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What sort of follow-up services would Australian breast cancer survivors prefer if we could no longer offer long-term specialist-based care? A discrete choice experiment

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Background: Early diagnosis and improved treatment outcomes have increased breast cancer survival rates that, in turn, have led to increased numbers of women undergoing follow-up after completion of primary treatment. The current workload growth is unsustainable for breast cancer specialists who also provide care for women newly diagnosed or with a recurrence. Appropriate and acceptable follow-up care is important; yet, currently we know little about patient preferences. The aim of this study was to explore the preferences of Australian breast cancer survivors for alternative modes of delivery of follow-up services.

Methods: A self-administered questionnaire (online or paper) was developed. The questionnaire contained a discrete choice experiment (DCE) designed to explore patient preferences with respect to provider, location, frequency and method of delivery of routine follow-up care in years 3, 4 and 5 after diagnosis, as well as the perceived value of 'drop-in' clinics providing additional support. Participants were recruited throughout Australia over a 6-month period from May to October 2012. Preference scores and choice probabilities were used to rank the top 10 most preferred follow-up scenarios for respondents.

Results: A total of 836 women participated in the study, of whom 722 (86.4%) completed the DCE. In the absence of specialist follow-up, the 10 most valued surveillance scenarios all included a Breast Physician as the provider of follow-up care. The most preferred scenario is a face-to-face local breast cancer follow-up clinic held every 6 months and led by a Breast Physician, where additional clinics focused on the side effects of treatment are also provided.

Conclusion: Beyond the first 2 years from diagnosis, in the absence of a specialist led follow-up, women prefer to have their routine breast cancer follow-up by a Breast Physician (or a Breast Cancer Nurse) in a dedicated local breast cancer clinic, rather than with their local General Practitioner. Drop-in clinics for the management of treatment related side effects and to provide advice to both develop and maintain good health are also highly valued by breast cancer survivors.

Breast cancer is the most common incident form of malignancy in Australia accounting for 28% of cancer diagnoses in 2008 (Australian Institute of Health and Welfare & Cancer Australia, 2012). It is a well-characterised disease with clear guidelines available through Cancer Australia for follow-up of women with early breast cancer (National Breast and Ovarian

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Cancer Centre, 2010). Cancer Australia has defined the aims and objectives of follow-up: to detect and treat local recurrence, to deal with adverse effects of treatment, to provide psychological support, to screen for a new primary breast cancer, review and update family history, observe outcomes of therapy and review treatment including the potential for new therapies (National Breast and Ovarian Cancer Centre, 2010). In addition, Cancer Australia identifies that there is a lack of clarity about the 'optimal duration and frequency of follow-up', and it is apparent that this is a contentious area (Dixon and Montgomery, 2008; Cameron, 2008).

Clinical cancer services around Australia are facing a rapid expansion in workload through a combination of three factors: (a) unprecedented ageing of the population leading to numbers in the cancer-prone age-groups growing more quickly than the incidence rates of cancer are falling; (b) higher proportion of cases of both incident and recurrent cancer being deemed treatable, with treatment regimes becoming progressively more complex; and (c) improving outcomes of treatment, expanding the pool of survivors (Australian Institute of Health and Welfare & Cancer Australia, 2012). There are economic and workforce imperatives to changing models of care and reconfiguring service provision within the public health sector. Relevant research suggests that nurses may be better at identifying psychological concerns and side-effects of drug treatment than clinicians (Dixon and Montgomery, 2008), and shared cared models of breast cancer follow-up between Cancer specialists and General Practitioners have recently been the focus of a demonstration project within Australia by Cancer Australia (Cancer Australia, 2013).

Patient preferences can also inform clinical decision-making and improve satisfaction and adherence to health programmes (Lancsar and Louviere, 2008). Discrete choice experiments (DCE) have become a commonly used technique in health economics (Ryan *et al*, 2006). The technique is an attribute-based measure of benefit, based on the assumption that interventions (e.g., breast cancer follow-up services) can be described by a number of salient or key attributes (characteristics) and that an individual's valuation of the intervention depends upon the levels of these attributes (De Bekker-Grob *et al*, 2012). Important attributes may be identified from literature reviews, expert clinical opinion, patient focus groups or individual patient interviews. Patients are given hypothetical scenarios comprising different levels of attributes and asked to choose between two or more alternatives. Patients' stated preferences reflect their perceived benefit, where benefit is defined in terms of the economic concept of 'utility' or value (Ryan *et al*, 2006).

