

BMJ Open A protocol for a discrete choice experiment: understanding preferences of patients with cancer towards their cancer care across metropolitan and rural regions in Australia

Shu Fen Wong,^{1,2} Richard Norman,^{3,4} Trisha L Dunning,⁵ David M Ashley,^{1,2} Paula K Lorgelly⁶

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For numbered affiliations see end of article.

Correspondence to

Dr Shu Fen Wong; shufen.wong81@gmail.com

ABSTRACT

Introduction: Medical decision-making in oncology is a complicated process and to date there are few studies examining how patients with cancer make choices with respect to different features of their care. It is also unknown whether patient choices vary by geographical location and how location could account for observed rural and metropolitan cancer differences. This paper describes an ongoing study that aims to (1) examine patient and healthcare-related factors that influence choices of patients with cancer; (2) measure and quantify preferences of patients with cancer towards cancer care using a discrete choice experiment (DCE) and (3) explore preference heterogeneity between metropolitan and rural locations.

Methods and analysis: A DCE is being conducted to understand how patients with cancer choose between two clinical scenarios accounting for different patient and healthcare-related factors (and levels). Preliminary qualitative research was undertaken to guide the development of an appropriate DCE design including characteristics that are important and relevant to patients with cancer. A fractional factorial design using the D-efficiency criteria was used to estimate interactions among attributes. Multinomial logistic regression will be used for the primary DCE analysis and to control for sociodemographic and clinical characteristics.

Ethics and dissemination: The Barwon Health Human Research Ethics Committee approved the study. Findings from the study will be presented in national/international conferences and peer-reviewed journals. Our results will form the basis of a feasibility study to inform the development of a larger scale study into preferences of patients with cancer and their association with cancer outcomes.

INTRODUCTION

Multiple studies have explored the preferences of patients living with cancer towards

Strengths and limitations of this study

- To the best of our knowledge, this is the first study to utilise a discrete choice experiment (DCE) to measure and quantify preferences of patients with cancer towards cancer care across metropolitan and rural regions.
- The incorporation of choice task questions will enable the researchers to elicit how patients with cancer weigh up their choices and consider trade-offs between different cancer care options.
- It is not feasible to include a complete list of patient and healthcare-related factors that may influence choices of patients with cancer in the DCE. Hence, a mixed qualitative approach was used to generate a list of factors that are most relevant and realistic in the current Australian cancer healthcare system.
- Participants are recruited from a mainly Anglo-Saxon population across a specific region in Victoria, Australia. The final results of the DCE may not be applicable to other Australian states.

preventative screening programmes, adjuvant therapies and information giving in palliative care.¹⁻⁴ For example, a recent review of 23 papers published between 1987 and 2003 evaluating patients' preferences towards adjuvant therapy in cancer found that there were four important determinants of their choices.⁴ These included the benefits and toxicities of treatment, experience of the treatment and whether they had dependants at home. However, their results were limited by the small sample sizes of the studies included in the review and the lack of data about psychological characteristics and specialist-related factors.

There are limited contemporary data about how patients living with cancer in metropolitan and rural areas make their

cancer-related decisions relating to diagnosis, investigations and treatments. Identified determinants of the health-seeking behaviour of patients with cancer include personality and cultural factors,^{5,6} access to healthcare,⁷ their socioeconomic status⁸ and geographical location.⁹ A large American study⁵ using data from the 2007 Health Information National Trends Survey (n=1482 rural and 6192 urban residents) found that rural patients were more likely to have fatalistic beliefs, which led to the lower likelihood that they would seek medical care. A study of patients with prostate cancer in rural Southwest Georgia¹⁰ also showed that rural patients who had a poor therapeutic relationship with their doctors were less likely to receive treatment after 6 months compared with urban patients.

