FULL PAPER

BJC

British Journal of Cancer (2015) 112, 1594–1602 | doi: 10.1038/bjc.2014.650

Keywords: prostate cancer; needs-based care; survivorship; incidence; side effects; resource allocation; prevalence; segmentation

Using routinely collected data to stratify prostate cancer patients into phases of care in the United Kingdom: implications for resource allocation and the cancer survivorship programme

K Yip*[,1,3], H McConnell[2,3], R Alonzi[1] and J Maher[1,2]

[1]Mount Vernon Cancer Centre, Rickmansworth Road, Northwood, London HA6 2RN, UK and [2]Macmillan Cancer Support, 89 Albert Embankment, London SE1 7UQ, UK

Background: Prostate cancer is the most commonly diagnosed malignancy in British men. The increasing use of PSA screening test has resulted in many more patients being diagnosed with this condition. Advances in its treatment have improved the survival rate among these patients. By 2040, the prevalence of prostate cancer survivors is expected to reach 830 000. Many of them will require medical support for the management of their progressive disease or long-term toxicities from previous treatments. Successful implementation of the cancer survivorship programme among these patients depends on a good understanding of their demand on the health care system. The aim of this study is to segment the population of prostate cancer survivors into different needs groups and to quantify them with respect to their phase of care.

Methods: Incidence, survival, prevalence and mortality data collected and reported by cancer registries across the United Kingdom have been used for the current study to provide indicative estimates as to the number of prostate cancer patients in each phase of the care pathway in a year.

Results: The majority of prostate cancer patients are in the post-treatment monitoring phase. Around a fifth of the patients are either receiving treatment or in the recovery and readjustment phase having completed their treatment in the preceding year. Thirteen percent have not received any anticancer treatment, a further 12% (32 000) have developed metastatic disease and 4% are in the final stage of their lives.

Conclusion: On the basis of our estimates, patients undergoing post-treatment monitoring phase will constitute the biggest group among prostate cancer survivors. The pressure to provide adequate follow-up care to these patients will be a challenge. There is limited data available to definitively quantify the number of prostate cancer patients who follow different pathways of care, and we hope this study has highlighted the importance of collecting and reporting of such data to help future health care planning for these patients.

Prostate cancer is the most commonly diagnosed malignancy in British men and accounts for the second highest number of cancer-related deaths (ONS, 2010). The incidence of prostate cancer has been rising since the mid-1970s. This is partially due to the lengthening of life expectancy, but also results from increased detection following TURP surgery and the widespread use of PSA testing. Forecasts of

*Correspondence: Dr K Yip; E-mail: kent.yip@nhs.net
[3]These authors contributed equally to this work.

Received 29 May 2014; revised 20 November 2014; accepted 1 December 2014; published online 19 March 2015

prostate cancer incidence, based on current trends in diagnosis, predict that by 2030 61 000 men in the United Kingdom will be diagnosed with the disease each year (Mistry *et al*, 2011). Moreover, by 2040, the prevalence of prostate cancer survivors will reach 830 000, accounting for 2.3% of the UK male population (Maddams *et al*, 2012).

The cancer survivorship programme in England was launched to improve and maintain health and well being, as well as to reduce disability related to cancer and its treatment among cancer survivors (Department of Health, MacMillan Cancer Support and NHS Improvement, 2010; Maher and McConnell, 2011; Department of Health MCSaNI, 2013). Its successful implementation is dependent on understanding the demand of cancer patients on the health care system. Quantifying the population of cancer survivors with respect to their phase of care (Mariotto *et al*, 2006) will help to achieve this. In this paper, we aim to segment the population of prostate cancer survivors into different needs groups using information available from national databases together with clinically led assumptions and consider the health economic implications on the basis of our results. Comparative figures for breast, colorectal and lung cancers have also been provided.

MATERIALS AND METHODS

Seven main phases on the care pathway for prostate cancer have been identified (Figure 1). Five of them have previously been defined for breast, colorectal and lung cancers (Maher and McConnell, 2011), namely:

- diagnosis and treatment
- rehabilitation – renamed here recovery and readjustment
- monitoring – initial and ongoing
- progressive disease – renamed here progressive care
- end of life.