Given limited resources, if we are considering designing new follow-up services that are both appropriate and acceptable to women, we need to understand which attributes of the service women value most. The aim of this study was to determine the preferences of breast cancer survivors for possible alternative modes of delivery of follow-up services in years 3, 4 and 5 after diagnosis.

MATERIALS AND METHODS

Producing scenarios. Salient attributes and levels for inclusion within the DCE were established from a literature review. We searched in PubMed from inception through to December 31, 2011, limiting to original papers, literature reviews or systematic reviews published in English. Key search terms were text words 'breast cancer', 'follow*', 'surveillance', 'monitoring', 'survivor*', and MESH terms 'patient satisfaction' and 'patient preference*'. Papers that focused on either the experiences of women undergoing breast cancer follow-up or on women's preferences for

alternative modes of delivery of follow-up services were sought. In reviewing the identified papers, greater weight was given to recent Australian publications.

A key set of papers included a recently published body of qualitative research on breast cancer follow-up in Australia. Australian women reported a high level of satisfaction with their current specialist-based care and an initial reluctance to consider models of care that would involve them moving away from the cancer specialist (Brennan *et al*, 2011a). There was also a perceived need for additional training of GPs or Breast Cancer Nurses if they were to have an increased role in follow-up care (Brennan *et al*, 2011b). Patients highlighted psychosocial needs and menopausal symptoms as areas of the follow-up consultation that needed improving (Brennan *et al*, 2011b).

While recognising advantages to GP follow-up, there was a stronger level of support for shared care between the GP and a specialist, rather than a complete transfer to GP led care (Brennan *et al*, 2011a). We explicitly excluded the shared care option as the objective of the study was to identify alternatives to specialist follow-up, and previous research has shown that respondents tend to prefer what they know best or have experienced (Salkeld *et al*, 2000; Kimmman *et al*, 2010a).

Four attributes relating to service organisation were identified: type of provider, location, frequency and method of delivery of routine follow-up care. A fifth attribute was created from 'gaps' described in the literature relating to existing service provision, with the intent to evaluate the perceived benefit of offering 'drop-in' clinics to provide additional support to women living with breast cancer. On the basis of the literature and expert consultation, three levels for each of the five attributes were developed to examine characteristics of interest to the Australian health care context:

1. Clinician

- (a) Breast Physician: usually General Practitioners who have undergone specialised training in breast medicine (http://breastphysicians.org/index.php?option=com_content&view=article&id=1&Itemid=2).
- (b) General Practitioner: local doctor providing whole person health care to individuals and families in the community, (<http://www.racgp.org.au/becomingagp/what-is-a-gp/what-is-general-practice/>).
- (c) Breast Cancer Nurse: registered nurse with additional training and certification in breast cancer care (National Breast Cancer Centre, 2005).

2. Frequency – every 6, 9 or 12 months.

3. Location – hospital clinic, general practice, local breast cancer follow-up clinic.

4. Method – face-to-face, telephone, alternate between face-to-face and telephone.

5. Drop-in clinics – treatment side effects, psychosocial support, secondary prevention.

The 5×3 design resulted in 254 (3^5) possible scenarios. We used a fractional factorial design and the techniques developed by Street and Burgess to reduce this to a more pragmatic 18 binary choice sets, which were 100% efficient for the estimation of main effects (Burgess, 2006). This design was then divided into three blocks or versions, each containing a total of six choice sets for presentation to participants. The detailed definition of the chosen attributes and attribute levels for the DCE are presented in Table 1.

The questionnaire started with a short introduction on the background to the research study and an explanation of what the questionnaire would involve (including a practice example).