There are reported deficiencies in the provision of certain healthcare services to rural areas in Australia.⁷ Rural patients are more likely to travel long distances to access healthcare services at an inconvenient time and incur additional out-of-pocket expenses.¹¹ Their cancer-related decisions may be suboptimal and could result in worse survival outcomes in rural-remote patients across Australia.¹² For example, Baade *et al*¹³ observed that patients with rectal cancer were more likely to have higher mortality rates the further away they lived from a radiotherapy facility (up to 6% for every 100 km distance). However, these patients' treatment choices such as the decline of adjuvant radiotherapy may have traded quality of life (for themselves and their families) against their overall outcomes. To date, we can only assume that these are informed choices, reflecting patients' opportunity cost, where they choose an alternative option that they value more.

Although several determinants of health-seeking behaviour of patients with cancer have been identified, few studies to date have compared and validated the importance of these factors in metropolitan and rural patients. To the best of our knowledge, the current study will be the first to measure and quantify preferences of patients with cancer towards cancer care across metropolitan and rural regions using a discrete choice experiment (DCE).¹⁴

This DCE is being conducted across the Barwon South Western Region (BSWR) in Victoria, Australia. Participating sites include metropolitan (Andrew Love Cancer Centre (ALCC), Geelong) and rural (Warrnambool and Hamilton Hospitals) oncology services. The BSWR is reported to have a slightly larger population of residents over 65 years of age (16.8%) compared with Victorian statistics (14%), with a subsequently higher dependency ratio.¹⁵ The level of cultural diversity (residents born overseas or with a non-English-speaking background) across BSWR was low (13%) and BSWR residents appeared to have a relative socioeconomic disadvantage compared with Australian averages.

The methodological details of our ongoing DCE study are described in this paper.

Aims

The study aims to explore the factors that influence and contribute to the decision-making of patients with cancer regarding their cancer care. The objectives of the study are:

- To examine the patient and healthcare-related characteristics that could influence the choices of patients with cancer about their medical care;
- To elicit how patients with cancer weigh up their choices and consider trade-offs between different cancer care options;
- To determine whether preferences of patients with cancer vary across metropolitan and rural regions.

METHODS AND ANALYSIS

Overview of approach and methods

Our study utilises both qualitative (focus groups and one-on-one interviews) and quantitative methods (DCE) to understand care choices of patients with cancer in a realistic clinical scenario.

Rationale for using DCE to examine the health-seeking behaviour of patients with cancer

A variety of methods have been employed to elicit patients' healthcare preferences. These methods include stated preferences (realistic, hypothetical choice scenarios) and revealed preferences (real-life choice scenarios) methods.¹⁶ Recently, DCE has gained popularity as the model of choice for eliciting stated preferences in healthcare research,¹⁴ including in oncology.^{17,18} A DCE enables hypothetical choices incorporating multiple characteristics to be used to simulate realistic scenarios (vignettes). A DCE also forces respondents to make trade-offs among different choice sets, unlike other methods such as ranking or rating. Consequently, a DCE enables researchers to gain more in-depth insight into the relative importance of each characteristic (referred to as an attribute).^{19,20}

The principle underlying a DCE is that the value of an option is determined by the value of its attributes.²¹ The design consists of a choice-based questionnaire that enables the simultaneous assessment of multiple attributes presented in the form of a clinical vignette. For example, Scott *et al*²² measured the preferences of parents who had children with respiratory illness, in relation to out of hours care models in an urban setting. The choice task involved two consultations described using the attributes of where the child was seen, whom the child saw, time taken from phone call to treatment being received and whether the doctor seemed to listen to the parents. Levels (eg, 20 min vs 60 min) were assigned to these attributes (eg, time taken between the telephone call and treatment being received) to assist participants to select their preferred choice task option. Participants chose their preferred consultation type based on varying attribute-level combinations; thus, the

authors were able to quantify how these attributes affected parents' choices.

DCE developmental process

When designing a DCE, the researchers must determine the study objectives,; the features (attributes) believed to define the topic of interest and decide what types of models will be used (figure 1).