The assumptions and calculations used to estimate the population in each of these five phases have been outlined in detail in Maher and McConnell (2011) and in the appendix. Active surveillance (AS) and watchful waiting (WW) are two additional phases unique to the management of prostate cancer and are summarised in Figure 1 along with the previously defined five phases. AS is defined as the time after the diagnosis of cancer but before the commencement of treatment with curative intent. WW is defined as the time after the diagnosis of cancer but before the commencement of treatment with palliative intent.

To summarise Figure 1 and the five phases of care previously reported, cancer incidence data, as collected by cancer registries across the United Kingdom, were used to estimate the number of patients requiring care in the year following diagnosis (that is, diagnosis and treatment). Patients who have survived the first year after their diagnosis and treatment fall into the recovery and readjustment phase. Prevalence data for patients who have been diagnosed with cancer for at least 2 years are used to estimate the number of people in the monitoring phase (minus those patients identified in progressive care). As the date of development of either frank metastatic disease or progressive disease on PSA criteria is not routinely collected by cancer registries, the population of patients in the progressive disease group is indirectly estimated using cancer mortality data. The analysis works on the basis that the median survival of patients with metastatic prostate cancer is at least 4 years from the time of diagnosis (Gravis *et al*, 2013; Hussain *et al*, 2013), hence the population of patients with frank metastatic disease but not in their last year of life can be estimated as $(4-1=3)\times$ the annual number of prostate cancer deaths. The assumed median survival for metastatic disease used in the calculation of progressive case phase varies by cancer type and we have not made an estimate for lung cancer due to its overall poor prognosis and hence difficulty in estimating this. The annual cancer mortality figure is used as a proxy for the number of patients in their last year of life requiring end of life care.

Data related to the proportion of patients who have chosen to undergo AS or WW at diagnosis are not readily available. A longitudinal observational database has been set up and maintained by the British Association of Urological Surgeons (McVey *et al*, 2010). On the basis of this data, it has been reported that 30% of patients with newly diagnosed cases do not receive any active cancer treatment (BAUS, 2011 – chart 104). This group

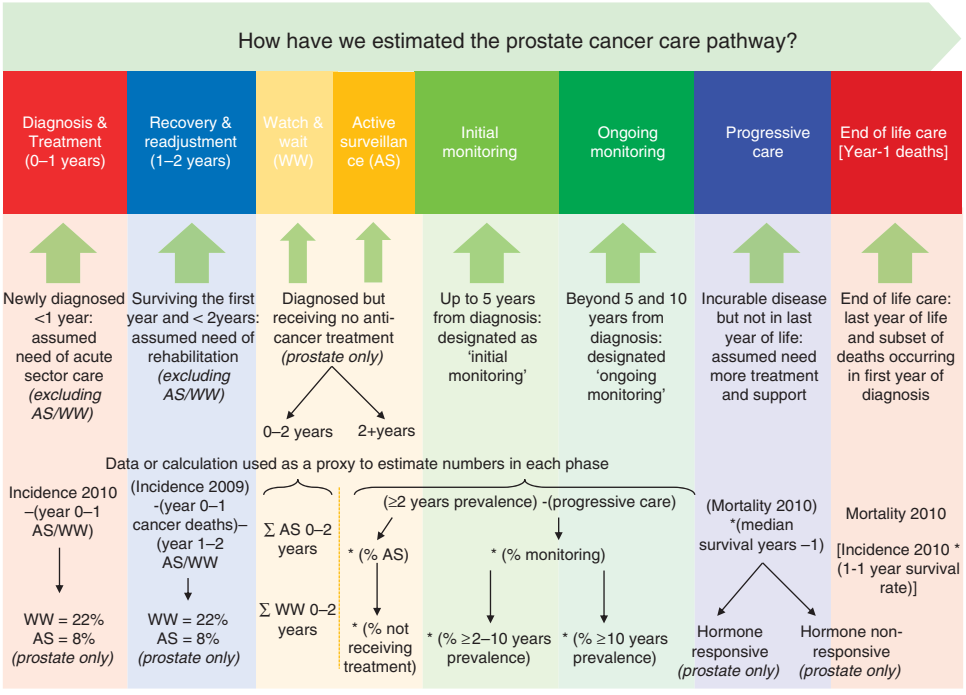

Figure 1. Assumptions and calculations used to estimate the prostate cancer care pathway.

