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Projecting prevalence by stage of care for prostate cancer and estimating future health service needs: protocol for a modelling study

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ABSTRACT

Introduction: Current strategies for the management of prostate cancer are inadequate in Australia. We will, in this study, estimate current service needs and project the future needs for prostate cancer patients in Australia.

Methods and analysis: First, we will project the future prevalence of prostate cancer for 2010–2018 using data for 1972–2008 from the New South Wales (NSW) Central Cancer Registry. These projections, based on modelled incidence and survival estimates, will be estimated using PIAMOD (Prevalence, Incidence, Analysis MODel) software. Then the total prevalence will be decomposed into five stages of care: initial care, continued monitoring, recurrence, last year of life and long-term survivor. Finally, data from the NSW Prostate Cancer Care and Outcomes Study, including data on patterns of treatment and associated quality of life, will be used to estimate the type and amount of services that will be needed by prostate cancer patients in each stage of care. In addition, Central Cancer Registry episode data will be used to estimate transition rates from localised or locally advanced prostate cancer to metastatic disease. Medicare and Pharmaceutical Benefits data, linked with Prostate Cancer Care and Outcomes Study data, will be used to complement the Cancer Registry episode data. The methods developed will be applied Australia-wide to obtain national estimates of the future prevalence of prostate cancer for different stages of clinical care.

Ethics and dissemination: This study was approved by the NSW Population and Health Services Research Ethics Committee. Results of the study will be disseminated widely to different interest groups and organisations through a report, conference presentations and peer-reviewed articles.

ARTICLE SUMMARY

Article focus

- To describe the statistical models we will develop to obtain estimates of the future prevalence of prostate cancer in Australia for each stage of clinical care.
- To describe how the methods developed will be used to determine:
  i. How many prostate cancer patients will need medical attention in the near future, and
  ii. What types of services they will need.

Key messages

- This study will provide the first Australian estimates of current health service needs and projections of future needs for prostate cancer patients.
- This information will be essential for ensuring that men with prostate cancer have adequate access to the different types of care they will require as they move through the disease trajectory.

Strengths and limitations of this study

Strengths

- Breakdown of prevalence according to health service needs by patient subgroup
- Development and testing of validated statistical methods for use in other settings
- Multiple population-based data sources: cancer registry, a patterns of care study and Medicare and Pharmaceutical Benefits data.

Limitations

- PIAMOD software has substantial data demands (requiring detailed specially-formatted input data including externally modelled survival estimates)
- Numerous decisions are required regarding the best statistical models for incidence and survival
- Several assumptions are needed regarding the future trends in incidence and survival.

INTRODUCTION

Prostate cancer is the most common non-skin cancer among Australian men with around 19 775 cases expected to be diagnosed in 2010.[1] This number is expected to increase significantly due to the growth and ageing of the population.[2] Moreover, the majority of prostate cancer patients will live much longer as a result of earlier detection through prostate-specific antigen (PSA) testing and improved treatment.[3] Therefore, the

numbers of new patients with prostate cancer and years of life living with cancer will both increase significantly in the future. As a consequence, the demands for health services will rise substantially. Despite these predictions, there is little or very limited information about the current or future service needs of prostate cancer patients in Australia.

Recent studies[4 5] suggested that there will be an acute shortage of medical oncologists to care for cancer patients in the USA within 15 years if this problem is not dealt with immediately. A similar shortage of cancer care professionals is evident in Australia.[6] There is, therefore, a need to take action now to accurately assess future requirements and ensure a sufficient supply of relevant medical specialists, oncologists and urological nurses for the care of cancer patients. In order to adequately predict the services that will be required, we must know how many men will be diagnosed with and live with prostate cancer and need to determine their ongoing medical requirements. However, due to data limitations and incomplete coverage of incident cases, the few studies[7–10] of cancer prevalence in Australia provide only limited information. Moreover, the resource requirements for treating newly diagnosed patients are very different from those for supporting long-term survivors and those with disease progression. Thus, estimates of cancer prevalence by the relevant stages of care are required to provide a more meaningful and useful measure for healthcare planning purposes.[11]

In this study, we will develop statistical models to obtain estimates of the future prevalence of prostate cancer in Australia for each stage of clinical care. The treatments required for each of these stages of disease will be based on data from the NSW Prostate Cancer Care and Outcomes Study (PCOS) and a literature review of prostate cancer treatment. The statistical models will initially be constructed using NSW Central Cancer Registry (NSWCCR) data. The methods developed in this study will help determine: (i) how many prostate cancer patients will need medical attention in the near future and (ii) what types of services they will require. This information will be essential for ensuring that prostate cancer patients have adequate access to the different types of care they require as they move through the disease trajectory.