Qualitative research prior to DCE

Prior to the DCE design, it is important to undertake qualitative research that includes a thorough literature review to establish what is important to key 'stakeholders' to determine the range of attributes and levels to be included in the final DCE design.²³ However, there is little evidence of rigour associated with this qualitative research and there are some publications describing how this qualitative research informs the final DCE design.²⁴

We conducted a literature review that generated a comprehensive list of factors that influence the health-seeking behaviour of patients with cancer towards cancer care. The list was not meant to be exhaustive; rather, it guided the development of topic guides to be used in the semistructured focus groups and telephone interviews.

A topic guide was used to stimulate discussion about the features of cancer care that were important to patients with cancer across rural and metropolitan regions. Topics for all participants included: (1) the overall expectations and experiences with the journey of patients with cancer; (2) knowledge about the patient's

condition and available treatment options; (3) the availability of social support networks; (4) the accessibility of healthcare services including the referral process and waiting time; (5) the type of health professionals (HPs) consulted; (6) the location of treatment facility and (7) the provision of financial or emotional resources. It was envisaged that these topics could potentially but not necessarily be included in the final DCE design.

Focus groups and one-on-one interview methods

Participants in the focus groups and telephone interviews included a) English-speaking patients with cancer presenting to, and b) HPs (both medical and nursing personnel involved in patient care), employed within the adult specialist oncology services at BSWR.

There was purposive sampling of participants to ensure maximum variation across sociodemographic and clinical characteristics to minimise selection bias.²⁵ Focus groups and telephone interviews were conducted separately for patient and HP participants by two researchers (SFW and PKL). Additionally, PKL took notes during the focus groups. The telephone interviews were conducted by one researcher (SFW). All interviews were digitally recorded and transcribed verbatim by a professional transcriber.

The final four focus groups (metropolitan HPs, metropolitan patients, rural HPs and rural patients) enabled us to identify a comprehensive range of patient and healthcare-related characteristics that influence patient choices. Nineteen participants (six metropolitan HPs, six metropolitan patients, three rural HPs and four rural patients) were involved in the semistructured focus

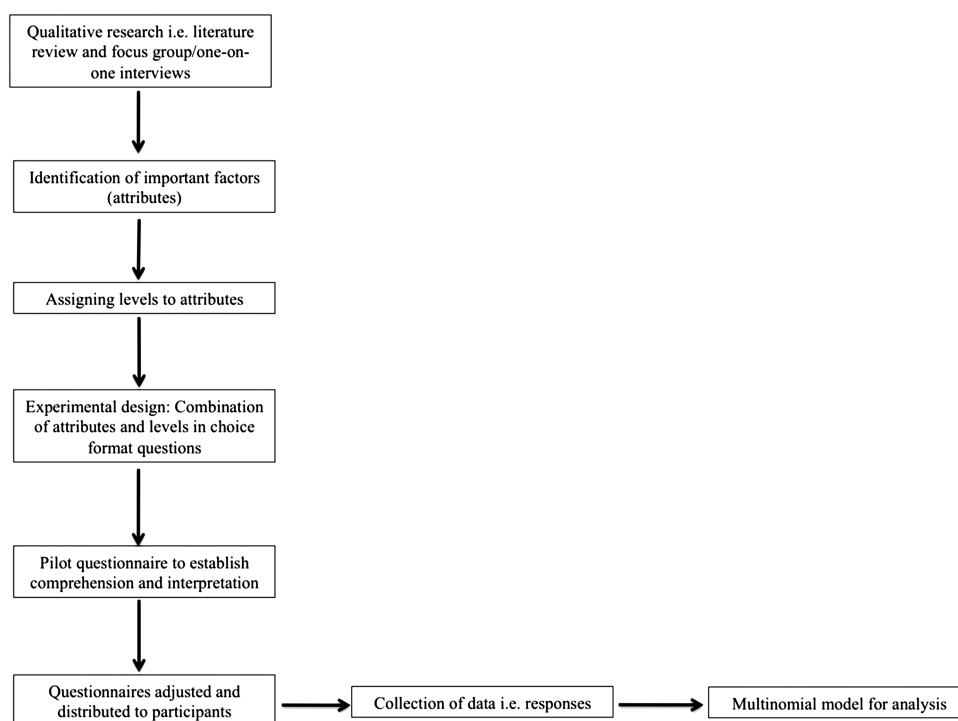


Figure 1 Key stages for developing a discrete choice experiment.

groups and two participants (one rural patient and one rural HP) were engaged in the one-on-one telephone interviews.