covers both patients on AS programme who may receive radical curative treatment at a pre-defined trigger (Dall'Era *et al*, 2012) and those undergoing 'watchful waiting' who will be started on palliative androgen deprivation therapy when their cancer becomes symptomatic. McVey *et al* (2010) reported that 21% of all recorded cases were classified as low-risk disease in 2006 (see Table 1 for the D'Amico criteria for risk stratification in prostate cancer, as used by McVey *et al* (2010)), and that 39% of these patients did not undergo immediate treatment. Thus, it can be estimated that 8% ($0.21 \times 0.39 = 0.0819$) of all patients with newly diagnosed cases of prostate cancer have low risk disease and undergo AS (see Figure 1 – AS 0–2 years). With regards to the remaining 22% ($30\% - 8\% = 22\%$) of all the newly diagnosed cases who do not have immediate anticancer treatment, we have made the assumption that they have intermediate/high-risk disease and have categorised them into the 'watch and wait' phase, acknowledging that this may well be an overestimate (see Figure 1 – WW 0–2 years). Thus, a proportion of the men newly diagnosed and who survive the second year after diagnosis, 8 and 22%, are categorised into 'active surveillance' and 'watch and wait', respectively (that is, taken out of the 'normal' diagnosis and treatment and recovery and readjustment phases, and represented separately and uniquely for prostate cancer).

The proportion of patients recruited into a prospectively conducted AS programme who go on to receive active treatment ranges from 14 to 41% (Klotz *et al*, 2010; Cooperberg *et al*, 2011a,b; Bul *et al*, 2013; Selvadurai *et al*, 2013), thus we have assumed that 70% of those patients who have opted for AS will remain treatment free in the long term (Dall'Era *et al*, 2012; see Figure 1 – AS 2+ years). For patients with intermediate/high-risk disease who have chosen a 'watch and wait' strategy, we have only estimated figures specifically for this group within 2 years of diagnosis as there are very limited data to be able to describe later complex pathways for this group. However, we assume after 2 years of 'watch and wait' that the patients in this group will either have died, have developed metastatic disease and been started on hormone treatment (that is, moved into the progress care phase) or remain alive and treatment free (that is, be part of the monitoring phase). We have not specifically allocated patients to any of these groups due to current insufficient data to make estimates and include 'watch and wait' patients beyond 2 years in our model.

For men in the progressive care phase, we subcategorise them into hormone responsive and non-hormone responsive. The proportion between these two groups is determined by the time from starting ADT to the development of castrate-resistant disease; this in turn is dependent on whether patients have frank metastases or just PSA progressive disease but without metastases when ADT is started. In the trial reported by Crook *et al* (2012), which compared continuous versus intermittent ADT in patients with PSA progressive, but not metastatic disease, the overall survival measured from the time of ADT commencement in both arms was similar at around 9 years, whereas the time from the development of castrate-resistant disease to death was slightly over 2 years. Moreover, the median time from the start of ADT to the development of castrate-resistant disease was more than 10 years in both arms. Hence, we can deduce that the majority of patients with PSA progressive disease who are on ADT are hormone responsive. However, in patients with frank metastases, the hormone responsive period is between 12 and 19 months (Gravis *et al*, 2013; Hussain *et al*, 2013) and their overall survival ranges from 44 to 58 months. Thus, a greater proportion of the patients with metastases on treatment will harbour non-hormone responsive prostate cancer. Without knowing the ratio between patients being started on ADT for PSA progressive disease and for metastatic cancer, we cannot assign proportions to patients with hormone responsive and hormone unresponsive disease in the progressive phase.

We use 2010 incidence, mortality and prevalence data for men with prostate cancer in the United Kingdom along with survival data. The most recent prevalence data available are currently for 2010, so other sources have been aligned to this year. These data are used along with the assumptions outlined above, summarised in Figure 1 and detailed in the appendix to estimate the prostate cancer pathway of care.

RESULTS

Incidence, survival, prevalence and mortality data collected and reported by cancer registries across the United Kingdom have been used for the current study to provide indicative estimates as to the number of people in each phase of the care pathway in a year (see Figure 2). We present new 2010 estimates for prostate cancer and comparative figures for breast, colorectal and lung cancer (using updated prevalence data from Maddams *et al* (2012)).