METHODS AND ANALYSIS

Data

To obtain estimates of the future prevalence of prostate cancer, we will develop statistical models using NSWCCR data. Cases diagnosed with first primary prostate cancers from 1972 to 2008 in New South Wales (NSW), and notified to the NSWCCR, will be included in this study. The registry data then will be linked, by the Centre for Health Record Linkage, to death records from the State Registrar of Births, Deaths and Marriages and the National Death Index to determine survival status as of 31 December 2009. The Cancer Registry maintains a record of all cases of cancer diagnosed in NSW residents since 1972, with notifications from multiple sources to maximise case ascertainment, and linkage to death certificates. Features of the registry data which make it an ideal source to estimate future cancer prevalence include long history of registration, good coverage of the population, stage information at diagnosis and follow-up of survival status of individual cases. Through the standard notification process, the CCR obtains episode data consisting of subsequent notifications for a patient after the primary cancer has been registered.

To estimate the type and amount of services needed for the management of prostate cancer patients, data from PCOS will be used to provide details of treatments received. This unique and highly valuable study with information on treatment and quality of life covers the largest population-wide cohort of both prostate cancer cases (n=1996) and controls (n=495) to have been actively followed for 5 years after diagnosis in Australia and internationally.

In addition we have linked Medicare (MBS) and Pharmaceutical Benefits (PBS) data for 85% of these PCOS cases covering the use of health services for an 8-year period from 2000 to 2008.

Detailed methods of analysis are described in the next section. Briefly, we will project future prevalence by stage of care for prostate cancer (2010–2018) using the Cancer Registry data; then the proportions of patients requiring different type of treatments, obtained from the PCOS study, will be applied to the projected prevalence to estimate the type and amount of health services needed. Finally, episode data from the Cancer Registry will be used to estimate the transition rates from early stage prostate cancer to metastatic disease. The MBS and PBS data will be used to complement the episode data on disease progression from early stage to metastatic disease, and to complement the PCOS data by providing the type and length of treatment and updated treatment information up to 2008.

Methods of analysis

To project cancer prevalence estimates by stage of care, we will adapt the approach used by Mariotto *et al*.[11] We will extend Dr Mariotto's work in two ways. First, we will add another stage of care, 'long-term survivors', who require only minor cancer-related resources. Second, we will incorporate survival by disease stage into the estimation of prevalence in combination with years since diagnosis. In this way, patient groups in each stage of care will be more homogeneous for the purpose of predicting healthcare needs.

Projection of future prevalence

We have estimated the limited duration prevalence (2006) with the counting method[12] using an SAS program we developed.[13] This method is considered to be the most reliable for populations covered by a cancer registry for a sufficient length of time.[14]

For cancer prevalence projections, we will first project numbers of new cases for a further 10 years using observed incidence data for 1979–2008 by fitting age-period-cohort (APC) models.[15 16] The number of incident cases will be estimated for each set of APC parameters assuming Poisson distributed incident cases. These estimated incidence counts from the APC models will be compared with the observed incidence and the model chosen will be that which gives the best fit to the observed data using both graphical assessment and statistical methods (Akaike Information Criterion).

Second, we will tabulate relative survival estimates by age group, period of diagnosis and follow-up interval after diagnosis using standard methods,[17] with data from the NSWCCR (1972–2008). We will then fit a mixture model to those tabulated relative survival estimates to extrapolate survival beyond the observed data (2010–2018).[18] The mixture models assume that the population of patients is a mixture of two groups with different prognoses: 'cured' patients with no excess risk due to the diagnosis of prostate cancer and those patients bound to die from prostate cancer. Men who are currently 'disease free' but whose prostate cancer will progress leading to death are in the latter group. The best model will be chosen using both graphical assessment and statistical methods (based on the differences between the observed values and the predicted values from the model).

