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Full Paper New pathways of care for cancer survivors: adding the numbers

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BACKGROUND: Two million people in the UK had a cancer diagnosis at the end of 2008. Understanding the number of people diagnosed with cancer with and without health needs is valuable information that can be used to inform service planning, treatment provision and support for people at the right time in the right place as demand grows over time.

METHODS: Using available data and clinically led assumptions about patient need and outcomes, we make indicative estimates. We quantify, for three common cancers, the number of people in each of the five main identified phases of the cancer care pathway. RESULTS: Estimates are provided for each phase of the pathway for breast, colorectal and lung cancers. We estimate that there are nearly 575 000 women a year with breast cancer in the care pathway at some point in the year, 8% are in the rehabilitation phase and 4% in the progressive illness phase. This compares to nearly 270 000 with colorectal and around 95 000 with lung cancer.

CONCLUSION: Using readily available data, we estimate the numbers of patients with different health needs. These numbers could inform the targeting of resources for service providers.

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Two million people in the UK had a cancer diagnosis at the end of 2008; some were diagnosed the previous week, whereas others were diagnosed more than 20 years ago (Figure 1; Maddams *et al*, 2009). With 309 000 new cases of cancer diagnosed in 2008, the number of people living with cancer is rising every day (Information Services Division (ISD) Scotland, 2010; Northern Ireland Cancer Registry, 2011; Welsh Cancer Intelligence and Surveillance Unit, 2010; Office for National Statistics, 2010a). If current trends continue, there will be 4 million cancer survivors (people living who have had a cancer diagnosis at some point in their lives) by 2030 (estimated, based on Maddams *et al*, 2009).

We estimate that around 245 000 people died in 2008 having had a diagnosis of cancer, of whom 64% died from their cancer and 36% died because of some other cause (see Figure 1; Information Services Division (ISD) Scotland, 2010; Northern Ireland Cancer Registry, 2011; Welsh Cancer Intelligence and Surveillance Unit, 2010; Maddams *et al*, 2009; Office for National Statistics, 2010a). This estimate is intended to be indicative only. Given the inaccuracies associated with death registrations and cause of death, more accurate estimates cannot be made (Office for National Statistics, 2010b). The estimated proportions are consistent with similar data for South West England (South West Public Health Observatory, Cancer Intelligence Service, 2009).

For some of these cancer survivors there may be a period of several apparently cancer-free years before the development of incurable metastatic disease, and then several further years living with incurable cancer before reaching the last year of life. In addition, cancer survivors may have treatment-related health problems ranging from the trivial to the very complex, some of which are amenable to intervention through secondary prevention or detection and effective management.

Understanding the number of people diagnosed with primary and secondary cancer is valuable information that can be used to inform service planning, treatment provision and support for people at the right time in the right place as demand grows over time.

Cancer survival is regularly reported, but little data are routinely reported by cancer registries about cancer survivors. This amplifies the assumption that cancer survivors have no particular needs requiring specific resources. The lack of segmentation of the population of survivors into different groups based on their need for services has hampered the progress of the survivorship programme.

The survivorship programme (Department of Health, Macmillan Cancer Support and NHS Improvement, 2010) aims to improve and maintain health and well-being and reduce disability related to cancer and its treatment. Interventions need to be targeted to populations where they will achieve the most benefit, and interventions that do not add value need to be replaced.

Data are currently not routinely collected to enable accurate calculation of the numbers at different phases of the care pathway. We therefore use available data together with clinically led assumptions to segment the survivorship population to enable service planning and resource allocation. We use and present these data to stimulate interest and debate to ensure that accurate data are collected and reported in the future.

MATERIALS AND METHODS

Using clinically led assumptions about patient need and outcomes, and available data on cancer incidence, survival, prevalence and mortality data, indicative estimates are made to quantify need across the cancer care pathway.

