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# **A discrete choice experiment to assess cancer patients' preferences for when and how to make treatment decisions**

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## **Abstract**

**Purpose:** Cancer patients can be overwhelmed when being confronted with their diagnosis and treatment options. Such information is often provided during one consultation between the patient and treating clinician. In order to achieve optimal cancer care, there may be justification for alternative consultation styles. We assessed, in a sample of adult medical oncology patients, their preferences for: i) attending one 40 minute consultation or two 20 minute consultations, and ii) receiving written only or both written and online information, when making a cancer treatment decision.

**Methods:** A cross-sectional survey using a discrete choice design of 159 adult medical oncology patients presenting for their second or subsequent outpatient consultation. Participants were presented with a set of hypothetical scenarios and asked to indicate their most and least preferred scenario. The scenarios contained a caveat explaining that there would be no difference between the available treatment options in terms of when treatment would be initiated, and the impact it would have on patients' life expectancy.

**Results:** 147 patients completed the DCE. Of these, 70% (n=103) preferred being provided with written and online information rather than just written information. This preference was statistically significant ( $p < 0.01$ ). 59% (n=86) of patients preferred two 20 minute consultations over one 40 minute consultation when making a treatment decision. Significantly more patients preferred two shorter consultations rather than one longer consultation when this was combined with written and online information ( $p < 0.01$ ).

**Conclusion:** When making a cancer treatment decision, clinicians should consider offering patients written and online information, combined with two shorter consultations.

**Key words:** Doctor-patient-communication, decision making, patient-centred care, discrete choice, optimal care

## **Introduction**

Involving patients in decisions regarding their cancer care to the extent they desire is considered best practice [1]. However, delivering such care can be challenging. Cancer treatment decisions often introduce patients to unfamiliar concepts, a specialised language and a high degree of uncertainty regarding potential outcomes [2]. Patients may experience distress and anxiety related to their diagnosis and prognosis which can interfere with their ability to understand and recall the considerable array of information they receive about their treatment options [3]. To help ease the burden patients may feel when making treatment decisions, consensus guidelines have suggested that patients should be provided with two consultations with a short time between each consultation, combined with information presented in multiple formats [4]. This strategy aims to ensure patients have adequate time to make an informed decision by affording them the opportunity to consider the information they receive, seek additional information and/or involve others [5]. Despite these potential benefits, patients are commonly provided with only one relatively long consultation when making decisions about their treatment [6,7]. To our knowledge, no study has assessed patients' preferences for the number and length of consultations and the format of information provided. Having such data will help inform clinicians about how to best conduct consultations with their patients in order to align care with patients' wishes. This is an important step towards delivering optimal, patient-centred cancer care.

### ***Discrete choice experiments to study patients' preferences***

A discrete choice design is a methodologically robust approach to measure the strength of an individual's preferences [8]. Discrete choice experiments (DCEs) are based on the assumption that decisions can be described by a number of key attributes and that an individual's choice is influenced by the levels of these attributes [9]. Participants are presented with a number of hypothetical scenarios comprised of different levels of attributes and are asked to indicate their preferred option for each scenario [10]. Compared to other methodologies used to elicit

patients' preferences, DCEs have a number of advantages, which include: i) the elimination of yes-response bias as patients are forced to elicit a preference; ii) an ability to quantitatively assess the overall value people place on different attributes, as well as the trade-offs they are willing to make between these attributes; and iii) reduced participant burden as they are only required to answer one single question [11].

## **Aims**

The overall objective of this study was to utilise a DCE to assess cancer patients' preferences for two characteristics of oncology consultations. Specifically, we assessed, in a sample of adult medical oncology patients, their preferences for:

- i. Attending either one 40 minute consultation, or two 20 minute consultations when making a treatment decision about their cancer; and
- ii. Receiving either written only or written and online information regarding their treatment options.

The scenarios contained a caveat explaining to patients that there would be no difference regarding patients' survival rates, as well as when treatment will be initiated.

## **Methods**

### ***Design***

This was a cross-sectional survey which included a DCE. It was part of a larger study which was undertaken in two medical oncology treatment centres in New South Wales, Australia. We recruited cancer patients who have made cancer treatment decisions in the past and were thus able to make informed choices regarding the proposed consultation styles. Recruitment took place from August 2015 to December 2016. The Hunter New England Human Research Ethics Committee has granted full ethics approval for this research (approval number: 14/11/19/4.04). Participants gave informed consent before taking part in this study.

### ***Inclusion criteria***

Patients were eligible for this study if they: i) were aged 18 years or over; ii) had a confirmed diagnosis of any type of cancer; iii) were English speaking; and iv) were presenting for their second or subsequent outpatient medical oncology consultation at one of the two treatment centres included in this study.