Table 1. Attributes and levels

Attributes	Levels	Description
Clinician	Breast Physician	Most are General Practitioners who have undergone additional training in breast assessment, planning and coordinating breast cancer treatment and counselling ^a
	General Practitioner + +	Your local doctor who provides person centred, continuing, comprehensive and coordinated whole person health care to individuals and families in their communities. ^a This is your own local doctor whom you normally see when you get sick (e.g., coughs and colds, blood pressure, diabetes, infections etc)
	Breast Cancer Nurse	A registered nurse who has completed extra study (a Graduate Diploma or higher at University) in the specialty of cancer nursing or its equivalent ^a
Frequency	Every 6 months	Follow-up visit scheduled every 6 months
	Every 9 months	Follow-up visit scheduled every 9 months
	Every 12 months + +	Follow-up visit scheduled every 12 months
Location	Hospital clinic	A breast cancer follow-up clinic at the hospital where you had your treatment, but you would no longer be seen by the cancer specialist/s who provided your surgery, chemotherapy or radiotherapy
	General practice + +	Your local general practice
	Local breast cancer follow-up clinic	A breast cancer follow-up clinic in your local area
Method	Face-to-face	A visit to a clinician where you would have a clinical breast examination and discussion about your well-being and issues related to your breast cancer care
	Telephone + +	At a scheduled time, a clinician telephones you and you have a discussion about your well-being and issues related to your breast cancer care
	Alternate between face-to-face & telephone	Your first appointment is a clinic visit, your second appointment is by telephone, your third appointment is a clinic visit and so on
It is important to note that if your care was provided by telephone but it becomes clear that you needed a face-to-face appointment, this would be arranged within 1 week		
Drop-in clinics	Treatment side effects clinic	For management of lymphedema, menopausal symptoms, sexual dysfunction etc that relate to your surgery, chemotherapy or radiotherapy for breast cancer
	Psychosocial support clinic + +	For identification, referral and management of depression, anxiety and issues relating to self-image, relationships and return to work
	Secondary prevention clinic	For advice about diet, alcohol and exercise, to both develop and maintain good health and reduce the risk of breast cancer returning

Notes: + + Reference group in modelling.
^aAdapted from sources outlined in Methods section.

The first section of the questionnaire contained the discrete choice experiment. In the preamble, participants were given a hypothetical context (Figure 1), followed by a comprehensive description of each of the attributes and levels. Women were then asked to complete six questions. Each question contained a pair-wise choice, and participants were asked to choose the option they most preferred for their routine follow-up appointments in years 3, 4 and 5 following diagnosis of breast cancer (Figure 2). The second section consisted of background information regarding demographics, family history, features related to breast cancer diagnosis, treatment and follow-up, and self-assessed level of anxiety regarding cancer and other health concerns (Gotay and Pagano, 2007) (Supplementary Appendix A). The questionnaire was designed principally for online administration. However, a paper version was made available upon request for women who expressed a preference for a paper version and/or who did not have easy access to the internet.

A small pilot study ($n = 10$) was administered by one author (TB) in a follow-up breast clinic at a major public hospital in Adelaide. The main objectives of the pilot study were to establish face validity and identify any problems in understanding the requirements of the questionnaire or individual questions. Feedback from the pilot study resulted in some minor changes in question wording to improve clarity.

Recruitment. Patients with a personal history of breast cancer, who had completed their primary treatment (surgery, radiotherapy and chemotherapy), were eligible for the study.

Women were recruited from a variety of settings including Breast Surgical Oncology clinics (SA only) in both the public and private health sector, local and national print media, and patient support and advocacy groups including Cancer Voices SA, Cancer Council Australia, Breast Cancer Network of Australia, National Breast Cancer Foundation and Register 4, over a 6-month period from May to October 2012.

Patients recruited through their treating clinician were provided with a study envelope at the end of their consultation if they met the inclusion criteria. The patient, if willing to participate, was asked to complete the questionnaire at home and return the questionnaire within the stamped addressed envelope provided, or alternatively access the survey online using the URL provided in the Letter of Invitation within the study envelope.

Patient support and advocacy groups were asked to disseminate a short description of the study to their members through their usual communication channels. Patients were also recruited through print media (a local newspaper, magazine for senior citizens and a state-based journal of the Australian Medical Association). Women who chose to participate could either complete the survey online or contact the research team requesting a study envelope to be posted to them.

Block randomisation occurred at the online survey site, and by ensuring that each clinician received an equal number of all three versions of the survey to provide to their patients.

Ethics approval. Approval was obtained from the Human Research Ethics Committees of the University of Adelaide, and

For the purpose of this study, please imagine the following:

Your breast cancer care is provided by a cancer specialist at the hospital for the first 2 years after your diagnosis and you are then discharged to follow-up care with a different clinician in a different location. This medical practitioner would be responsible for your routine follow-up appointments in years 3, 4 and 5; however, if a serious problem arose, you would be referred immediately back to the cancer specialist who provided your initial treatment (please note that your follow-up would still continue beyond 5 years, but for the purpose of this study we would like you to focus on years 3, 4 and 5). You would be expected to attend your routine follow-up appointments at this new location. This new location also runs weekly “drop-in” clinics for further advice and support about living with breast cancer. These “drop-in” clinics are in addition to your routine follow-up appointments, require no booking, and you can use them as little or as often as you wish.