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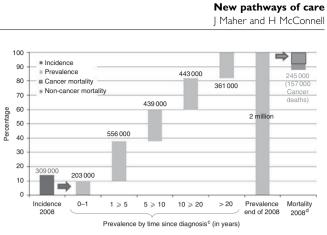


Figure I People newly diagnosed, people living with cancer by year since diagnosis and deaths for people with a cancer diagnosis, UK, 2008.^{a,b} ^aAll cancers exclude non-melanoma skin cancer (ICD-10 C44), except for cancer deaths that include deaths from all malignancies. ^bIncidence is the number of newly diagnosed cases and is a count of tumours in 2008. Mortality is a count of deaths due to cancer in 2008. Prevalence is a count of the number of people living with cancer at the end of 2008. ^cPrevalence measures time since diagnosis up to 1, 5, 10 or 20 years. For example, '1≥5 years' means more than 1 year and up to 5 years since diagnosis and '>20 years' is more than 20 years since diagnosis. ^dThe number of deaths for people with a cancer diagnosis, 245 000, is estimated assuming that the rate of increase in prevalence is 3.2% (Maddams et al, 2009) and using incidence and mortality data. Prevalence is increasing at 3.2% a year; thus, approximately 64 000 people are added to the prevalent stock at the end of 2008. The increase in prevalence (64 000) is a product of new cases and deaths. With 309 000 new cases and 157 000 cancer deaths in 2008, we estimate that approximately 88000 people die from other causes; therefore, we estimate that there were 245000 deaths for people with a cancer diagnosis. Sources: Maddams et al (2009); Cancer Research UK (2010); Information Services Division (ISD) Scotland (2010); Northern Ireland Cancer Registry (2011); Welsh Cancer Intelligence and Surveillance Unit (2010); Office for National Statistics (2010a, b).

We acknowledge that individual pathways for patients will vary greatly and this estimation is indicative only. For example, some people will go through all phases in the pathway, some will experience only one or two phases, some will spend varying amounts of time in each phase, requiring differing levels of support and some people will not die from their cancer but may suffer from consequences of either the disease or its treatment.

Assumptions

Five main phases on the care pathway have been identified (Figure 2):

- diagnosis and treatment (assumed to be the year from diagnosis),
- rehabilitation (assumed to be the year after treatment, estimated as the second year after diagnosis),
- monitoring (includes those at risk of recurrence or treatment complications but with no active cancer or treatment-related illness, and is split here between early and later monitoring),
- progressive illness (includes incurable cancer, but not those in the last year of life, and significant treatment-related illness),
- end of life (includes those in the last year of life presented with a subset diagnosed in the same year).

The flow of people into and out of different phases of the pathway is dynamic, but our model aims to estimate the number of people in the phases in a given year. Therefore, we assume that prevalence numbers more than 2 years from diagnosis and counted at a point in time reflect the stock in a year, and that incidence and mortality data capture the flow of cancer patients into and out of survivorship phases. Those dying from causes other than cancer have been excluded – we estimate that in total around 90 000 people with a cancer diagnosis in the UK died from causes other than cancer in 2008 (estimated, see Figure 1). Some of these people may in fact die from conditions related to their cancer or from the late effect of cancer treatment; however,

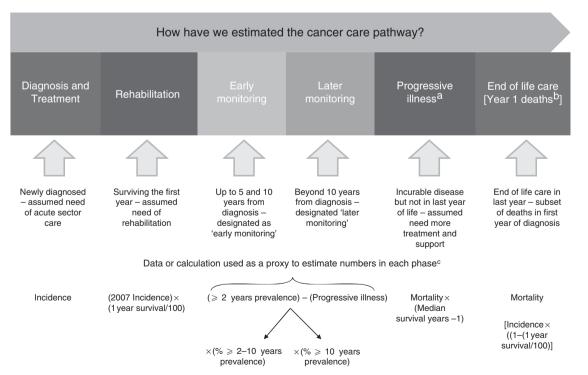


Figure 2 Assumptions and calculations used to estimate the cancer care pathway. ^aThe numbers in the progressive illness group will be underestimated and the numbers in the monitoring groups overestimated as estimates for significant late effects have not been made. ^bWe calculate a subset of deaths in the first year of diagnosis to clarify the risk of double counting in diagnosis and treatment and end of life care. ^cUnless otherwise stated data are for 2008.