### ***Recruitment***

Eligible patients were identified by clinic staff, using daily clinic lists. On check-in to their appointment clinic staff asked eligible patients if they would be willing to talk to the research team about the study. Informed consent was obtained by a trained research assistant by consecutively approaching patients who indicated they were willing to talk to the research team. Consenting patients completed a pen-and-paper survey via their preferred method (mailed or via email) within one week after recruitment (baseline) and three months later (follow-up). The DCE assessed in this study was included as part of the follow-up survey. Non-responders received a reminder telephone call two weeks after receiving a survey, and two weeks later. Clinic staff recorded the age and gender of non-consenters who provided permission, which allowed for examination of consent bias.

### ***Measures***

#### *DCE to examine patients' preferences for consultation type and format of information*

The DCE included in this study consisted of two attributes, with two levels each. Attributes and levels were based on a literature review and discussions among the research team, which included experts in the areas of health behaviour, oncology and statistics. The attributes, their levels and the caveat included in the scenarios are described in Table 1 and Figure 1. To assess the acceptability and feasibility of the approach, the DCE was pilot tested with experts in health behaviour and oncology, as well as with breast cancer patients (n=7) attending a cancer treatment centre in New South Wales, Australia. Each study participant was presented with

four scenarios and was asked to indicate their most and least preferred scenario. The scenarios were shown in a randomly selected order. The DCE involved only two attributes with two levels each. This kept patients' choices relatively simple. A "no information" option was not included in the DCE design given healthcare providers' ethical obligation to provide some information about their treatment options to patients in order to obtain informed consent for the suggested procedure.

**Table 1** Attributes and levels of the DCE

Attributes	Levels
Number and length of consultations	One 40 minute consultation Two 20 minute consultations
Format of information provided	Written only Written and online

**Figure 1** Scenarios patients could choose from to indicate their most and least preferred consultation type and format of information

Imagine the following: Your doctor has told you about different treatment options for your cancer. He has asked you to decide which treatment you would like to have.

Importantly:

- There is no difference between the treatment options in terms of how they will affect your length of life.
- However, the treatment options have different pros and cons. Your doctor believes that it is important that the decision is yours. He is happy for you to have either type of treatment. The decision depends on how you feel about the pros and cons of the options.
- Whichever treatment you choose it will start in two weeks from your first appointment.

We are interested in finding out what you think would help you most in making this decision.

If you were in that situation, which of the scenarios below would you like most? Also, which of the scenarios would you like least? For each question please choose one option only by ticking one of the relevant boxes:

	One 40 minute consultation and written information only	One 40 minute consultation and written and online information	Two 20 minute consultations and written information only	Two 20 minute consultations and written and online information
I would like <b>MOST</b> <u>Please tick one box in this row:</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I would like <b>LEAST</b> <u>Please tick one box in this row:</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### *Demographic and cancer characteristics*

For this study the following self-reported demographic and disease related characteristics were evaluated: sex, age, cancer type.

### *Statistical analysis*

All analyses were conducted in Stata 14.2. and R 3.2.3 (2015-12-10). Consent bias with regards to sex and age were assessed using Chi-squared tests. The DCE data were analysed using descriptive statistics, Pearson's Chi-squared test with Yates' continuity correction and an ordinal regression model. This enabled us to examine the trade-offs patients made when choosing between the different levels of the attributes.

## **Results**

### *Participants*

For the larger study, 455 eligible patients were approached. Of these, 379 (83%) consented to participate in the larger study. Two-hundred-fourteen patients (47% of all eligible patients approached) were sent a three month follow-up survey including the DCE, of which 159 (74%) returned a completed survey. Most participants were female (n=116, 73%) and were receiving treatment for breast cancer (n=91, 58%). Participants had a mean age of 64 years (see Table 2).

There were no significant differences between consenters and non-consenters in terms of age and sex ( $p > 0.05$ ).

