnosis (diagnosed from 2009-2013) in the observed cancer prevalence count were excluded from the regression model, however they were still included in the final count after the modelling had occurred. This was to ensure that undue weight was not given to patients who were still at high risk of dying from their cancer [(4)].

Prostate cancer prevalence was modelled differently. Only data prior to 1992 was used in the negative binomial regression to counter the effect that the prostate-specific-antigen (PSA) test may have had on the recorded incidence of prostate cancer after its introduction in 1992 [(9)]. Due to no data being available for Northern Ireland prior to 1992, an assumption was made that the trend in prevalence for Northern Ireland before 1992 was the same as that for England. Therefore, the trend for "pre-PSA" prostate cancer in England was applied to the earliest data available for Northern Ireland.

For all combinations of cancer site, sex, age group and nation of residence, prevalence estimates were modelled back to a point where the estimated prevalence for the combination was fewer than one whole person. At this point it was assumed that the prevalence estimate for that year and all previous years was zero.

Stata SE version 13.1 was used to construct the negative binomial regression models used in the analysis, using the generalised linear model "glm" command. A predict function was then used to estimate the prevalence in earlier years where observed data were not available.

Results

Overall Results

In total, at the end of 2013 it was estimated that there were 2,273,156 people living after a cancer diagnosis in the UK, with England making up the majority of this population (82%) compared to Northern Ireland with 3% (Table 1).

26% of people living after a cancer diagnosis were females with breast cancer followed by 15% for prostate cancer, 12% for colorectal cancer and 3% for lung cancer. The majority of the population was female (57%) and most patients were diagnosed between the ages of 40-69 years (62%). For England specifically, the most prevalent age groups were 70-79-year olds (27%) followed closely by 60-69 years old (25%) (Table 1).

Table 1: The number of people living at the end of 2013 after a cancer diagnosis in the UK

		Number of Patients	Percentage
UK		2,273,156	100%
Nation			
	England	1,869,280	82%
	Scotland	205,477	9%
	Wales	128,833	6%
	Northern Ireland	69,566	3%
Cancer site			
	Females breast	594,481	26%
	Prostate	333,767	15%
	Colorectal	268,568	12%
	Lung	64,214	3%
	All other malignant neoplasm (exc C44)	1,012,126	45%
Sex			
	Male	978,945	43%
	Female	1,294,211	57%
Age at diagnosis			
	0-39	309,717	14%
	40-69	1,398,732	62%
	70+	564,707	25%
Age at index date (31st December 2013) *			
	0-9	4,462	0.2%
	11-19	9,966	1%
	20-29	24,137	1%
	30-39	53,048	3%
	40-49	133,171	7%
	50-59	255,451	14%
	60-69	468,106	25%
	70-79	506,556	27%
	80-89	324,718	17%
	90+	76,616	4%

*England observed data only (1971-2013)

Figure 2 describes the breakdown of modelled cancer prevalence that were combined with observed cancer prevalence to estimate the complete cancer prevalence for the UK. 22% of the overall complete cancer prevalence estimate in Northern Ireland was based on modelled data. Conversely, for England 0.7% of the overall figure was modelled. When combined to form the total for the UK, 2% was estimated – also indicating the majority that the English cancer population has within these estimates.

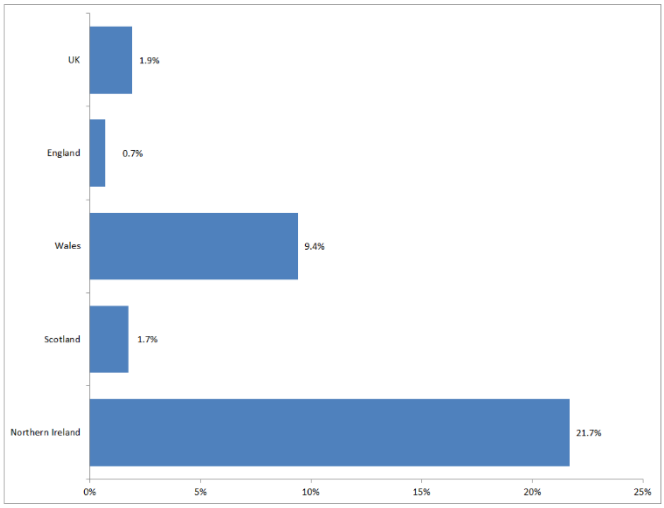

Figure 2: Proportion of modelled data used to derive complete cancer prevalence for the UK and constituent nations

Time since diagnosis (UK results by cancer site)

In the UK, the distribution of the prevalence population by time since diagnosis differed between cancer site. 66% of the lung cancer population were within 5 years since diagnosis compared to 50%, 43% and 33% for prostate, colorectal and female breast cancer respectively (Table 2).