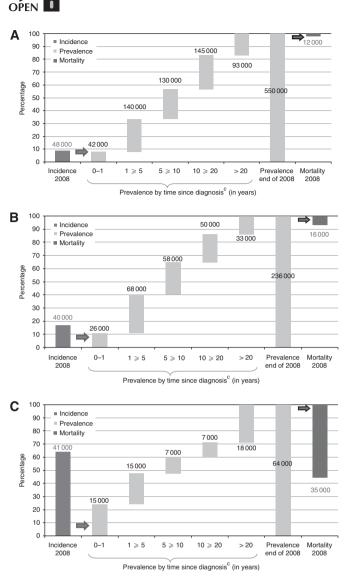


Figure 3 (A) Women newly diagnosed, living with breast cancer by year since diagnosis and breast cancer deaths, UK, 2008.^{a,b} (B) People newly diagnosed, living with colorectal cancer by year since diagnosis and colorectal cancer deaths, UK, 2008.^{a,b} (C) People newly diagnosed, living with lung cancer by year since diagnosis and lung cancer deaths, UK, 2008.^{a,b} ^aFemale breast (ICD-10 C50). Colon, rectum and anus (ICD-10 C18-C21). Lung, bronchus and trachea (ICD-10 C33-C34). ^bIncidence is the number of newly diagnosed cases and is a count of tumours in 2008. Mortality is a count of deaths due to cancer in 2008. Prevalence is a count of the number of people living with cancer at the end of 2008. ^cPrevalence measures time since diagnosis up to 1, 5, 10 or 20 years. For example, '1≥5 years' means more than I year and up to 5 years since diagnosis and '>20 years' is more than 20 years since diagnosis. The prevalence estimate for men with lung cancer more than 20 years from diagnosis is likely be overestimated by ~8000. Sources: Maddams et al (2009); Cancer Research UK (2010); Information Services Division (ISD) Scotland (2010); Northern Ireland Cancer Registry (2011); Welsh Cancer Intelligence and Surveillance Unit (2010); Office for National Statistics (2010a, b).

there are currently no data to allow the quantification of these groups. As more data become available, we may be able to include some of these people in the cancer care pathway.

Data and limitations

The analysis is based on the collation of available data on cancer incidence, survival, prevalence and mortality from available



sources to provide indicative estimates as to the number of people in each phase of the care pathway in a year.

Data for all cancers are, unless otherwise stated, for all malignant neoplasms excluding non-melanoma skin cancer (ICD-10 C00-C97 excluding C44). We estimate pathways for three cancer types:

- Breast cancer in women (ICD-10 C50),
- Colorectal cancer, which includes colon, rectum and anus (ICD-10 C18-C21) and
- Lung cancer, which includes lung, bronchus and trachea (ICD-10 C33-C34).

Figures 3A-C presents 2008 incidence, mortality and prevalence data for the UK for breast, colorectal and lung cancer. These data are used along with survival data and clinical assumptions to estimate the pathways of care. How the data are used to quantify the number of people in each phase is described below.

Diagnosis and treatment

Cancer incidence data are used as a proxy to estimate the number of people requiring care, supervised and delivered by the acute sector in the year following diagnosis. Cancer incidence data for 2008 are collected by Cancer Registries across the UK. We use published data for each nation for England, from the Office for National Statistics (2010a), and from the national registries of each of the Celtic Nations ((ISD) Scotland, 2010; Welsh Cancer Intelligence and Surveillance Unit, 2010; Northern Ireland Cancer Registry, 2011).

Rehabilitation

If cancer survivors had rehabilitation services, such as physiotherapy, occupational therapy, dietetics, lifestyle assessment and planning after cancer treatment, patients could return to normal life more quickly. For example, there is evidence that, for some cancers, doing recommended levels of physical activity can reduce the risk of recurrent cancer and mortality (Holmes et al, 2005; Meyerhardt et al, 2006; Kenfield et al, 2011). On the basis of patient questionnaires following up cancer survivors after treatment, one study found that 30% reported five or more unmet needs at the end of treatment, and for the majority of them (60%) the situation had not improved 6 months later (Armes et al, 2009). We have therefore estimated that people in this phase of the pathway are identified as those who have survived the first year after diagnosis and hence may require rehabilitative support in their second year after diagnosis. Estimates are calculated using 1-year survival (Office for National Statistics and London School of Hygiene and Tropical Medicine, 2011) and cancer incidence from 2007 to estimate the number of deaths in the first year. This is then subtracted from cancer incidence in 2007 to give an estimate of those alive in their second year after diagnosis. Rehabilitation services could be supervised and delivered in the acute sector or the community.

