

- Ensure that key demographic and cancer data are routinely and systematically collected on cancer registration forms and by clinical cancer registries to aid monitoring for high risk groups (e.g. Aboriginal and Torres Strait Islander people and culturally and linguistically diverse groups); include cancer stage as a routine data item in cancer registries
- Make routine data supply to Cancer Council SA and other cancer-control agencies an integral part of the work of health authorities with dedicated budget lines for data provision
- Introduce programs of routine data release so that Cancer Council SA and other external agencies can obtain the data they need on a timely and regular basis for their work
- Extract additional data for high-risk groups including low SES populations, rural and remote communities, culturally and linguistically diverse groups, Aboriginal and Torres Strait Islander people and the elderly, to inform service delivery
- Use data linkage to construct repositories of linked de-identified data that cover the whole cancer trajectory and which can be used to extract data to support cancer-control initiatives
- Advocate to Australian Health Ministers for a greatly simplified and harmonised data governance arrangement across government jurisdictions, such that data access can be achieved across widely dispersed data repositories.

### Acknowledgements

The authors would like to acknowledge the significant

work of the Public Health Information Development Unit at the University of Adelaide, upon which this article is based. In particular, the authors would like to thank Associate Professor John Glover, Dr Diana Hetzel and Ms Su Gruszin.

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## UNDERSTANDING HOW CONSUMERS WOULD LIKE TO ENGAGE IN THE RESEARCH DECISION-MAKING PROCESS

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### Abstract

There is an increasing emphasis on community and consumer engagement in cancer research, from identifying priorities to reviewing grants from a consumer perspective. It is clear that there is great interest from the community and consumers to be more actively involved in research, and many organisations and research institutions have responded by convening consumer advisory panels, including consumers on boards and committees, and including consumers and the community in forums and research seminars. While the opportunities available for consumers to participate in research are welcome, current mechanisms to engage with consumers often appear to be tokenistic and bureaucratic. Bedside to Bench, a research, community engagement and health education organisation, conducted

an online, consumer engagement in research survey over four weeks. The aim of the survey was to determine when and how cancer patients and their families how they would like to be involved in research. The survey was developed following feedback from consumers at the Australian Pancreatic Genome Initiative's annual research symposium, that suggested current opportunities for consumers to engage in research were limited. Eighty two cancer patients and carers responded to the survey. The majority of respondents (82%) stated that they were interested in being involved in the decision-making process in relation to cancer research. The greatest area of interest was in having access to the results of research projects (23%) and providing feedback to researchers once the projects are developed (23%). Other areas of interest were the development of research projects with researchers (17%), identification of research priorities (17%), with the lowest area of interest being grant reviews (13%). The results of this study suggest that the majority of consumers want to be involved in research in some way, however, given the option, there is potentially only a subset of consumers interested in the review of research grants. What is clear is that, whatever the mechanisms for consumer engagement, strategies, policies and resources need to be available in order to support all stakeholders improve the practice of research involving consumers. The results of this study will be useful to guide future research and policy decisions in relation to consumer engagement in research.

There is an increasing emphasis on community and consumer engagement in cancer research, from identifying priorities to reviewing grants from a consumer perspective. It is clear that there is great interest from the community and consumers to be more actively involved in research, and many organisations and research institutions have responded by convening consumer advisory panels, including consumers on boards and committees, and including consumers and the community in forums and research seminars.<sup>1-6</sup>

Bedside to Bench is a health education, community engagement and research not-for-profit that works with the community, researchers, health practitioners and policy makers to facilitate a meaningful and productive relationship between each stakeholder group through workshops, facilitated meetings and education. Our model of engagement creates an environment where consumers are engaged in research, as part of the research team, with the aim of ensuring that research addresses the needs of consumers and has a clear pipeline for application.

In May 2013, the Australian Pancreatic Genome Initiative (APGI, [www.pancreaticcancer.net.au](http://www.pancreaticcancer.net.au)) held its annual research symposium. The symposium provided consumers and researchers with an update on the APGI's national study investigating the underlying genetic changes in pancreatic cancer, by studying the DNA from tissue and blood samples from pancreatic cancer patients across Australia. Of the 101 symposium attendants, 49 were consumers and community members, demonstrating a high level of consumer interest in the work of the APGI. This is a particularly high number of consumers given it is a poor prognosis cancer, which traditionally struggles to maintain high levels of consumer engagement or interest in research because of the nature of disease. The symposium included three presentations from APGI members in relation to pancreatic cancer research, and two non-pancreatic cancer specific presentations focusing on existing mechanisms for consumer engagement in research. During the two consumer engagement presentations, Cancer Council NSW, Cancer Australia and National Health and Medical Research Council consumer and community engagement mechanisms were described. Following the presentation, there was an open discussion, where many of the consumers suggested that the current mechanisms appeared to be tokenistic and bureaucratic.