Table 2: The distribution of complete cancer prevalence by time since diagnosis stratified by cancer site (UK results)

	Time since diagnosis (years)				
	0	**1-5**	**6-10**	**11-20**	**>20**
Female breast	45,532 (8%)	151,529 (25%)	144,612 (24%)	173,459 (29%)	79,349 (13%)
Prostate	41,526 (12%)	128,109 (38%)	101,206 (30%)	59,242 (18%)	3,684 (1%)
Colorectal	29,774 (11%)	86,466 (32%)	64,013 (24%)	62,943 (23%)	25,372 (9%)
Lung	20,037 (31%)	22,620 (35%)	8,798 (14%)	7,323 (11%)	5,436 (8%)
All other malignant neoplasms (Exc C44)	106,831 (11%)	269,692 (27%)	213,886 (21%)	240,112 (24%)	181,605 (18%)

Female breast cancer had the highest proportion of patients diagnosed over five years prior to the index date with 67% compared to only 34% for lung cancer. Whilst 49% of prostate cancer patients were diagnosed over five years prior, only 1% of the population was diagnosed over 20 years prior, compared to lung cancer patients who had the second lowest proportion of 8% (Table 2).

Time since diagnosis (nation results by cancer site)

Table 3 shows the distribution of the complete cancer prevalence by time since diagnosis. 40% of the total UK prevalence population were within five years of diagnosis at the end of 2013 (N = 902,116). 13% of the total UK prevalence population were diagnosed over 20 years prior to the index date.

Table 3: The distribution of complete cancer prevalence by time since diagnosis stratified by cancer site (nation results)

		Time since diagnosis (years)					
		0	**1-5**	**6-10**	**11-20**	**>20**	**Total**
Nation (All cancers combined)							
	UK	243,700 (11%)	658,416 (29%)	532,515 (23%)	543,079 (24%)	295,446 (13%)	2,273,156 (100%)
	England	202,635 (11%)	549,011 (29%)	443,278 (24%)	451,028 (24%)	223,328 (12%)	1,869,280 (100%)
	Scotland	21,474 (10%)	56,869 (28%)	45,773 (22%)	48,729 (24%)	32,632 (16%)	205,477 (100%)
	Wales	13,257 (10%)	34,463 (27%)	29,037 (23%)	28,623 (22%)	23,453 (18%)	128,833 (100%)
	Northern Ireland	6,334 (9%)	18,073 (26%)	14,427 (21%)	14,699 (21%)	16,033 (23%)	69,566 (100%)
England							
	Female breast	38,024 (8%)	126,459 (26%)	121,396 (25%)	145,713 (29%)	62,407 (13%)	493,999 (100%)
	Prostate	35,411 (12%)	109,107 (38%)	85,408 (30%)	50,947 (18%)	3,022 (1%)	283,895 (100%)
	Colorectal	24,384 (11%)	70,804 (32%)	52,587 (24%)	51,215 (23%)	19,802 (9%)	218,792 (100%)
	Lung	15,904 (31%)	18,272 (36%)	7,041 (14%)	5,899 (12%)	4,010 (8%)	51,126 (100%)
	All other malignant neoplasms (Exc C44)	88,912 (11%)	224,369 (27%)	176,846 (22%)	197,254 (24%)	134,087 (16%)	821,468 (100%)
Scotland							
	Female breast	3,934 (8%)	13,414 (26%)	12,260 (23%)	14,483 (28%)	8,212 (16%)	52,303 (100%)
	Prostate	2,866 (12%)	8,774 (38%)	7,030 (30%)	4,133 (18%)	429 (2%)	23,232 (100%)
	Colorectal	2,812 (11%)	8,363 (32%)	6,167 (23%)	6,389 (24%)	2,784 (10%)	26,515 (100%)
	Lung	2,469 (32%)	2,601 (34%)	1,072 (14%)	823 (11%)	699 (9%)	7,664 (100%)
	All other malignant neoplasms (Exc C44)	9,393 (10%)	23,717 (25%)	19,244 (20%)	22,901 (24%)	20,508 (21%)	95,763 (100%)
Wales							
	Female breast	2,446 (8%)	7,621 (24%)	7,355 (23%)	9,012 (28%)	5,480 (17%)	31,914 (100%)
	Prostate	2,330 (12%)	7,056 (38%)	6,123 (33%)	2,947 (16%)	190 (1%)	18,646 (100%)
	Colorectal	1,641 (11%)	4,698 (32%)	3,384 (23%)	3,334 (23%)	1,520 (10%)	14,577 (100%)
	Lung	1,104 (31%)	1,156 (32%)	399 (11%)	357 (10%)	541 (15%)	3,557 (100%)
	All other malignant neoplasms (Exc C44)	5,736 (10%)	13,932 (23%)	11,776 (20%)	12,973 (22%)	15,722 (26%)	60,139 (100%)
Northern Ireland							
	Female breast	1,128 (7%)	4,035 (25%)	3,601 (22%)	4,251 (26%)	3,250 (20%)	16,265 (100%)