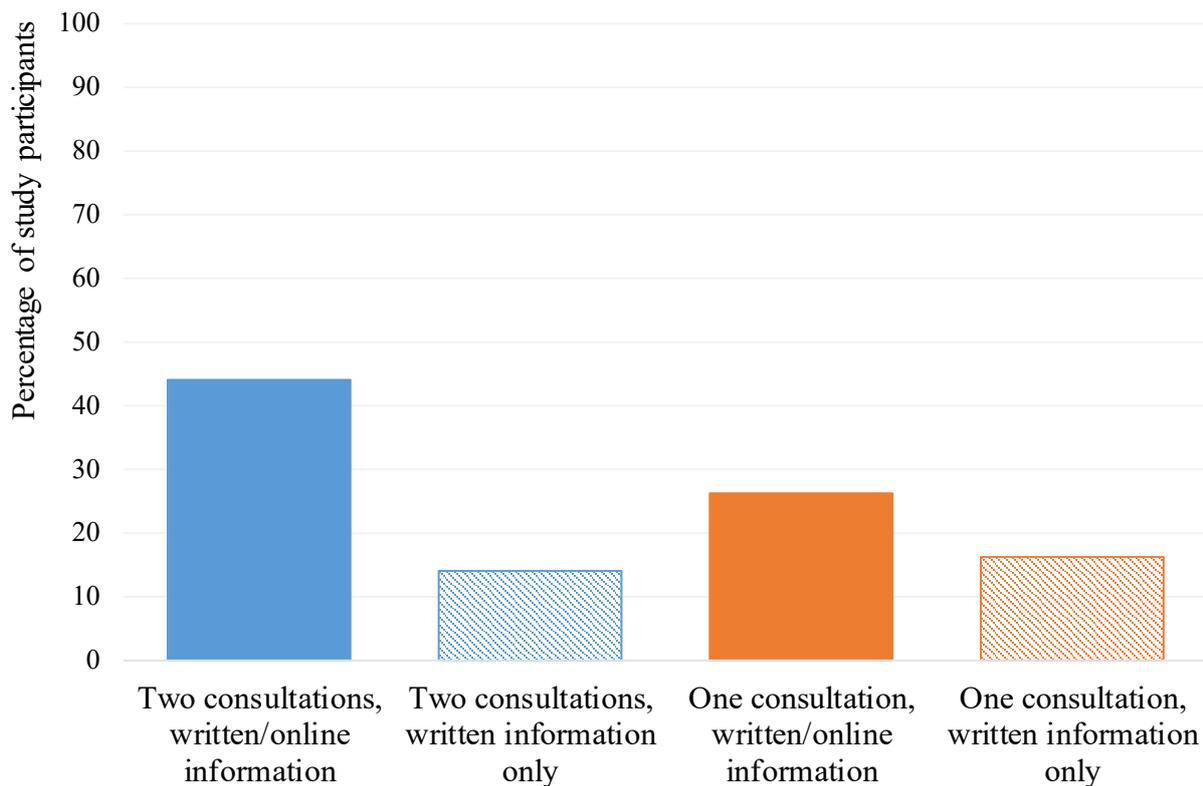
**Table 2** Demographic and cancer characteristics of respondents

<b>Demographics</b>	<b>No. (%) of patients (n=159)</b>
Age in years, mean (SD)	64 (12)
Sex	
<i>Male</i>	43 (27)
<i>Female</i>	116 (73)
Primary cancer location	
<i>Breast</i>	91 (58)
<i>Colon</i>	16 (10)
<i>Prostate</i>	10 (6.3)
<i>Lung</i>	9 (5.7)
<i>Others</i>	32 (20)

### ***Patients' preferences***

Ninety-two percent of study participants (n=147) completed the DCE. Of the four scenarios presented to patients, the most preferred option was to receive two consultations along with written and online information (n=65; 44%; see Figure 2). The second most preferred scenario chosen by patients was being provided with one consultation and written and online information (n=38, 26%). The least preferred scenarios included one consultation and written information only (n=23; 16%), and two consultations with written information only (n=21, 14%). The ordinal regression analysis showed that statistically significantly more patients preferred being provided with written and online information rather than written information only ( $p < 0.01$ ). Comparatively, there was no main effect for the attribute of consultation length. However, a significant interaction between the two attributes was found with significantly more patients preferring to receive two 20 minute consultations over one 40 minute consultation, when this was combined with being provided with written and online information ( $p < 0.01$ ).

**Figure 2** Patients' preferences for scenarios



## Discussion

Our findings highlight that some patients would prefer receiving information regarding their treatment options in multiple formats and would like to have time to consider their options in order to make informed decisions. To our knowledge, this is the first study to elicit patients' preferences for the number and length of consultations and the format of information provided when making a cancer treatment decision. Most patients in our study preferred being provided with written and online information regarding their treatment options, combined with two consultations. While we did not directly elicit patients' reasons for their choices, potential reasons may include that this consultation style could allow patients to better “digest” the abundance of information presented during the consultation and help overcome their feeling of being overwhelmed [12]. Specifically, providing information via multiple formats can help patients access information according to their preferences which can increase patients' satisfaction with the consultation and help them better cope with their cancer [13]. It might also

help overcome poor health literacy and enhance patients' understanding and recall of the information provided [14].