It was from this ad-hoc feedback that an online survey was designed and conducted over a four week period, to ask cancer patients and their families how they would like to be involved in research, with the aim of informing policy decisions to ensure that future engagement is meaningful.

## Methodology

An online survey was developed by the authors, following the collection of feedback from consumers at the Australian Pancreatic Genome Initiative's annual research symposium that suggested that the current opportunities for consumers to engage in research were limited. The survey was delivered through SurveyMonkey (Survey Monkey, Palo Alto, CA). The survey was solely advertised on the Bedside to Bench Facebook page. People who had experienced cancer as a patient or carer were invited to complete the survey. In an attempt to reduce bias, the advertisement on Facebook was intended to attract anyone who had been affected by cancer as a patient or carer, as opposed to experienced consumer representatives.

The survey was designed to collect minimal, non-identifiable, demographic information from participants and included a series of questions in relation to whether they were interested in participating in cancer research, whether they had previously been involved in the consumer review of grants, at what stage they would like to be involved in research, level of interest in the consumer review of grants, and barriers to participating in the consumer review of grants.

A content analysis was conducted by the authors using a conventional content analysis approach, in which categories were directly derived from the participant's open-ended responses, based on common themes.<sup>7</sup> The responses from participants who did not complete certain questions were excluded in the data analysis to ensure accuracy. Each week, the researchers met to discuss categories and resolve any discrepancies. The proportion of respondents in each category was analysed and the frequency and percentage that each category represented was calculated.

## Results

Eight categories were identified by the researchers and had the following definitions:

**Time burden:** Responses that indicated participants had limited time available for grant reviews and/or had other commitments.

**Lack of qualification and research experience:** Expression of concerns that short-term training would not provide sufficient knowledge for participating in grant reviews and opinions that others were better qualified to make such important decisions.

**Lack of interest:** Expression of no interest in grant reviews.

**Conflict of interest:** Participants with previous/current contribution in cancer research expressed a concern that the participation might compromise their professional judgments.

**Lack of current cancer experience:** Opinion that past cancer experience might be irrelevant to the current grant review process.

**Previous participation:** Participants with previous grant reviewing experience did not want to be involved in the process again.

**Health concerns:** The health effects due to cancer treatment.

**Travel burden:** Expressed that travelling to the grant review venue was a deterrent.

## Demographic information

Eighty two individuals responded to the survey, of which 31% were cancer patients, 62% were family members/carers of cancer patients and 7% were both a carer and a patient. Just over half (54%) of respondents were from NSW, 9% were from Victoria and Queensland, and the remaining respondents were from South Australia, Western Australia, Tasmania and overseas. The mean age for patients was 55 years and for carers 44 years; respondent ages were categorised into the following age groups, 35% 40-45 years, 32% 25-20, 18% 55-69, 4% under 25 years and 11% over 70 years of age.

## Cancer type and date of diagnosis

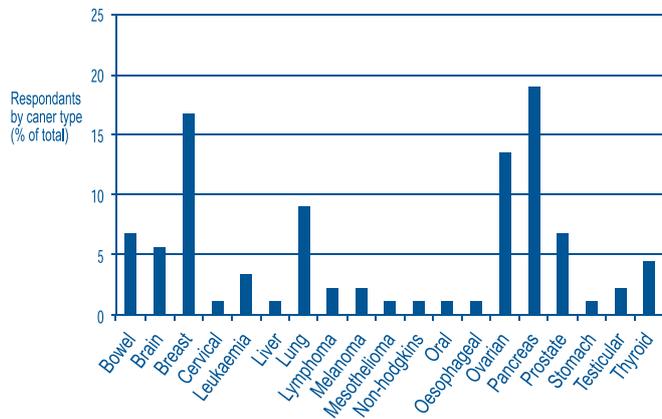
The majority of respondents had experienced pancreatic cancer (19%), followed by breast (17%), ovarian (14%), bowel (7%), prostate (7%) and brain (6%) cancers. The remaining types of cancer represented are available in figure 1. Participants were asked to identify the date of cancer diagnosis, either as a patient or a carer. A third (33%) of respondents stated a date of diagnosis between 2011-2013, 23% between 2006-2010, 11% between 2000-2005 and 15% before 2000. The remaining participants (18%) did not provide a response.

## Questions in relation to consumer participation in research

Participants were able to select multiple responses to these questions. The majority of respondents (82%) stated they were interested in being involved in the decision-making process in relation to cancer research. The greatest area of interest was in having access to the results of research

projects (23%) and providing feedback to researchers once the projects are developed (23%). Other areas of interest were the development of research projects with researchers (17%), identification of research priorities (17%), with the lowest area of interest being grant reviews (13%) (figure 2).

Figure 1: Cancer types represented in this survey.