Qualitative analysis of focus groups and one-on-one interviews

The qualitative data from the audiotaped sessions and facilitator notes were analysed using the qualitative method of thematic analysis²⁶ between two authors (SFW and PKL) and another (TLD) who was not involved in the literature review or the facilitation of the focus groups. The transcripts were read and analysed by the three researchers independently, to identify and compare all major and minor themes. These themes were manually summarised in the text and tables before being interpreted and discussed with coresearchers.²⁷ The themes were subsequently grouped to classify the similarities and differences between the metropolitan HPs, metropolitan patients, rural HPs and rural patients.

Our study indicated that the availability of a social support network, especially family, was of paramount importance and influenced patients' decisions about seeking or accepting medical attention. The doctor-patient relationship was also highlighted by patient participants as being influential in time to diagnosis, investigations and treatments. Participants also preferred to consult an HP who was familiar with their history or who was perceived to have higher levels of medical qualifications.

Potential obstacles to accessing healthcare included the lack of primary care providers (general practitioners: GPs) and specialist services in rural areas compared with metropolitan areas, which may result in delayed medical attention or referral to a metropolitan facility. Distance travelled appeared to be of importance for rural patients. The financial costs associated with medical treatment also posed a significant burden to rural patients who were more likely to have additional out-of-pocket expenses associated with time away from work, fuel, car park and accommodation expenses.

The level of health literacy appeared to be inconsistent from the perspectives of both HPs and patients. Interestingly, differences in the health-seeking behaviour of patients with cancer were not observed, but HPs described rural patients as being less passive in their behaviour compared with metropolitan patients.

Development of attributes and levels for DCE

Six key patient and healthcare-related characteristics that appeared to be important to patients during their cancer journey were identified and included in the patient choice tasks (vignettes). These attributes were: (1) whom they consult for their cancer condition; (2) whether the doctor knows them; (3) the number of weeks they had to wait to see a doctor; (4) the presence of family/friends; (5) the distance they had to travel for their appointment (one-way) and (6) their out-of-pocket

costs in attending an appointment. These attributes formed the basis of our final DCE design. We assigned levels that patients with cancer could easily relate to and that were applicable to the current health systems or potentially available to each attribute.

Recently, it has become common to use prior assumptions about parameters rather than to assume, a priori, that parameters are zero.^{28–30} The argument in favour of prior assumptions is that the design is more efficient because researchers can maximise the information from each choice set and exclude dominant alternatives.³¹

We hypothesised that patients with cancer would prefer to consult a GP they were familiar with or a HP they felt had higher levels of expertise and experience compared with another HP. Patients were also more likely to attend treatment facilities that were easily accessible in terms of distance travelled and the number of weeks they had to wait for an appointment, or if they had appropriate social supports. Potentially higher out-of-pocket expenses incurred to attend a treatment facility were presumed to deter patients from accessing healthcare.

The cost parameter was designed to be broad, catering for both public and private sector patients with cancer. In Australia, patients will face varying levels of healthcare-related costs depending on factors including: (1) whether a primary care provider is bulk billing; (2) the level of private health insurance coverage and (3) the private copayment charges that are determined by the individual specialists. We also have to take into account additional expenses such as income loss with time off work, the need for medical escorts, fuel and car park expenses as well as accommodation (subsidised vs own). The final attributes and levels used in the choice tasks are summarised in [table 1](#).