Offering two consultations might facilitate the involvement of patients' support persons by affording them the opportunity to consider the information provided by the doctor and discuss the treatment options with the patient in-between two consultations. This might be valued by patients who feel more certain about their decision after consulting their support persons [15]. However, a number of patients in our study wished to receive one longer consultation rather than two shorter ones. It might be that these patients perceive urgency and prefer to make treatment decisions as soon as possible in order to take immediate action and prevent a worsening of their cancer [16]. This preference could also be due to practical constraints, such as support persons' ability to attend multiple consultations or patients' travel time to the clinic.

***Clinicians should offer patients the option of presenting information in multiple formats in two consultations***

The variation across patients' preferences suggests that a patient-centred approach towards oncology consultations is required whereby care is tailored to patients' preferences for information provision and decision making. This requires clinicians to have a clear understanding of a person's preferences. However, previous research indicates that clinicians do not always have an accurate understanding of when and how patients would prefer to receive information about their treatment options [17]. Clinicians' misperceptions regarding patients' comprehension of information [18] and preferred involvement in treatment decisions have been reported previously [19]. Asking patients directly about their preferences for information provision and decision making has the potential to reduce the discord between patient and clinician estimates [20]. Wherever possible, patients should also be offered the option of receiving information about their treatment options in multiple formats and having two consultations. Where appropriate, clinicians should emphasise to patients that it is usually safe to take some time to consider their options before making a decision.

### ***How to overcome some of the barriers to providing two consultations when making cancer treatment decisions***

Clinicians might question the feasibility of providing two consultations for every patient in routine practice. For example, patients living in rural areas may have difficulties travelling to the clinic twice in order to attend two consultations. In these instances, an alternative option might be to hold the second consultation via phone or online. Using videoconferencing to conduct oncology consultations allows rural patients to receive consultations closer to their homes, and has been shown to minimise healthcare access difficulties [21]. This approach has also been found to be acceptable to patients and healthcare providers and can result in net savings to the patient and healthcare system compared to usual care [22]. It can be implemented in many geographically distant areas which require lengthy travel to access healthcare [22].

There may also be concerns that providing two shorter consultations would increase clinicians' perceived time pressure. For instance, they might need more time associated with the increased number of consultation letters to write [23]. However, helping patients understand the information provided to them and involving them in treatment discussions occurring at an early stage can lead to more succinct discussions later which might ultimately save time [24]. It also has the potential to improve a number of patient outcomes, including decreased anxiety and fear of cancer recurrence, increased satisfaction with the consultation and higher quality of life [25,26].

### ***Limitations and implications for future research***

It has been argued that patients' preferences for choosing hypothetical scenarios may differ from their preferences for making actual treatment decisions. However, a number of studies have compared actual choices with stated preferences and found that parameters from both were similar [27-29]. Telser and Zweifel compared willingness-to-pay values for health-related goods derived from actual choices with ones derived from a DCE and found a close

correspondence between the two results [30]. Despite including numerous cancer types, this sample was overrepresented by women diagnosed with breast cancer. Thus, there is a need to investigate patients' preferences for different consultation styles in other cancer populations, including with males. These patients may have different preferences for information provision and decision making. Having such data will help examine the generalisability of our findings. We also do not know how different consultation styles may affect patient outcomes. It has been suggested that tailoring consultations according to patients' preferences can improve a number of patient outcomes, including increased patient satisfaction and emotional well-being [31]. Intervention trials are needed to assess prospectively the impact of receiving two consultations along with written and online information, rather than one consultation and written information only. Two consultations might increase costs for patients receiving care in those healthcare settings where patients have to pay per consultation. It might also increase patients' waiting times. We did not collect information on how patients would trade-off increased costs and waiting times with receiving their preferred consultation style. More research is needed to assess whether these factors would impact on patients' preferences for different consultation styles.

## **Conclusion**

Based on our findings, cancer patients seem to prefer the idea of being provided with written and online information combined with two shorter consultations, rather than having one consultation and written information only. Wherever possible, clinicians should offer patients this consultation style to allow for time to “digest” the presented information and support patients with making informed treatment decisions. Given the variation across patients' preferences, it is essential that clinicians ask their patients about their decision making preferences and tailor care accordingly. This can help ensure that cancer patients receive optimal, patient-centred care.

## **Author contributions**

**Conception and design:** All authors

**Collection and assembly of data:** All authors

**Data analysis and interpretation:** Laura Wall, Anne Herrmann, Rob Sanson-Fisher, Alix Hall

**Manuscript writing:** Anne Herrmann, Rob Sanson-Fisher, Alix Hall

**Final approval of manuscript:** All authors

**Accountable for all aspects of the work:** All authors

## **Compliance with Ethical Standards**

**Disclosure of potential conflicts of interest:** We have no competing interests to declare.

**Research involving Human Participants and/or Animals:** All procedures performed in this study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

**Informed consent:** Informed consent was obtained from all individual participants included in this study.

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