Only a small proportion of respondents (18%) stated that they were not interested in participating in cancer research decision-making in general, with deterrents including lack of scientific knowledge and research experience, conflict of interest and time burden (figure 3).

Figure 2: Stages of research and decision-making process consumers expressed interest participating in.

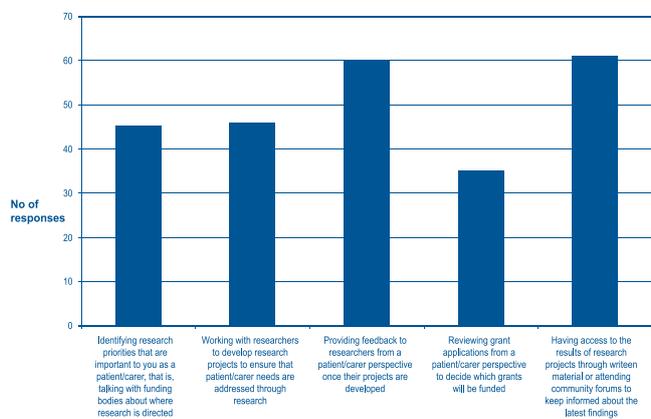
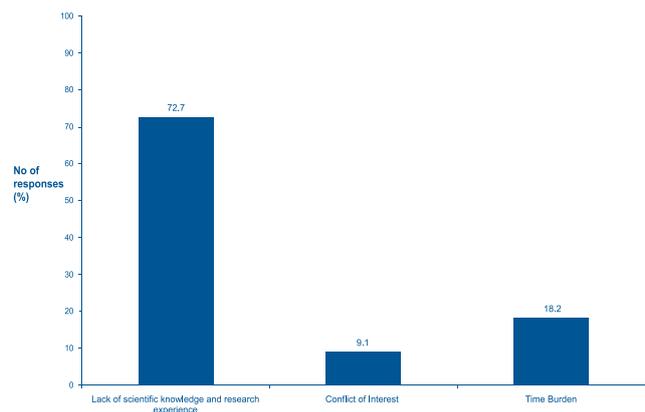


Figure 3: Reasons consumers state for not wanting to participate in research.

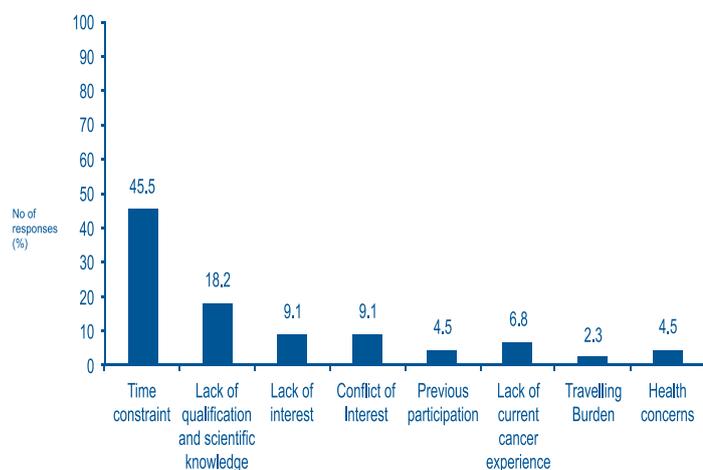


### Questions specifically related to the consumer review of grants

Respondents were asked specifically about their interest in participating in the consumer review of grants, and if yes, how much time they were prepared to commit to the review. Of the respondents who stated that they would be interested in reviewing grants (43%, n=35), the majority stated that they were prepared to travel (71%). In relation to time commitment, 10 respondents were prepared to commit at least six days to the process, four would commit three-five days, 11 would commit two days and 10 would commit one day. Of the 35 respondents who stated that they were interested in the review of grants, 14 had previously attended a training or seminar in relation to community engagement in research.

A higher number of participants (52%, n=43) stated that they were not interested in the consumer review of grants. The reasons respondents did not want to participate were time burden (46%), others better qualified to make decisions about funding (18%), lack of interest (9%), conflict of interest (9%), lack of current cancer experience (7%), previous participation (5%), health concerns (5%), and travelling burden (2%) (figure 4).