Finally, prevalence projections will be estimated from model-based incidence and survival estimates, implemented using PIAMOD (Prevalence, Incidence, Analysis MODel) software.[19] These projections are based on two different assumptions: (i) incidence and survival for prostate cancer will remain constant at the same level as the most recent 3-year average (as used by Mariotto *et al*[11]); and (ii) incidence and survival trends in the past will continue into the future.

Projecting prevalence by stage of care

Patients, according to years since diagnosis and cancer stage at diagnosis, will be assigned to one of five stages of care: initial, continued monitoring, recurrence, last year of life and long-term survivor. The initial care stage is the first 12 months after diagnosis. The majority (>85%) of cases in this stage will be those diagnosed with early stage disease. The last year of life stage will cover the 12 months prior to death. The last year of care will override the other care stages for cases with short survival; most of the cases included in this stage will be those with metastatic cancer. The continued monitoring stage will include cases who survived the first 12 months after diagnosis but underwent treatment or active monitoring for disease recurrence. Cases with recurrence are those patients diagnosed with initially localised disease, but whose cancer then progresses after initial therapy. Long-term survivors will be those patients diagnosed more than 10 years previously and with no evidence of disease progression or recurrence, requiring less intensive follow-up.

As treatment for prostate cancer depends heavily on disease stage at diagnosis and this information from the cancer registry is incomplete,[3] we will redistribute the cases coded as having unknown stage (about 50% of total cases) to either localised stage or regional/distant spread. In the Cancer Registry data, the 50% of prostate cancer cases who were coded as having unknown stage had a 10-year relative survival of 85.5%. The 10-year relative survival for men with localised stage or regional/distant spread was 99.6% and 49.8%, respectively. We proportionally assign cases with unknown stage to localised stage (approximately 72%) or to regional/distant spread (28%). When the relative survival estimates for each stage group are applied to the re-assigned cases, the overall relative survival estimate for those coded as unknown stage by the Cancer Registry becomes 85.6%. Thus we can be reasonably confident that the assignment is valid because the sum of the 10-year relative survival estimates for the two re-assigned groups is close to that for the original group with unknown stage (85.5%).

Testing and validation of the models

We will use historical data to test the models by comparing the actual prevalence for 2004–2008 obtained from the direct counting method[12] and the projected numbers from the models using data from earlier years (1994–2003). We will use sensitivity analysis to assess the impacts of realistic changes in incidence and survival in the future on estimates of prevalence. For example, increased PSA testing plus a lower PSA threshold for biopsy and increased number of core samples per biopsy will lead to an increase in incidence in the future. These changes should also result in stage shifting towards an earlier stage, and thus survival should also improve as a result. Advances in treatments in the future may also increase survival, but improvement is likely to be incremental according to past experience. We will model the impact of various cancer control interventions, including prostate cancer testing and treatment, on current trends, and future trends based on different scenarios.

Disease progression model

Limited evidence from international studies estimated that about a quarter of patients with localised prostate cancer progress to metastatic disease.[20] We will provide the first Australian evidence on the transition rates from localised or locally advanced prostate cancer to metastatic disease, using episode data from the CCR (consisting of notifications sent after initial diagnosis). These episode data are routinely collected but not routinely reported. MBS and PBS data will be used to complement the CCR data. For example, a change in monitoring, testing and referral patterns after radical prostatectomy and regular PSA tests, such as multiple PSA tests in a short period followed by consultations with a urologist or oncologist, may indicate a rising PSA level and disease recurrence or progression.

Published studies indicate that of patients undergoing active surveillance, about 24%–30% subsequently receive curative treatment during follow-up[21 22] and among patients who initially had aggressive therapy, 15%–40%[23 24] experience cancer recurrence within 5 years of surgery. These patients need either deferred curative therapy or salvage radiation therapy and/or salvage prostatectomy. Therefore, it is important to include these two groups of patients in the estimation of service needs for prostate cancer. The disease progression model will provide estimates of the proportions and numbers of men requiring these types of services.