You will be asked to answer six questions about hypothetical breast cancer follow-up programs. Each question contains a pair of options for you to choose between. The features of the follow-up programs will differ in the following five ways:

1. Which clinician would provide your care
2. How often your appointments would be
3. Where your follow-up appointment would occur
4. Type of routine follow-up appointment
5. Type of additional drop-in clinics offered

Figure 1. Preamble to DCE.

Programme A	Programme B
Breast Physician	General Practitioner
Every 6 months	Every 12 months
Local breast cancer follow-up clinic	Hospital clinic
Face-to-face	Alternate between face-to-face and telephone
Psychosocial support clinics available	Secondary prevention clinics available

☐ Programme A

☐ Programme B

* Scenarios varied over 18 pair-wise choices

Figure 2. Example of a DCE question*.

each of the three public and three private Adelaide hospitals participating in the study.

Socio-economic status. Socio-economic status was classified using the Socio-Economic Indexes for Areas, 2006 (SEIFA 2011 had not been released at the time of writing), from the Australian Bureau of Statistics (<http://www.abs.gov.au/AUSSTATS/abs@.nsf/allprimarymainfeatures/356A4186CCDDC4D1CA257B3B001AC22C?opendocument>). The Postal Area (POA) Index of Relative Socio-Economic Advantage and Disadvantage (IRSAD) was applied to derive national deciles from individual postcodes, with decile 1 indicating the most disadvantaged and decile 10 the most advantaged areas.

Data analysis. The DCE data were analysed within a random utility maximisation framework (McFadden, 1973). The empirical model to be estimated is specified as: $U_{ijt} = x'_{ijt}\beta_i + \varepsilon_{ijt}$, where U_{ijt} is the utility individual i derives from choosing alternative j in choice scenario t , x_{ijt} is a vector of observed attributes of alternative j , β_i is a vector of individual specific coefficients reflecting the desirability of the attributes and ε_{ijt} is a random error term. In order to investigate the potential for preference heterogeneity, the mixed logit model, also known as the random parameter logit model, was utilised (McFadden and Train, 2000; Hole, 2007; Eberth *et al*,

2009). Within the mixed logit model, the β_i is expressed as $\beta + \eta_i$, where β constitutes the vector of average preferences of the population for each attribute and η_i is the individual's specific preference components. In this study, it is assumed that all coefficients of attribute levels are random with normal distribution and are freely correlated. The utility function for the DCE was of the following form:

$$U_{ijt} = (\beta_1 + \eta_{1i})\text{Physician}_i + (\beta_2 + \eta_{2i})\text{Nurse}_i + (\beta_3 + \eta_{3i})\text{Six Months}_i + (\beta_4 + \eta_{4i})\text{Nine Months}_i + (\beta_5 + \eta_{5i})\text{Follow up Clinic}_i + (\beta_6 + \eta_{6i})\text{Hospital Clinic}_i + (\beta_7 + \eta_{7i})\text{Face 2 face}_i + (\beta_8 + \eta_{8i})\text{Alternate}_i + (\beta_9 + \eta_{9i})\text{Sideeffects}_i + (\beta_{10} + \eta_{10i})\text{Prevention}_i + \varepsilon_{ijt}$$

where Physician and Nurse are dummy variables for Breast Physician and Breast Cancer Nurse in the clinician attribute, SixMonths and NineMonths are dummy variables indicating every 6 or 9 months in the follow-up frequency attribute, FollowupClinic and HospitalClinic are dummy variables representing local breast cancer follow-up clinic and hospital clinic in the location attribute; Face2face and Alternate are dummy variables indicating face-to-face and alternate between face-to-face and telephone for the

Table 2. Mixed logit estimates for total sample

			Mean coefficient		s.d.	
Attributes	Levels	Reference level for each attribute	Coefficient	s.e.	Coefficient	s.e.
Clinician	Breast Physician	Compared with having General Practitioner to provide your care	2.692**	0.331	1.911**	0.279
	Breast Cancer Nurse		1.167**	0.207	2.191**	0.315
Frequency	Every 6 months	Compared with the frequency of appointments is every 12 months	0.375*	0.166	1.615**	0.298
	Every 9 months		0.178	0.149	1.049**	0.284
Location	Local breast cancer follow-up clinic	Compared with the follow-up appointment location is at local general practice	1.118**	0.172	0.805*	0.349
	Hospital clinic		0.016	0.169	1.232**	0.341
Method	Face-to-face	Compared with the routine follow-up appointment by phone	2.711**	0.311	1.855**	0.334
	Alternate face-to-face and telephone		2.145**	0.256	1.476**	0.295
Drop-in clinics	Treatment side effects clinics	Compared with the psychosocial support clinic	0.898**	0.196	1.240**	0.377
	Secondary prevention clinics		0.404*	0.186	1.567**	0.326
Log likelihood			-2218.025			
AIC			4566.050			
N			722			
Observations			4332			

Abbreviations: AIC = akaike information criterion; N = number of Halton draws: 500. Random parameters correlated.
 ** $P < 0.01$,
 * $P < 0.05$.

method attribute, Sideeffects and Prevention are dummy variables for treatment side effects clinic and secondary prevention clinic for the Drop-in clinics attribute. All attributes were dummy coded, with one level for each attribute coded as the referent (refer to Tables 1 and 2 for referent levels).