Monitoring

Prevalence data (Maddams *et al*, 2009) are used as a proxy to estimate the number of people in early or later monitoring based on time since diagnosis. Those people with 'progressive illness' are excluded from the monitoring phase.

'Early monitoring' might be seen as the phase in which there is no active cancer or treatment-related consequence requiring intervention, but there is a significant risk of occurrence. It might be expected that monitoring would be supervised by specialists, for example, by producing a plan of tests. This could be delivered in the community or acute sector. The period of high risk may vary from 2 to 10 years depending on the cancer considered. 58



After this higher-risk phase, patients may still be at a small risk of late recurrence but may also be at continued risk of an increase in chronic illness such as heart disease or osteoporosis (Khan *et al*, 2011b), which could have been reduced through proactive intervention. This will particularly be the case for those treated at a younger age (Oeffinger *et al*, 2006). Additional monitoring in this later phase may well be appropriate in primary care. To illustrate the approach, we have identified as 'early monitoring' those surviving up to 5 and 10, but more than 2 years from initial diagnosis. 'later monitoring' identifies those surviving 10 or more years from initial diagnosis.

Progressive illness

A majority of those patients who die of cancer after the first 2 years will die of metastatic disease. The date of the first abnormal scan is currently not routinely collected by cancer registries. This makes it difficult to estimate the number of people who have progressive cancer, but are not in the last year of life, who will have particular health needs.

We have used cancer mortality data as a proxy for the number of people with metastatic cancer in a year. Progressive illness will vary in length by cancer type and we use median survival (minus one to exclude those in the last year of life) and cancer mortality to estimate people with progressive illness. We have used the estimate of a median survival of 2.5 years for metastatic colorectal cancer, as this was used in the recent Department of Health Frontier report (Frontier Economics, 2010), and clinical consensus of a median 3 years survival for breast cancer (remembering that those in their last year of life are excluded from this estimate). We have not included progressive consequences of treatment in this estimate, which would reduce the numbers in the 'monitoring' phase and increase the numbers in the 'progressive illness' phase, particularly for pelvic cancers

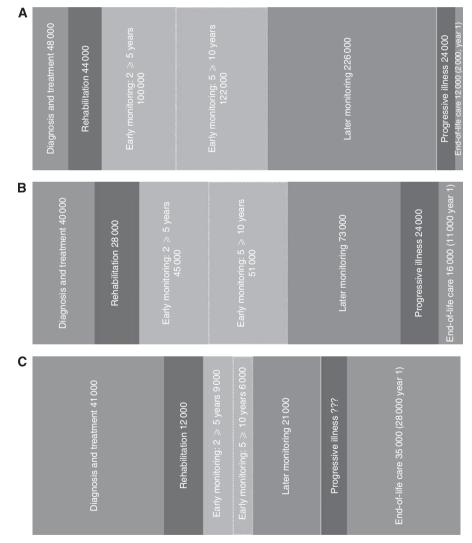


Figure 4 (**A**) Breast cancer care pathway: estimating the number of women in the UK, 2008*. (**B**) Colorectal cancer care pathway: estimating the number of people in the UK, 2008*. (**C**) Lung cancer care pathway: estimating the number of people in the UK, 2008*. (**C**) Lung cancer care pathway: estimating the number of people in the UK, 2008*. (**C**) Lung cancer care pathway: estimating the number of people in the UK, 2008*. (**C**) Lung cancer care pathway: estimating the number of people in the UK, 2008*. (**C**) Lung cancer care pathway: estimating the number of people in the UK, 2008*. (**C**) Lung cancer care pathway: estimating the number of people in the UK, 2008*. (**C**) Lung cancer type, the size of the boxes reflects the approximate proportion of people in each phase (however, there is double counting for people who are diagnosed and die in the same year – these numbers are indicated in brackets; i.e., 'XX 000 year 1'). Median survival for incurable disease was taken from Frontier Economics (2010) and is 3 years for breast and 2.5 years for colorectal. Estimates for progressive illness for lung cancer have not been made. Estimates for later monitoring for lung cancer exclude 8000 men > 20 years from diagnosis. The total for men in this group was thought to be an overestimate and is likely to be nearer 6000 than the modelled 14 000 (Maddams et al, 2009). Sources: Maddams et al (2009); Office for National Statistics (2009, 2010a, b); Cancer Research UK (2010); Frontier Economics (2010); Information Services Division (ISD) Scotland (2010); Northern Ireland Cancer Registry (2011); Welsh Cancer Intelligence and Surveillance Unit (2010); Office for National Statistics and London School of Hygiene and Tropical Medicine (2011).