We estimate pathways for the top four cancer types:

- prostate cancer (ICD-10 C61),
- female breast cancer (ICD-10 C50),
- colorectal cancer, which includes colon, rectum and anus (ICD-10 C18-C21), and

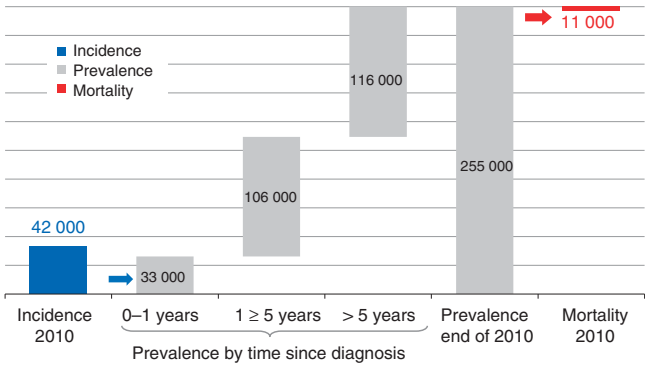

Figure 2. People newly diagnosed, people living with prostate cancer by year since diagnosis and deaths for people with a prostate cancer diagnosis, UK, 2010. Data notes: prostate cancer (ICD-10 C61). Incidence is the number of newly diagnosed cases and is a count of tumours in 2010. Prevalence is a count of the number of people living with cancer at the end of 2010. Mortality is a count of deaths due to cancer only in 2010. In addition, a number of men living with prostate cancer will die from other causes. Sources: Office for National Statistics; Information Services Division (ISD) Scotland; Welsh Cancer Intelligence & Surveillance Unit; Northern Ireland Cancer Registry; Cancer Research UK Cancer mortality – UK statistics (Nov 2010); Maddams *et al* (2009).

Table 1. D'Amico risk stratification for localised cancer

Low risk	PSA $< 10\ ng\ ml^{-1}$ and Gleason score = 6 and clinical stage T1c or T2a
Intermediate risk	PSA $> 10\ ng\ ml^{-1}$, but $< 20\ ng\ ml^{-1}$, or Gleason score = 7 or clinical stage T2b
High risk	PSA $> 20\ ng\ ml^{-1}$ or Gleason score 8–10 or clinical stage T2c or T3

Abbreviation: PSA = prostate specific antigen level.

- lung cancer, which includes lung, bronchus and trachea (ICD-10 C33-C34).

The number of patients going through the care pathway in a specific year with prostate cancer is estimated to be around 265 000 in 2010. This is higher than the total prevalence for 2010 (Maddams *et al*, 2012) of 255 000 as our estimate also includes flows into and out of the care pathway over the year and is not a point in time estimate (however, we have excluded any obvious possible double counting of patients in the proportions presented, that is, those dying within a year of diagnosis). Around a fifth of this population are either receiving treatment or in the recovery and readjustment phase having completed their treatment in the preceding year. By far, the majority of patients are in the post-treatment monitoring phase (154 000). Around 13% (34 000) have not received any anticancer treatment, a further 12% (32 000) have developed metastatic disease and 4% are in the final stage of their lives. The proportions of patients in each phase for prostate cancer are as shown in Figure 3 alongside the three other most common cancers.

The progressive care phase accounts for a greater proportion of the total patient population in prostate cancer compared with breast, lung and colorectal cancers. This is due to the relatively slow growing nature of prostate cancer among patients with relapse following radical treatment. Recent advances in the management of castrate-resistant disease are likely to increase this proportion further (de Bono *et al*, 2010, 2011; Scher *et al*, 2012; Parker *et al*, 2013).

DISCUSSION

Segmenting the population of survivors into different groups is particularly relevant to prostate cancer for various reasons. First, the health service demands of prostate cancer survivors are highly heterogeneous and dependant on the phase of care they are in. Second, prostate cancer has a distinct prognosis compared with other common cancer types. Third, an enormous amount of health care resources is dedicated to this cancer group worldwide

Figure 3. Cancer care pathway – estimating the number of people in the United Kingdom, by cancer type, 2010. Data notes: for each cancer type, the size of the boxes reflects the approximate proportion of people in each phase. However, it should be noted that there is double counting for people who are diagnosed and die in the same year An approximation of this is presented in brackets within the end of life phase for each cancer, that is, for prostate cancer of the total of 11 000 men classified as end of life, around 2000 men die within the first year of diagnosis (2000, year 1). Percentages presented in the text exclude those who die in the first year, in the denominator. Female breast cancer (ICD-10 C50), prostate cancer (ICD-10 C61), 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). Sources: estimated based on Maddams *et al* (2009, 2012); Office for National Statistics and London School of Hygiene and Tropical Medicine, 2012. Cancer Survival Rates - Cancer Survival in England: Patients Diagnosed, 2006–2010 and Followed up to 2011; Cancer Research UK Cancer mortality – UK statistics (Nov 2010); Personal Communication for incidence trends from Office for National Statistics, Information Services Division (ISD) Scotland, Northern Ireland Cancer Registry, Welsh Cancer Intelligence and Surveillance Unit.