Prostate	919 (11%)	3,172 (40%)	2,645 (33%)	1,215 (15%)	43 (1%)	7,994 (100%)
Colorectal	937 (11%)	2,601 (30%)	1,875 (22%)	2,005 (23%)	1,266 (15%)	8,684 (100%)
Lung	560 (30%)	591 (32%)	286 (15%)	244 (13%)	186 (10%)	1,867 (100%)
All other malignant neoplasms (Exc C44)	2,790 (8%)	7,674 (22%)	6,020 (17%)	6,984 (20%)	11,288 (32%)	34,756 (100%)

The distribution for the England population was almost identical to the UK population described above. For Scotland and Wales, a slightly higher percentage of the prevalence population, 16% and 18% respectively, were diagnosed over 20 years prior to the index date. However, both nations have roughly the same proportion of patients in the more recent year groups (diagnosed 0-10 years prior to index date).

For Northern Ireland, the difference compared to both the UK and other nations was more pronounced. Only 9% (N = 6,334) were diagnosed in the last year (2013) compared to 11% for the UK. There was also a smaller proportion of patients in each of the other year groups except for the >20 years from diagnosis group where 23% of the cancer prevalence population are distributed, compared to 13% for the UK.

Discussion

Observed cancer prevalence is published across the UK. In Northern Ireland it is published with official statistics in documents such as 'Incidence, prevalence and survival statistics: 1993-2017' which currently present 25-year cancer prevalence in 2017 (N. Ireland Cancer Registry. https://www.qub.ac.uk/research-centres/nicr/CancerInformation/official-statistics/BySite/All-Cancers-excl-NMSC/). In Scotland, cancer prevalence data is published on the Information Services Directorate (ISD) Scotland website and contains 20-year cancer prevalence in 2017 (ISD Scotland https://www.isdscotland.org/Health-Topics/Cancer/Cancer-Statistics/All-Types-of-Cancer/). In England, observed cancer prevalence is published on the National Cancer Registration and Analysis Service (NCRAS) website (http://www.ncin.org.uk/local_cancer_intelligence/tcst and http://www.ncin.org.uk/about_ncin/segmentation). In England, Scotland, Wales and Northern Ireland, local area cancer prevalence is presented in Macmillan's Local Cancer Intelligence website (https://lci.macmillan.org.uk/). This observed cancer prevalence data varies in both the index date and the duration since diagnosis. Through modelling, in the way we have set out, it should allow the creation of more comparative data across the UK with the same duration since diagnosis.