Estimation of type of care needed

Finally, we will explore the impact of future prevalence on the healthcare resources that will be required by patients at different stages in the natural history of the disease as follows.

We will first obtain the proportions of patients undergoing different cancer treatments including surgery, androgen deprivation therapy and radiotherapy from the completed PCOS study. Literature on the proportions of prostate cancer patients requiring different treatments at each stage of their cancer journey will also be used to estimate the number of patients who need each treatment including active surveillance. Routinely available MBS and PBS data will be used to model changes in the trends for different types of treatment.

Then we will apply the proportions of patients requiring surgery, radiotherapy, pathology tests and other services to the estimated prevalence data to provide accurate and useful information on future demands for healthcare. Data on the quality of life of men with prostate cancer from the PCOS study, particularly sexual and/or urinary complications and problems after aggressive therapy, will be used to estimate the psychosocial and other supportive needs of patients at different time points after diagnosis of prostate cancer.

We will also explore socio-economic and rural/urban differences in the use of health services. We will allocate individual patients into urban or rural residents or into three categories according to socioeconomic status[25] based on their residential address recorded at the time of diagnosis. We will address the service needs of those men from rural or socioeconomic disadvantaged areas to address issues of equity and access as found in three recent Australian studies.[26–28]

Sensitivity analysis and testing of assumptions

Factors that will influence future prostate cancer incidence can be categorised into (i) growth and ageing of the population and (ii) level of PSA testing in the population. As a result of more established patterns of routine PSA testing,[29 30] the incidence of prostate cancer over the next 10 years is unlikely to repeat the pattern of a sharp increase followed by a decrease seen in the early to mid-1990s. As an alternative, we will project future incidence based on the assumption that the current increase (2003–2008) is likely to continue rather than the trend of the whole period of 1972–2008.

The results of clinical trials comparing treatment options for prostate cancer could impact on the day-to-day practice of prostate cancer management. However, historical data indicated that most advances in cancer treatment are incremental. Clinical trials showed that new treatment for patients with advanced prostate cancer had only limited benefits, thus the impact of treatment advances in the short-term future should be minimal on the prediction of future service needs. Nevertheless, such changes in treatment and survival will be closely monitored and allowed for in the models based on recent and ongoing clinical trials.

ETHICS AND DISSEMINATION

This study was approved by the NSW Population and Health Services Research Ethics Committee in April 2009 and an amendment requesting an additional 2 years of incidence data and updated survival status was approved in January 2011. A report will be written and disseminated widely to cancer care providers, the Prostate Cancer Foundation of Australia, policy makers and health service planners in NSW. Results of the study will be presented to different interest groups, using appropriate language for each audience. Presentations will be made to national and international conferences, and manuscripts will be submitted to peer-reviewed national and international journals.

DISCUSSION

This study will develop methods to obtain estimates of the prevalence of prostate cancer by stage of care, and the resulting type and amounts of services that will be needed in the future for prostate cancer patients. This information is critical for the timely assessment of the resources and infrastructure needed for cancer care services: for initial diagnosis and treatment, continuing therapy, treatment of subsequent disabilities and side effects, screening and treatment for recurrence and progression, and long-term counselling and support. This information is important to ensure the adequate provision of services for all Australian men diagnosed with prostate cancer. It will help address potentially widening socio-economic and rural/urban disparities in prostate cancer outcomes by examining equity issues in the provision of care for subgroups in the population. The methods developed will be applied to an Australian-wide perspective to obtain national estimates of the future prevalence of prostate cancer for different stages of clinical care.

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Competing interests None.

Ethics approval This study was approved by the NSW Population and Health Services Research Ethics Committee.

Contributors XQY and DOC initiated the project; DPS and MSC assisted with further refinement of the protocol; XQY drafted the manuscript; DOC, DPS, MSC, MP and BM critically reviewed the manuscript; MP will provide a clinical perspective of the project and assist with interpretation and dissemination of the results to healthcare planners and providers; BM will provide a consumer's perspective of the research and assist with dissemination of the results to key stakeholders; all authors approved the final draft of the manuscript.

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Notes