Experimental design and construction of choice sets

The combination of attributes and levels in the study resulted in ($3^6=$) 729 possible profiles (hence 729² possible choice pairs). A full fractional design, incorporating all possible combinations, is, in some circumstances, valuable because it enables all interaction effects to be investigated. However, given the numbers of dimensions and levels in this case, the full fractional design is not appropriate, particularly for patients with cancer who are unlikely to be able to consider a large number of choice sets.

Thus, one author (RN) developed a smaller fractional factorial design (FFD) in Ngene using the D-efficiency criteria³² to select between competing designs. A 128-profile FFD allowed us to select a set of choices, which enabled exploration of the main effects (the effect of each independent variable on the dependent variable) and possible interactions (preferences for one attribute depend on the level of another).³³

A maximum of eight choice tasks per participant were considered feasible, given the nature of the participants.

Table 1 Final attributes and levels chosen for the discrete choice experiment

Attributes	Descriptions	Levels	A priori expectations
Whom you consult for your cancer condition:	Whether you see a specialist (medical oncologist, radiation oncologist) for your cancer condition vs your local general practitioner/nurse practitioner with supervision from a specialist. The supervision can occur through phone or email support, but you do not actually see the specialist in person	Medical specialist in a cancer centre Medical specialist in a general hospital setting Nurse practitioner or general practitioner with support/advice from a medical specialist—phone, email or video conference such as telemedicine	In general, a positive preference for a medical specialist in a cancer centre compared with other healthcare providers is expected
Whether the doctor knows you:	This depends on how well the doctor knows you in terms of your background and medical history	The doctor has access to your medical notes and knows you well; for example, your usual general practitioner or specialist The doctor has access to your medical notes but does not know you; for example, a locum doctor at your usual general practitioner or specialist practice The doctor has no access to your medical notes and does not know you; for example, a new practice	In general, a negative preference for a doctor who is not familiar with the patient and patient's medical history is expected
Number of weeks you have to wait to see a doctor:	How long you have to wait to see a general practitioner	1 week 3 weeks 6 weeks	In general, a positive preference for a shorter waiting time is expected
The presence of family/friends:	Whether you have the support of family/friends and if they can escort you to your medical appointments	Family/friends can accompany you to the appointments and stay with you overnight if required Family/friends can accompany you to the appointments but are unable to stay with you overnight if required Family/friends are unable to accompany you to the appointments	In general, a positive preference for the presence of family/friends is expected
Distance you have to travel for your appointment (one-way):	How long it takes to travel to your appointment, whether by public transport or private car, including transit times	30 min 1–2 h 2–3 h	In general, a negative preference for a longer travelling time is expected
Your out-of-pocket costs in attending an appointment:	These costs could include fuel, parking, meals, accommodation if required and private co-payments or medical gap expenses if seeing a private specialist	\$150 \$300 \$500	In general, a positive preference for lower costs is expected

While we believed that a proportion of participants would be able to cope with more than eight choice tasks, we felt other patients would struggle. We wanted to ensure a broad representation of the patient population in our DCE data; hence, we randomly blocked 128 choice sets into 16 sets of 8 choice tasks each. This means that each participant answered only a subset of the choice tasks from the FFD.

Some DCEs include an opt-out option or current care as a third choice in the vignette; however, we chose not to include an opt-out option because it was considered to be unrealistic, given that we were recruiting patients attending oncology services. Participants were asked to choose their preferred appointment (appointment A vs appointment B) for each choice task. An example of a choice task is shown in figure 2.

Questionnaire design and DCE validity

The questionnaire opened with an introduction about the purpose of the study. Importantly, a detailed description of each attribute and level was given before the choice tasks were presented to help participants understand what was required. Additional sociodemographic, disease and treatment-related characteristics were collected to assess how these characteristics might influence choices.

Patient participants were also asked whether they would allow the researchers to access data about them collected by the Evaluation of Outcomes study (ECO), which collects data items not limited to patient participant demographics (patient age, gender, geographical location), medical condition and treatment administered. ECO is a collaboration between the Victorian Department of Health, the Cancer Council Victoria and the Barwon South Western Regional Integrated Cancer Service. An opt-out option was provided for patients who chose not to have their ECO data accessed.