From the fitted model, a statistically significant parameter estimate for an attribute level indicates its importance in influencing the preferences of respondents. A positive (negative) sign indicates that this attribute level is preferred (not preferred) to the base level of the attribute. Internal validity (i.e., the extent to which results are consistent with *a priori* expectations) was tested by examining the sign and significance of parameter estimates. We expected all attributes to have a significant influence on preferences for follow-up. On the basis of our literature review and expert opinion, the *a priori* assumptions were that more frequent face-to-face visits with a General Practitioner (GP)/specialist GP (Breast Physician) in a local community setting close to home, which provided additional psychosocial support clinics, would be the most preferred follow-up options for years 3–5 in our hypothetical scenarios.

The main outputs from the mixed logit model are estimates of the proportions of respondents who prefer each attribute level, compared with the reference level for each attribute. For example, for the attribute 'health-care provider', the proportion of the population with a preference for Breast Physician compared with a General Practitioner can be estimated. Following Kimman *et al.* (2010a), a series of interaction terms between the attribute levels and respondents' characteristics (reflecting socio-economic status, education and clinical characteristics including the number of years since initial diagnosis, age at diagnosis and the type of breast cancer diagnosed) were included into the utility function to further explore possible observable sources of preference heterogeneity.

Preference scores (V_j —also called 'indirect utility scores'; Ryan *et al.* 2006) were generated as the sum of the model coefficients for

every combination of attribute levels. The probability that each combination of attribute levels is the most preferred scenario (P_j) is further calculated as:

$$P_j = \frac{\exp(V_j)}{\sum_{k=1}^J \exp(V_k)}$$

where $j = 1, \dots, J$. In this paper, only the 10 most highly ranked scenarios are considered.

RESULTS

Characteristics of respondents. A total of 836 women accessed the survey, of whom 722 (86.4%) completed the DCE and were included in the analysis. Of the participants, 75.6% were born in Australia and 98.2% were non-indigenous. The largest number of responses were from the most densely populated states (New South Wales 26.7%, South Australia 26.5%, Victoria 19.8% and Queensland 17.2%), but all states and territories were represented. At diagnosis, the majority of women had early invasive breast cancer (74.1%) and were between 40 and 60 years of age (67.8%). The largest group of respondents were 2–5 years post diagnosis (40.7%), followed by women 5–10 years post diagnosis (26.6%). Most study participants (83.5%) saw a cancer specialist (breast surgeon, medical oncologist, radiation oncologist and specialist registrar in training) most frequently for their breast cancer follow-up. Complete characteristics of the respondents are presented in Supplementary Appendix A.

Discrete choice experiment results. The mixed logit estimates for the total sample are reported in Table 2. As hypothesised *a priori*, all attributes were found to have a significant influence on preferences for follow-up. The results indicate that women demonstrated strongest positive preferences for a Breast Physician

(followed by a Breast Cancer Nurse), 6-monthly visits, local breast cancer clinic, face-to-face attendance (followed by alternate face-to-face and telephone) and drop-in clinics for treatment side effects (followed by secondary prevention; all $P < 0.05$). The parameter estimates relating to face-to-face follow-up and the Breast Physician were in the expected direction, providing evidence of internal validity. The statistically significant standard deviation (s.d.) of all random coefficients ($P < 0.05$) also confirmed the existence of preference heterogeneity. As all coefficients of attribute levels are assumed to be normally distributed, the mixed logit estimates relating to the mean coefficient and s.d. for each attribute level were applied to calculate the distribution of preference heterogeneity. For example, the coefficient (s.d.) of Breast Physician is 2.692 (1.911), indicating that 92% of the respondents exhibited a preference for the breast cancer follow-up service to be provided by a Breast Physician. Similarly, the results indicate that 70% of respondents would prefer to see a Breast Cancer Nurse over a General Practitioner and 59% of respondents would prefer to have appointments every 6 months over every 12 months.