(Roehrborn and Black, 2011). The UK annual cost was estimated to be around £90 million for the year 2001–2002 (Sangar *et al*, 2005), a figure that has undoubtedly increased immensely over the last 10 years, particularly following the introduction of novel drug therapies for castrate-resistant disease that cost as much as £40 000 per year per patient.

Compared with cancers of the lung and gastrointestinal tract, prostate cancer carries a relatively favourable prognosis. Even without treatment, many men will not develop life-threatening disease during their lifetime and some will remain asymptomatic throughout. There are proportionally more prostate cancer survivors in the progressive (metastatic) phase of the disease due to the relatively slow rate of progression in prostate cancer and its prolonged response to hormone therapy. Hence, the proportion of men surviving with a diagnosis of prostate cancer is likely to far exceed the proportion undergoing treatment following initial diagnosis. This prevalence of prostate cancer is a function of both incidence and survival, and will continue to increase as long as more people are diagnosed with the disease than die with or from it.

Also unique to prostate cancer are the treatment strategies of AS or watch and wait, which have been the subject of intense debate. These strategies are based on the fact that prostate cancer tends to occur in later life and that the majority of patients with localised disease, including those with relatively high-risk tumours, will die of something else (Lawrentschuk and Klotz, 2011; Daskivich *et al*, 2013). Furthermore, the morbidity that results from the disease itself is often less severe and more easily treated than the side effects of treatment. Several large-scale clinical trials, including the PIVOT trial that randomised between radical prostatectomy and AS, have failed to show that intervention reduces all-cause or prostate cancer mortality, as compared with observation alone (Wilt *et al*, 2012). Results from two AS studies (Klotz *et al*, 2010; Selvadurai *et al*, 2013) are reassuring, as there have only been five (Klotz *et al*, 2010) and two prostate cancer-related deaths (Selvadurai *et al*, 2013), respectively, and the majority of patients (70%) remain treatment free. Despite this, the fear of a cancer diagnosis and the undoubted success of modern radical therapies for localised disease drive many men towards treatment. This balance between radical primary intervention and AS has substantial implications for resource planning. If the proportion of patients entering surveillance following initial diagnosis were to change significantly, the number of patients in each phase of the care pathway would also change, without affecting overall prevalence. By applying our model, we have been able to show that increasing the percentage of newly diagnosed patients with low-risk prostate cancer who undergo AS from around 40 to 80% will result in a 6% absolute percentage point increase in the AS phase as a proportion of the entire prostate cancer survivor population from 6 to 12%. Historically, the standard protocol applied to follow up patients under AS consists of three monthly PSA check, digital transrectal prostate examination and a second prostate biopsy, usually carried out 18–24 months after the first one to identify patients whose disease has increased in terms of Gleason grade and who should thus be commenced on active treatment. A rise in the number of patients under AS may potentially result in increased demand for regular clinical follow-up appointments. The use of multiparametric MR imaging for patients under AS has been increasingly advocated and will also have significant cost implication (Moore *et al*, 2013; NICE, 2014).

The most expensive phases of prostate cancer care are immediately after diagnosis, when patients undergo treatment, and within the last year of life (Krahn *et al*, 2010). The use of increasingly hypofractionated radiotherapy schedules for the treatment of early prostate cancer (Dearnaley *et al*, 2012), which will significantly reduce the total number of radiotherapy sessions for patients, can potentially drive down treatment cost and should be a factor to consider in the future in evaluating the resource demand of prostate cancer patients in the treatment phase. However, the majority of prostate cancer patients, as demonstrated in this study, are in the post-treatment monitoring group. Maddams *et al* (2011) showed that prostate cancer survivors had the highest levels of health service utilisation 5 or more years after diagnosis compared with other cancer patients. Moreover, deficiencies with the current system of follow-up for prostate cancer survivors have been reported (O'Brien *et al*, 2010). The current focus of cancer care is on initial diagnosis, primary treatment and the last year of life (Maher and McConnell, 2011), yet for most prostate cancer survivors their health care service demands are likely to resemble those of patients with chronic conditions.