The face validity of the questionnaire was tested with focus group patient participants, of which 10 out of 11 questionnaires were returned. This was then used to refine the comprehension, options and wording of the DCE.²⁰ Half of the participants felt that the questionnaire was confusing and difficult to interpret, which suggested that the questionnaire might be particularly burdensome and cognitively demanding to our group of patients. Subsequent changes to the text and layout were made based on participants' comments which included: (1) the addition of an example choice task question to demonstrate how to answer the questions and (2) a reiteration that participants only choose one of the two options.

The theoretical validity of the design will be explored in the ongoing study by examining the signs and significance of parameter estimates. If the attributes are well defined, they will behave in line with a priori expectations, particularly in the dimensions where it is reasonable to assert a monotonic relationship, such as cost.³⁴

Participant sampling and recruitment

Sample size calculation for DCE studies in healthcare is a developing field, and one where rules of thumb around observations per choice set are still employed. Hall *et al*³⁵ had suggested that 20–30 respondents per choice set can provide precise parameter estimates, while Lancsar and Louviere³⁶ suggested that it is unusual to require more than 20 observations per choice set to estimate a reliable model. In this study, with a design of 128 choice tasks in blocks of 8, this would be achieved with a sample size of 320. Similarly, Marshall *et al*³⁷ estimated that a sample size of 100–300 respondents in healthcare could be appropriate given the constraints on resources and specific medical conditions, which may limit participation rates.

Eligibility criteria for participants in the DCE include: patients with cancer over 18 years attending the BSWR oncology services since January 2009, who are able to read and write English and are willing and able to give informed consent. We invited the three adult oncology services across the BSWR (ALCC, Warrnambool and Hamilton hospitals) to assist with participant recruitment. Questionnaires were manually marked with a unique letter to determine which oncology service had distributed the questionnaires; this will allow us to compare participation rates as well as variations in characteristics and responses across metropolitan and rural regions in patients with cancer.

We decided to allocate a larger number of questionnaires to metropolitan ALCC compared with rural Warrnambool and Hamilton Hospitals, given that ALCC services a higher proportion of patients, including metropolitan and rural patients, and is the only treatment facility across BSWR to provide radiotherapy services.

Receptionists and HPs at the BSWR oncology services will distribute the questionnaires to all eligible patients when they check in for their appointments. Patient participants will be given the options of completing the questionnaire:

- A. In the waiting room and to return the questionnaire to reception staff where they will store the questionnaire in a secure storage container; OR
- B. At home and to return the questionnaire with a postage paid envelope to the care of one of the researchers (SFW).

ANALYTICAL PLAN

A multinomial logit (MNL) model will be used to understand the trade-offs between the features of cancer care included in the choice tasks. The analysis of preferences of patients with cancer towards an appointment will allow us to investigate which patient and healthcare-related factors (and levels) influence their choices for cancer care. Their responses will also enable us to establish the importance of these factors (and levels) and their interactions with patient-related

Which Appointment would you prefer? (*please tick box below*)

Appointment characteristics	Appointment A	Appointment B
Whom you consult for your cancer condition	Medical Specialist in a general hospital setting	Nurse practitioner or general practitioner with support/advice from a medical specialist – phone, email or video conference such as telemedicine
Whether the doctor knows you	The doctor has access to your medical notes but does not know you, for example a locum doctor at your usual general practitioner or specialist practice	The doctor has access to your medical notes and knows you well, for example your usual general practitioner or specialist
Number of weeks you have to wait to see a doctor	6 weeks	3 weeks
The presence of family/friends	Family/friends are unable to accompany you to the appointments	Family/friends can accompany you to the appointments but are unable to stay with you overnight if required
Distance you have to travel for your appointment (one-way)	30 minutes	1 - 2 hours
Your out-of-pocket costs in attending an appointment	\$500	\$150

Prefer Appointment A

Prefer Appointment B



Figure 2 Structure of a discrete choice task.

characteristics (age, gender, level of education and income, the availability of social support networks, non-English-speaking background, general health status and experience with cancer).