The extent to which preference heterogeneity was related to observable characteristics was explored by including the interaction terms between respondents' characteristics and attribute levels. No interaction terms were found to be statistically significant suggesting that preference heterogeneity was largely unobservable and was not systematically related to respondents' characteristics.

Predicting choice probabilities for different breast cancer follow-up scenarios. To illustrate respondent preferences for the factors in combination, Table 3 presents the 10 most valued surveillance strategy scenarios, all of which included a Breast Physician as the provider of follow-up care. The most preferred scenario is a face-to-face local breast cancer follow-up clinic held every 6 months and led by a Breast Physician, where additional clinics focused on the side effects of treatment are also provided.

The data indicate that women would prefer to reduce the frequency of follow-up from 6 to 9 months rather than alter the location or method of delivery, but they would accept alternating methods of delivery, and follow-up to be based at a hospital based clinic, to a decrease in follow-up frequency to 12 monthly. The rankings also show that women would be prepared to accept alternating methods of delivery (face-to-face and telephone-based visits) before switching the location of the clinic to a hospital setting.

DISCUSSION

Our results demonstrate clear preferences of Australian breast cancer survivors for delivery of their follow-up care in the absence of specialist follow-up in years 3, 4 and 5. Breast Physicians were the most preferred provider, followed by Breast Cancer Nurses and then General Practitioners. Breast Physicians bring a specialist level of knowledge to survivorship care with many of the benefits of a GP approach (Brennan and Jefford, 2009). The observed preference for Breast Cancer Nurses to local GPs suggests that specialised training in breast medicine is valued by respondents. Additional reasons for this order of preferences could be explored by qualitative research, but was beyond the scope of this study. A follow-up service located in the community had broad appeal to women, and, while face-to-face visits were preferred, women would consider alternating face-to-face visits with telephone contact if this meant that the frequency of contact with the follow-up service was not reduced.

To our knowledge, this is only the second discrete choice experiment investigating patient preferences for breast cancer follow-up and the first in an Australian context. Kimman *et al* (2010a) used DCE methodology to assess patient preference for the first year of breast cancer follow-up in the Netherlands, described by attributes of attendance at an educational group programme, frequency of visits, waiting time, contact mode and type of health-care provider, for 331 women. The authors demonstrated that 'overall patient satisfaction would be similar if patients were followed up by a medical specialist alternating with a Breast Cancer Nurse compared with follow-up by a medical specialist only'. Kimman *et al* (2010a) also found preference heterogeneity for most attributes, 'indicating that one strategy does not fit all'.

It is important to note that our study differs from Kimman's study in a number of key areas. First, we elicited the views and preferences of a large sample of Australian women previously treated for breast cancer, with no fixed time since completion of treatment. Second, the attributes and levels included in our study were also notably different from those selected by Kimman *et al* (2010a). The attributes and levels were carefully chosen to reflect the Australian health system and the current policy context whereby alternative modes of delivery of follow-up services are being considered to reduce the burden upon cancer specialist. Hence, the cancer specialist was removed from the scenario. Deliberately removing the cancer specialist from the follow-up

Table 3. Preference scores & predicted probabilities within the top 10 breast cancer follow-up scenarios							
Clinician	Frequency	Location	Method	Drop-in clinics	Preference score	Probability	Rank
Breast Physician	Every 6 months	Local breast cancer follow-up clinic	Face-to-face	Treatment side effects clinics	7.794	0.192	1
Breast Physician	Every 9 months	Local breast cancer follow-up clinic	Face-to-face	Treatment side effects clinics	7.597	0.158	2
Breast Physician	Every 6 months	Local breast cancer follow-up clinic	Face-to-face	Secondary prevention clinics	7.300	0.117	3
Breast Physician	Every 6 months	Local breast cancer follow-up clinic	Alternate face-to-face and telephone	Treatment side effects clinics	7.228	0.109	4
Breast Physician	Every 9 months	Local breast cancer follow-up clinic	Face-to-face	Secondary prevention clinics	7.103	0.096	5
Breast Physician	Every 9 months	Local breast cancer follow-up clinic	Alternate face-to-face & telephone	Treatment side effects clinics	7.031	0.090	6
Breast Physician	Every 6 months	Local breast cancer follow-up clinic	Alternate face-to-face & telephone	Secondary prevention clinics	6.734	0.067	7
Breast Physician	Every 6 months	Hospital clinic	Face-to-face	Treatment side effects clinics	6.692	0.064	8
Breast Physician	Every 9 months	Local breast cancer follow-up clinic	Alternate face-to-face & telephone	Secondary prevention clinics	6.537	0.055	9
Breast Physician	Every 9 months	Hospital clinic	Face-to-face	Treatment side effects clinics	6.495	0.052	10