A chronic disease has a long duration, slow progression (World Health Organisation) and sufferers may experience limitation to their functional status, productivity and quality of life (Institute of Medicine of the National Academies, 2012). Ongoing lifestyle adjustments by the affected individuals and regular interactions with the health care systems are also required (The Chronic Care Model).

For patients with prostate cancer, the median overall survival from treatment to death is more than 10 years (Bolla *et al*, 1997), during which time their quality of life can be significantly compromised in many ways (Eton and Lepore, 2002; Sanda *et al*, 2008). Androgen deprivation therapy is used in all stages of prostate cancer and can cause debilitating toxicities such as sexual dysfunction, fatigue, hot flushes, depression and reduced physical functions (Alibhai *et al*, 2010), as well as increasing the risk of developing ischaemic heart disease, diabetes (Keating *et al*, 2006) and osteoporotic fractures (Shahinian *et al*, 2005) in the long term. Surgical and radiation treatments can result in lifelong urinary and bowel complications such as urinary incontinence, impotence rectal bleeding and diarrhoea, which are known to be under-reported unless patients are specifically questioned. Once uncovered, these symptoms are frequently ignored by health professionals. This is due to a lack of awareness of data that demonstrates that a systematic approach to enquiry and diagnostic testing can reveal multiple causes of poor bowel control, each of which needs diagnosing and treating with simple interventions that can improve symptoms significantly (Henson *et al*, 2013). Other important elements to improve and maintain health and well being during the late monitoring phase include: the early introduction of patient-reported outcome measures to promote the feasibility of at a distance self-assessment (Maher, 2013); encouraging the reinforcement of information about the risk of future problems (and what can be done about them); ensuring primary care, teams record risk related to treatment as part of their electronic record; ensuring clear routes of access through a trusted source, for example, a specialist nurse; and evidence-based diagnostic pathways and management guidelines including brief interventions with at least one specialist team.

Although some of the acute treatment-related side effects are best dealt with by hospital-based specialists, many of the longer-term complications will require community-based care. Historically, primary care physicians have had an important role in the management of many chronic illnesses (Rothman and Wagner, 2003), and their input to ensure good quality cancer care has been recognised (Campbell *et al*, 2002). Despite this, many cancer survivors in the United Kingdom do not look to their general practitioners for their long-term cancer-related care for a variety of reasons (Khan *et al*, 2011). The pressure placed on hospital-based uro-oncology teams to follow up an ever expanding population of men with apparently stable prostate cancer following their treatment has led to the development of alternative follow-up services, such as nurse-led PSA virtual follow-up clinics that can be performed over the telephone or by email (Turner and Wells, 2012). Greater involvement of general practitioners, with

appropriate support from hospital-based specialists may potentially provide relief to this pressure and improve the management of long-term chronic side effects due to patients' previous cancer and its treatment (Allgar and Neal, 2005). In terms of the timing for follow-up appointments, initial post-treatment review by hospital specialists may help to identify those with early local relapse who may benefit from further focal salvage treatment (Bolla *et al*, 2005; Trock *et al*, 2008; Mendenhall *et al*, 2012). However, during the ongoing monitoring phase, when recurrence becomes less likely, patients may benefit more from their GPs' experience in managing chronic complications. Given the size of the population in the post-treatment monitoring phase shown, any change in follow-up practice can have significant implications for resource allocation between the hospitals and the communities, and among the different specialties within hospitals due to the multidisciplinary nature in the management of the post-treatment complications among these patients.

From the time when this data were recorded, the biggest changes in prostate cancer management have occurred in the progressive illness phase. Since 2008, there has been increasing use of docetaxel as first line palliative chemotherapy in patients who have developed castrate-resistant disease (Collins *et al*, 2007). Abiraterone and enzalutamide is now approved by the National Institute for Heath and Care Excellence (NICE) and other agents with proven survival benefit following progression after chemotherapy may also be used routinely in the near future (de Bono *et al*, 2010, 2011; Scher *et al*, 2012; Brady *et al*, 2013; Parker *et al*, 2013). The resulting lengthening of median survival for metastatic cancer suggests that our value of over 30 000 for patients in the progressive illness phase may well be an underestimate. Given that this is one of the most resource-dependent phases of the prostate cancer care pathway (both in terms of expense and need for support), this figure needs to be closely scrutinised over coming years.