(Andreyev *et al*, 2011). As more data become available, we anticipate these estimates could be refined. Estimates for progressive illness for lung cancer have not been made.

End-of-life care

Cancer mortality data (Cancer Research UK, 2010) are used as a proxy for the number of people requiring end-of-life care. Those who die from cancer within a year of diagnosis will be included in both diagnosis and treatment and end-of-life care, and we also estimate the number of patients who die in the year following diagnosis (as a subset of end-of-life care) to clarify the risk of double counting in the diagnosis and treatment and end-of-life care phases. To estimate those patients who are diagnosed and die within the year, we use 1-year survival to estimate those who die in the first year of diagnosis. Identification of those in the last year of life is a key part of the draft NICE Quality Standards for End of Life Care (NICE (forthcoming) Quality Standard on End of Life Care) and the proposed end-of-life tariff (Hughes-Hallet *et al*, 2011).

The number of people who die within a year of diagnosis varies greatly by cancer type and depends on short-term survival. We know from other recent research that at the end of 2008 more than a quarter of all people with a cancer diagnosis, who were in their last year of life at that point in time, were also diagnosed within that same year (Maddams *et al*, 2011).

RESULTS

Figures 4A-C provide estimates of the number of people in each phase of the care pathway for three of the most common cancers in the UK – breast (women only), colorectal and lung cancer. These cancers accounted for just over 40% of new diagnoses in 2008 (Information Services Division (ISD) Scotland, 2010; Office for National Statistics, 2010b; Welsh Cancer Intelligence and Surveillance Unit, 2010; Northern Ireland Cancer Registry, 2011).

For breast cancer (Figure 4A), because of its relatively good prognosis, the majority of women in the UK will be in a monitoring phase during any one year. Breast cancer is the most commonly diagnosed cancer in women in the UK, and thus each year large numbers of women are also in the diagnosis and treatment phase. However, as a consequence, most of these women (44 000 or around 8% of women in the year) would benefit from rehabilitative support following treatment. A further 24 000 (4%) will have incurable disease in the year (but are not in the last year of their life), and a relatively small proportion of women are in the last year of their life; that is, requiring end-of-life care (2%).

The proportion of cancer survivors in the monitoring phase is lower for colorectal and lung cancer survivors than women with breast cancer, because of the poorer prognosis of these cancers, particularly lung cancer.

For lung cancer (Figure 4C), the number of people in both diagnosis and treatment and end-of-life care is substantial – $41\,000$ and 35 000 in the year. However, with poor 1-year survival for lung cancer (around 30%; Office for National Statistics and London School of Hygiene and Tropical Medicine, 2011), the majority of those newly diagnosed will also be counted in our end-of-life mortality figures (estimated here as 28 000 of the 35 000 dying in the year).

The data also demonstrate that people with a lung cancer diagnosis do survive; thus, there are still, albeit lower numbers than breast and colorectal survivors, many people diagnosed requiring rehabilitative services (12 000) and a significant number of people who do survive up to 5, 10 and 20 years beyond initial diagnosis (Figures 3C and 4C).

Given that the majority of people dying of lung cancer do so in the first year following diagnosis (Office for National Statistics and London School of Hygiene and Tropical Medicine, 2011), we have not estimated progressive illness but we assume that as treatments improve there will be an increasing number of survivors who will be in progressive illness for incurable disease.