scenarios was also designed to help reduce the effect of people tending to prefer what they know best (the so called 'status quo bias' (Salkeld *et al*, 2000), which had been reported in the Kimman *et al* (2010a) study. By including a Breast Physician, a Breast Cancer Nurse and a General Practitioner, we were able to examine how women's preferences might be influenced by specialised knowledge of breast medicine (specialist GP vs general GP) and clinician craft group (specialist GP vs specialist nurse). We also chose not to offer a shared care option, as we sought to identify the single key clinician women would prefer to oversee their follow-up care. A community based site for follow-up was offered as an alternative to hospital based care, where the opportunity to attend drop-in clinics to address areas of unmet need was also provided. By offering a hypothetical local breast cancer follow-up clinic, we could assess whether a publicly funded community location for follow-up would be acceptable to breast cancer survivors.

Brennan *et al* (2011b) identified a perceived need for additional training of GPs or Breast Cancer Nurses if they were to have an increased role in follow-up care. Our study has confirmed that if patients cannot see a breast cancer specialist, the specialised knowledge of breast medicine is of more importance to women than the clinician craft group. This is in contrast to a Canadian randomised controlled trial of long-term follow-up for early-stage breast cancer, which demonstrated that follow-up by the patient's own family physician was a safe and acceptable alternative to traditional hospital-based specialist-led follow-up (Grunfeld *et al*, 2006). Mitigating factors include a 55% study recruitment rate, which suggest that almost half of the patients 'will be unwilling to have follow-up care transferred to their family physician' (p 853), and the authors also state that the study did not specifically measure the 'special psychosocial and supportive care concerns' of breast cancer patients. Our study demonstrates a high level of patient support for breast cancer nurses as providers of follow-up care in the absence of follow-up provided by a medically qualified cancer specialist. This finding is in line with the results of a Swedish randomised multicentre study that compared a nurse-based follow-up system with clinic visits on demand to routine follow-up by a specialist in oncology or surgery (Koinberg *et al*, 2004). The study demonstrated that the two strategies were similar in terms of patients' well-being, satisfaction and access to medical services, and there was no difference between the groups concerning time to recurrence or death.

Brennan *et al* (2011b) also highlighted psychosocial needs and menopausal symptoms as areas of the follow-up consultation that needed improving. Our study showed that patients valued drop-in clinics for treatment-related side effects (which includes menopausal symptoms) most strongly, over secondary prevention clinics and psychosocial support clinics. This suggests that sequelae of breast cancer treatment are currently not being adequately addressed during follow-up. Our results concur with three recent observational studies in Australia, examining the prevalence and severity of morbidity in breast cancer survivors. One study revealed that many breast cancer survivors report long-term breast-related morbidity (functional status, cosmetic status and breast-specific pain) that was unaffected by time since surgery, and that the extent of loco-regional therapies were significant predictors of poorer health-related quality of life outcomes (Tian *et al*, 2013). Another study followed participants for over 6 years, allowing for the estimation of the prevalence of a predefined range of adverse treatment effects over time (Schmitz *et al*, 2013). At 6 years after diagnosis, more than 60% of women were experiencing one or more adverse treatment effects, but the proportion of women experiencing three or more side effects decreased throughout follow-up. The results are most applicable to women who had extensive axillary surgery (as recruitment occurred before sentinel lymph node biopsy becoming widespread in Australia); however, the study may still underestimate the true prevalence of adverse

treatment effects, as it did not capture chemotherapy and endocrine therapy-related sequelae. Another smaller study found that women with higher levels of symptom burden following treatment for early breast cancer reported significantly higher interference with personal goals and objectives, and psychological distress, than women with a lower symptom burden (Stefanic *et al*, 2013).