The key limitation to our study is in the availability and collection of appropriate data on which to segment the population of prostate cancer survivors into different needs-based groups. As such, we have used clinically led assumptions and the limited literature available in this area alongside available data to create our model. There are three areas of particular importance to mention in regard to the limitations due to availability of data for the study and the assumptions we have had to make in order to create a model to estimate needs-based groups for cancer survivors. First, our assumption that all patients with newly diagnosed prostate cancer who have intermediate- or high-risk disease and not undergone immediate cancer treatment have chosen the WW pathway may result in an underestimate of the total proportion of patients in the AS phase. Some patients in the lower end of the intermediate-risk group may well also be under AS programme and be suitable for radical treatment in the future. Data are not available to identify specifically the proportion of patients who are in the 'active surveillance' or 'watch and wait' groups, nor is it available in enough detail for each of the risk groups to stratify them in the model more specifically. Second, there has been a trend across both sides of the Atlantic that patients with low-risk prostate cancer make up an increasing proportion of the overall prostate cancer population (Cooperberg *et al*, 2004; McVey *et al*, 2010); thus, our figure of 8% as the proportion of all patients with prostate cancer being in AS may also be an underestimate. Moreover, the data on which BAUS based their report was collected back in 2010 and may not accurately reflect the current practice. Third, using the annual prostate cancer-specific death rate to estimate the number of patients with metastatic disease may also have resulted in a conservative estimate of the number of patients in the progressive care phase; a significant proportion of these patients are likely to be elderly with multiple co-morbidities and may well die from other causes.

In conclusion, we have demonstrated that patients undergoing post-treatment monitoring phase will constitute the biggest group among the population of prostate cancer survivors. The pressure to provide them with follow-up care to manage their treatment-related side effects, reassure those without disease recurrence and detect early relapse in patients suitable for salvage treatment will remain a challenge. We also predict that patients in the AS phase will form an increasing proportion of the overall prostate cancer patient population. Although advances in therapeutics are likely to prolong patients' survival and increase the number in the post-treatment monitoring group, advances in diagnostics, such as the use of novel imaging and laboratory-based biomarkers in the AS follow-up protocol, may improve our confidence in selecting patients suitable for conservative management and hence increase the AS population and reduce that of the post-treatment monitoring group. The balance between these two groups will be an important determinant in terms of resource allocation. We hope that this study highlights the limited data available to be able to definitively quantify the number of men who follow different pathways of care and stimulates recognition of the importance of reporting and collecting data on a number of measures in order to empirically quantify different needs groups and validate our assumptions. We also hope our estimates of the proportion of patients in different phases of their disease will stimulate future work to collect quantitative data related to the health care needs of patients at each stage of their prostate cancer, and be used to plan future services to meet the needs of these patients.

ACKNOWLEDGEMENTS

We acknowledge the use of data for this analysis collected by cancer registries across the United Kingdom and input from Roger Kockelburgh and Mark Emberton in the original ideas behind the prostate cancer analysis.

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APPENDIX

The assumptions and calculations used to estimate the population in each of the five phases outlined previously in Maher and McConnell (2011) [3] have been included in this appendix. The references can be found in the original publication. These five main phases on the care pathway include:

(1) diagnosis and treatment (assumed to be the year from diagnosis)
(2) rehabilitation (assumed to be the year after treatment, estimated as the second year after diagnosis)
(3) 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)
(4) progressive illness (includes incurable cancer, but not those in the last year of life, and significant treatment-related illness)
(5) 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 the 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 United Kingdom died from causes other than cancer in 2008. Some of these people may in fact die from conditions related to their cancer or from the late effect of cancer treatment; however, 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.

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 United Kingdom. We use published data for each nation for England, from the Office for National Statistics 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. 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. 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 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 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. 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, which could have been reduced through proactive intervention. This will particularly be the case for those treated at a younger age. 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, and clinical consensus of a median 3-year 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. As more data become available, we anticipate that these estimates could be refined. Estimates for progressive illness for lung cancer have not been made.

End-of-life care

Cancer mortality data 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. 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.