**Figure 4:** Reasons consumers state for not wanting to participate in the consumer review of grants.



## Discussion

Consumer and community engagement seeks to involve participants to play an active role in the decision making process of research.<sup>8</sup> The results of this survey suggest that the greatest area of interest for consumers participating in research is at the beginning of the research process, providing feedback to researchers once research projects are developed, and at the end of the process, hearing the results of research projects. The area of least interest in relation to involvement was in priority setting and making decisions about research funding. This is in contrast to existing literature, where consumer involvement in the decision-making process has been observed as evolving over time to address several concerns found in traditional research, particularly concerns in relation to the relevance of research to patient needs and cancer care services, and

the need to increase community engagement in health related decisions.<sup>9-11</sup>

Within our survey results, there were inconsistencies in relation to the responses to the question about participating in the consumer review of grants. The inconsistency arose when the question of grant review was posed as a separate question, rather than an option in a series of questions. One explanation for this may be that when information on the amount of time attendance at workshops and overall commitment needed was provided, participation in the review of grants was less appealing. While there is no way in this review to accurately determine the reason for this, we can infer that in the absence of options, consumers may be more willing to participate in the consumer review of grants, however given the option, the preference would be to engage in research in other ways.

There have been a number of studies involving consumers in all stages of research, from study design, proposal review, data collection and analysis and result dissemination.<sup>12-15</sup> The joint partnership allowed a direct influence on all aspects of the studies and was found mutually beneficial. Many studies have also found that consumer involvement in the research agenda provided different perspectives and insight into major concerns of cancer patients and the experience in dealing with the disease,<sup>1,2,4,5,16</sup> therefore enhanced the relevance, appropriateness and practicability of research questions and protocols to the community and potentially improved participation rates.<sup>3,13,15,17</sup> It is also acknowledged that additional resources are required, including support for researchers who wish to welcome consumers as co-researchers.<sup>3</sup> The importance of an organisational framework,<sup>6</sup> sufficient funding and resources to support consumer involvement,<sup>10,12</sup> and a change in attitudes from traditional research to partnership have been recognised,<sup>10</sup> and it is recommended that research and institutional policy adapt to reflect this need.

Consumer collaboration in disseminating research findings to the community has been suggested to increase the credibility and accessibility of the findings.<sup>2,3,6</sup> For the community, scientific skill and knowledge enhancement increased consumers' confidence and provided them a degree of control in the research.<sup>6,9,10,17</sup> There are established benefits to consumer engagement in all aspects of research, however our survey suggests that there is a preference for participation at specific points in time, leading to a misalignment between consumer preference in how they wish to be engaged in research, and the overall benefits that consumer engagement offers to research outcomes.

There were some concerns from consumers in our study in relation to whether they were suitably qualified to make decisions on research funding. Andejski et al found that both consumers and researchers sitting on scientific merit and grant review panels were concerned about the lack of scientific background of consumers.<sup>10</sup> Personal bias due to a consumer's personal perspective and experience was also added to the concerns of researchers, and could lead to power imbalance between consumers and researchers.<sup>11</sup> While these problems could be avoided by

ensuring plain language was used whenever possible, making the language more accessible by researchers,<sup>13</sup> and providing training to consumers,<sup>3,6,13,15</sup> it does not address the key issue identified in this study which questions whether the consumer preference is being involved in the review of grants, or other activities.

This study was limited, as only a small sample population was included, it was open for a short period of time (four weeks), and the number of people who saw the survey is unknown, so it is not possible to provide an estimate of response rate. There is also limited existing research, making it difficult to discuss findings in the context of consumer engagement in research. In addition, the generalisability of consumers' interests across a larger population was questionable, due to an absence of participants coming from minority ethnic backgrounds and with rare cancer types.<sup>4-6,15,16</sup> This survey did not account for ethnic backgrounds, however rare cancer types were well represented. This was largely opportunistic and a result of the recent work of Bedside to Bench across a number of low prevalence and poor prognosis diseases. Nevertheless, the issue of underrepresentation should be considered in any study design involving consumers in order to maximise inclusion while avoiding tokenism.<sup>6</sup>

Although tension, distrust and conflicts have been observed in the interaction between consumers and researchers,<sup>12,13</sup> this interaction also serves as a platform for negotiating the problems. Through communication and agreement on both parties' roles and obligations, and having flexibility to renegotiate those roles and obligations, successful collaboration could be fostered.<sup>11</sup> This is where the concept of inviting consumers to be involved as part of the research team demonstrates an opportunity for meaningful engagement. Previous models of consumer engagement in Australia have focused on building networks of consumers for researchers to draw upon. While there are benefits to this model in relation to resourcing, it does not facilitate the development of a working relationship between researchers and consumers, and encourages the tokenistic interaction that has been a criticism of consumer engagement in research from many stakeholders, as researchers need only 'access' a consumer once a year for the purpose of grant applications.

## Conclusion

Consumer and community engagement in research has been gradually implemented. A number of benefits, limitations and challenges have been identified to both consumers and the community, and researchers. The results of this study suggest that consumers want to be involved in research in some way, however given the option,

there is potentially only a subset of consumers interested in the review of research grants. What is clear is that there is a place for consumers in all facets of research. Whatever the mechanisms adopted for consumer engagement, strategies, policies and resources need to be available in order to support all stakeholders, which in turn will improve the overall practice of involving consumers in research decision-making.

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