Our findings also indicate that although face-to-face visits with a clinician were preferred, women would consider alternating face-to-face visits with telephone contact if this meant that the frequency of contact with the follow-up service was not reduced. This supports previous research that demonstrated cautious support for alternative modes of delivery of care. For example, a US study suggested that, for women to accept an alternative model of care, they need to understand what it entails, and to be reassured about the safety of the new option. In that study, patients rated a virtual telephone/internet visit as having less impact on cancer-related worrying and cancer survival, than face-to-face visits with clinicians (Mayer *et al*, 2012). The authors suggested that a lack of detail in the definition of a virtual visit within the questionnaire may have led to misunderstanding about this option and contributed to the negative response. In contrast, a randomised equivalence trial in the United Kingdom, comparing traditional hospital follow-up and telephone follow-up by breast cancer nurses, after treatment for breast cancer with low-to-moderate risk of recurrence, demonstrated that 'patients in the telephone arm of the study had higher levels of satisfaction but did not have higher levels of anxiety as a result of foregoing clinical examinations and face-to-face appointments' (Beaver *et al*, 2009). In addition, there was no difference between the two groups in time to detection of recurrent disease. These findings are similar to a Netherlands study, which addressed patient satisfaction with nurse-led telephone follow-up in the first year after curative treatment for breast cancer (Kimman *et al*, 2010b). The researchers concluded that regular phone contact with a breast care nurse, and a one year mammography combined with a hospital visit, was of equal value to traditional hospital follow-up visits, in terms of access of care, technical competence, interpersonal aspects and general satisfaction.

While breast physician-led follow-up in local breast cancer clinics were the top nine most preferred scenarios in our study, there are some foreseeable barriers to implementing breast physician-led clinics in the community in Australia. For example, some have noted doubt about 'whether the current and future availability of breast physicians is adequate to meet the need of the increasing numbers of breast cancer survivors in Australia' (Bell *et al*, 2013). A recent pilot study in Western Australia hypothesised that patients treated for breast cancer would benefit from targeted therapy delivered by general practitioners based on recommendations of a multidisciplinary team (MDT) based in primary care (Jiwa *et al*, 2013). This small study demonstrated that, while MDT is feasible in primary care, and most patients who then consult a GP will benefit, the logistics of organising the reviews (meeting venue, breast care nurse as care coordinator, access to an electronic health record), and the cost implications of providing care in the community 'need careful consideration'. Current funding systems may have an impact here. Under current Australian funding arrangements, patients treated in the community (including GP visits) may be subject to payment of a 'gap fee' above the Commonwealth Government Medicare rebates, whereas patients who are treated in State health funded hospitals are not charged a fee for further care at public hospitals (Jiwa *et al*, 2013).

The advent of widespread Internet access and growing experience with video-conferencing may provide a more attractive option for women in rural and remote areas of Australia, who could be seen by their local General Practitioner and have regular case conferences with multiple care providers simultaneously from

their own home or local general practice clinic. Further research could apply DCE methodology to investigate the preferences of women who live in rural and remote areas, for this new mode of technology.

The strengths of our study include the large sample size ($n = 722$) and national sample frame. The attributes and levels in the study were informed by international literature and contemporary qualitative research on the experiences, needs and preferences of breast cancer survivors in Australia (Jiwa *et al*, 2010; Brennan *et al*, 2011a, b; Jiwa *et al*, 2011; Lawler *et al*, 2011). The limitations of this study include lack of recruitment by breast clinicians in states and territories other than South Australia, that women had to be literate in English to participate, and we were unsuccessful in recruiting breast cancer survivors of Aboriginal or Torres Strait Islander descent (ATSI comprised <2% of the respondents). The results may not be representative of women from non-English speaking backgrounds or indigenous communities, but addressing these limitations was beyond the scope of the current study. Nonetheless, our study sample is large and diverse, and is likely to be generalisable to English-speaking women in Australia.

Identification of training requirements, and careful workforce planning and modelling would be required to ensure that 'specialist GP' led breast cancer follow-up clinics avoid exacerbating current GP workforce shortages (Jiwa *et al*, 2007). It would also be important to explore barriers to specialists discharging their patients to follow-up by a different clinician and how this may be influenced by characteristics of the individual professional, the patient (e.g. age, co-morbid anxiety or depression, social support, urban vs rural/remote etc), the primary breast cancer (e.g. low, medium or high risk of recurrence) or other factors.

CONCLUSION

In the absence of cancer specialists, in years 3, 4 and 5 following diagnosis, Australian women would prefer to have their routine breast cancer follow-up provided by a Breast Physician (or a Breast Cancer Nurse) in a dedicated local breast cancer clinic, rather than with their local General Practitioner. Drop-in clinics for the management of treatment-related side effects and to provide advice to both develop and maintain good health are also highly valued by breast cancer survivors.

In the light of financial pressures that reduce the feasibility of almost all follow-up services being provided by breast cancer specialists, this study provides important insights into those attributes of a breast cancer follow-up service that women value most. Our results can help inform the design of alternative service pathways that are acceptable to patients, for which further assessments of costs and patient outcomes can be undertaken.

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