Figure 4B shows the pathway for people with a colorectal cancer diagnosis. Colorectal cancer has a poorer prognosis than breast cancer but much better survival than for those with lung cancer. The 5-year survival for colorectal cancer is over 50% compared with less than 10% for men and women with lung cancer and over 80% for women with breast cancer (Office for National Statistics and London School of Hygiene and Tropical Medicine, 2011). Our phases clearly reflect this pattern, with the number of women in the breast cancer monitoring phases higher in both proportion and volume.

The third most commonly diagnosed cancer in the UK in 2008 was colorectal cancer (Information Services Division (ISD) Scotland, 2010; Office for National Statistics, 2010b; Welsh Cancer Intelligence and Surveillance Unit, 2010; Northern Ireland Cancer Registry, 2011). The number of people in diagnosis and treatment for colorectal cancer is therefore slightly lower than that for lung cancer, 40 000 compared with 41 000. With its much better prognosis, the number of people in rehabilitation is much higher than that for lung cancer at 28 000. We estimate that nearly 170 000 people will be in the monitoring phase of our pathway, with most of these in 'early monitoring' (57%).

We know that cancer survivors can have cancer or non-cancerrelated health problems many years after initial diagnosis. A study presenting provisional results for colorectal cancer, which aims to map the cancer patient's journey by looking at patients' hospital inpatient activity, shows that nearly two-thirds of colorectal cancer patients still alive between 5 and 7 years after their diagnosis were identified as having ongoing health problems both related or unrelated to their cancer diagnosis (Wells *et al*, 2011).

DISCUSSION

A key part of the charity Macmillan Cancer Support's survivorship approach (Department of Health, Macmillan Cancer Support and NHS Improvement, 2010) is to identify those who are at risk of disability or disruption to productive lives as a result of cancer and its treatment and to intervene. Understanding the number of people diagnosed with cancer and their position in the pathway is valuable information that can be used to inform service planning, treatment provision and support for people at the right time in the right place as demand grows over time.

Cancer survivors have ongoing, unmet, needs. Up to 10 years after diagnosis, those patients with breast and colorectal cancer are more likely to visit their GP than people without a cancer diagnosis (Khan *et al*, 2011a). Cancer survivors can spend significant amounts of time in hospital many years after diagnosis (Maddams *et al*, 2011). With increasing survival, it is likely that more people will suffer from consequences of their cancer treatment in later years.

The current focus of cancer care is on initial diagnosis and treatment and the last year of life. There is an assumption that the remaining group of cancer survivors has either no health-care needs or the same health-care needs as each other and the rest of the population. Consequently, the majority of people with a cancer diagnosis may not be identified by health providers as requiring support. We estimate that this current focus could exclude the majority of women with breast cancer and people with colorectal cancer, as well as a significant proportion of people with lung cancer.

CONCLUSION

This is the first attempt to use readily available data to segment the population living with cancer into needs-based phases to allow targeting of interventions and redistribution of resources. We have modelled three tumour groups to illustrate the potential utility of presenting data in this way. We believe the data are directionally



correct and that similar estimates can and should be developed for other cancers.

These data convey the critical need for the development of survivorship services and shows the survivorship population as needs-based phases that will allow targeting of interventions and redistribution of resources. We know that the number of people living with cancer is increasing and, if current trends continue, is set to double by 2030 (estimated, based on Maddams *et al*, 2009). To ensure that we have services and resources to meet this increasing demand, we need to make sure that we are effectively targeting those in need when they need support to help them recover, identify late effects early and die well.

Further work is needed to break down the phases; this work could include, for example, quantifying more precisely the time at which patients start and finish treatment and the number of people requiring support for specific long-term effects.

New data sources within the cancer intelligence community, such as the chemotherapy data set, which is currently in development

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(National Cancer Intelligence Network, 2011a), and the radiotherapy data set (National Cancer Services Analysis Team, 2011), may provide more detail in the future. The National Cancer Dataset Project (National Cancer Intelligence Network, 2011b) and other initiatives that link data sets will make it possible to break down our identified phases of the care pathway in more detail in the future to ensure that we can tailor our interventions most effectively.

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