Summary of findings

We used cancer registration data from the four UK nations to enable the most complete enumeration of the current cancer population. We found that across the UK there were over 2.27 million people alive on 31st December 2013 following a cancer diagnosis. Our results showed that lung and female breast cancers accounted for 3% and 26% of the prevalent population at the end of 2013, respectively. The distribution of these cancers in the incident cancer population have been reported, accounting for 12% and 15% in 2013, respectively (CancerData) [10]. This difference in findings could be explained by the poorer prognosis for lung cancer compared to female breast cancer. Five-year net survival (2012-2016) for lung cancer was 11.1/15.0% (male/female) and 86.7% for female breast cancer [11]. It can be argued that whilst it is important to focus on the number of people diagnosed, the healthcare and social care systems must be aware of complete cancer population to be able to plan for and provide the best possible care for cancer patients. Additionally, we found that more than one in four cancer patients alive in 2013 were aged 70-79 at the time of their cancer

diagnosis. When looking at the age of cancer in England at the end of 2013, nearly one in two (48%) patients were aged over 70. As the population ages and people living with cancer live longer due to improvements in early diagnosis, treatment and management of cancer there will be increased numbers of older people living with cancer. This will necessitate more system resources to cope with this increase, which should be planned and shaped for considering the complex needs of this patient group.

Understanding the different challenges that the prevalent population provides is crucial for the provision of services, most importantly in understanding where there are differences between different groups of people within the prevalent population. Whilst knowing the overall number of patients is important, the needs of these cancer patients can vary depending on a variety of factors, such as time since diagnosis. Overall 40% of the prevalent population in the UK are between zero and five years from diagnosis. Typically, this can be considered as a period where patients are either undergoing active management of their cancer or believe that their cancer could return [12]. The type and volume of management will differ greatly for the 13% of the UK population diagnosed over 20 years ago who would typically require a reduced amount of direct care for their cancer, but may be living with long term and late effects of cancer and their treatment [13]. This is even more pronounced for the 4% who are living for over 30 years since diagnosis [13]. In Northern Ireland, 23% of the cancer prevalence population were more than 20 years from diagnosis compared to 13% for the UK. The reasons for this are not clear but it could be linked to the age profile in Northern Ireland or the completeness of records of vital status.

Strengths and Limitations

One of the strengths of this study is that it utilises high quality cancer registration data from each of the UK nations to give a unique understanding of the whole UK cancer population and the differences between the individual nations. This study builds on the work of Maddams et al [4] and has prompted the creation of a standardised operating procedure in the UK for the calculation of both observed and complete cancer prevalence, which has been adopted by UKIACR to provide a basis for reporting prevalence from routine cancer registration data within all four cancer registries. [6] Additionally, only 2% of our estimate of complete

cancer prevalence in the UK was modelled and this is likely to improve over time as the cancer registries become older.

The findings should be interpreted whilst considering the study limitations. First, our estimate of complete cancer prevalence in the UK dates back to the end of 2013 and prevalence will have increased since then. Nevertheless, this study offers a methodology for estimating UK wide cancer prevalence for the first time and could be used for future iterations. Second, a major limitation to this study is that due to the restrictions of modelling, we were unable to examine age at time of diagnosis by patient characteristics within each nation in more granularity. Yet, this data can be used in conjunction with detailed limited-duration observed cancer prevalence to provide a more comprehensive representation of prevalence, especially in nations where there is very little need for modelled data. Third, due to the introduction of PSA testing in the early 1990s, we were unable to use data following this date in the modelling approach. As the incidence of prostate cancer was much lower before the use of PSA testing, this has therefore led to an underestimation of the prostate cancer prevalence [9]. This is mainly a limitation in Northern Ireland where there is no data available prior to 1992. Nevertheless, our approach has shown that for some nations, especially England and Scotland, the use of detailed limited-duration observed cancer prevalence using the full back history of the registry should be sufficient for complete cancer prevalence calculations as it only relies on a small amount of modelled data.

Implications for policy and research

Our findings are important for healthcare and social care services across the UK. In order to provide the resources to support the best possible care for everyone living after a cancer diagnosis, an understanding of the complete cancer population is required. This work is based on the approach developed by Maddams et al [4] and provides a detailed understanding and perhaps more importantly a standardised methodology for calculating cancer prevalence across the UK nations (and elsewhere where the required data are available), allowing for further comparisons between the nations. Due to the importance of this work, and the predicted increase in cases, it is imperative that annual updates to cancer prevalence calculations, even if only observed cancer prevalence, become a routinely reported statistic. This would ensure that healthcare and

social care systems have the latest data to effectively plan and deliver appropriate care for those living after a cancer diagnosis throughout the UK, regardless of when they were diagnosed.

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