An MNL approach was selected over a mixed MNL approach for the baseline analysis, as it will allow us to model the kind of preference heterogeneity we are more interested in, specifically heterogeneity based on

the observed characteristics of patients in metropolitan and rural regions. The mixed MNL has the added advantage of allowing regression coefficients to be drawn from a distribution (and not determined by observed characteristics). However, our study will focus on predictable differences in preferences, so we will employ the MNL approach for primary analysis, although we intend to explore the data with the mixed

MNL and generalised MNL models,³⁸ both of which can be estimated in STATA due to the recently released codes.^{39 40}

The cost parameter will be modelled as a continuous variable so that we can estimate the willingness to pay (WTP) for moving between levels of each of the other parameters. We can also estimate CIs around these WTP.⁴¹

To explore differences in preferences between groups, we will run a regression with each of the parameters interacting with each of the sociodemographic characteristics in turn. For example, we will interact a binary metropolitan respondent variable with each of the levels described in table 1 (with the exception of the omitted level in each dimension).

To explore the impact of the sociodemographic characteristic on preferences, we will test for the joint significance of the coefficients on the interaction terms. We will also run the models separately for the different demographic groups (for instance, metropolitan and rural respondents) and compare the resultant WTP estimates.

ETHICS AND DISSEMINATION

All focus groups and one-on-one interview participants were given a participant information and consent form to ensure that they were fully informed about the nature and objectives of the interviews and possible risks associated with participation prior to the interviews and digital recording.

Given that the DCE questionnaire will be distributed to participants by non-research staff (receptionists and non-research HPs), written consent for all participants is not possible. The DCE opening page will inform potential participants that participation is voluntary and should they decide to participate, they are to complete and return the questionnaire via the two methods described in the DCE. Contact details of the lead researcher (SFW) will be available should they have any questions.

All participants will be advised that any data generated during the interviews and DCE questionnaire will be confidential and anonymous. All identifiable details will be removed during future dissemination of the research findings, in presentation and/or publication formats.

The DCE analysis will provide a comprehensive coverage of preferences of patients with cancer towards features of their cancer care, and whether there is preference heterogeneity by metropolitan and rural locations. Specifically, these findings could be used to improve on current provision of cancer healthcare to patients across metropolitan and rural regions by:

A. Highlighting areas of preferred intervention from the perspectives of patients with cancer. For example, these issues may relate to early and increased provision of volunteer transport and subsidised accommodation as well as financial assistance to rural patients with cancer who potentially face higher out-of-pocket

expenditures. Additional support for dependants of cancer patients will alleviate some of the reservations patients have about leaving home to access healthcare in a metropolitan facility;

- B. Disseminating knowledge about the relative importance of patient choices and increasing awareness of the potential differences between metropolitan and rural patients with cancer. These results will be presented at oncology conferences, that is, the American Society of Clinical Oncology and the Medical Oncology Group of Australia annual scientific meetings, and published in peer-reviewed journals;
- C. Forming the basis of a pilot study to determine if and how much choices of patients with cancer influence their overall survival. Data from the DCE will be linked to the ECO and analysed to determine if patient choices could independently influence cancer outcomes. These findings will inform the researchers of the feasibility of conducting the study on a larger scale to study choices of patients with cancer and their interactions with other confounding variables.

Author affiliations

¹Department of Medicine, Barwon Health, Deakin University, Geelong, Victoria, Australia

²Andrew Love Cancer Centre, Barwon Health, Geelong, Victoria, Australia

³School of Public Health, Curtin University, Perth, Western Australia, Australia

⁴Centre for Health Economics Research and Evaluation, University of Technology, Sydney, New South Wales, Australia

⁵School of Nursing and Midwifery, Barwon Health, Deakin University, Geelong, Victoria, Australia

⁶Centre of Health Economics, Monash University, Melbourne, Victoria, Australia

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Competing interests None.

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