



The voice of people affected by cancer

Consumer Involvement in Research (CIR):

Does it work?

An Evaluation of Cancer Voices' CIR Program

July 2016

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From Consumers participating in Cancer Voices CIR Program

“The project leaders appear genuinely interested in consumer involvement and my input has been welcomed and integrated.”

“My advice reflects what I understand to be the broad views and priorities of people affected by cancer. It's important to ask what may seem to be the obvious questions from this perspective - ones which the researchers may not have considered.”

“My suggestion on project aims was taken up and incorporated - should make the project more useful to meeting patient needs”

“The training covered all aspects of research. Very good strategies were workshopped to ensure the consumer could work in a collaborative way with the researcher.”

“I am proud to be a consumer rep. and a part of Cancer Voices. I have been involved with Cancer Voices CIR Program throughout its first ten years. Watching it grow from a good concept to a now very well regarded and accepted service to connect researchers with informed consumers. WELL DONE, Cancer Voices ! This is the sort of thing that needed to be put in place, but only doable by an independent cancer consumer advocacy group.”

From researchers participating in Cancer Voices CIR program

“My consumer provided by Cancer Voices has played a major role in my research - he has a personal connection with the cancer I study and is highly committed”.

“Personally, I have found interacting with the consumer assigned to me to be inspiring and motivating”

“The consumer’s comments helped to focus the research so that the needs of consumers/cancer patients were addressed”

“Before having a consumer representative involved, you think you have a consumer perspective fully in mind. After having a consumer representative involved, you see it is very easy to overlook simple issues that are important to address. With a researcher hat on it is easy to prioritise what is more easily 'do-able' over what is most relevant to do”.

“As a researcher Cancer Voices is a very important conduit for me to get in touch with consumers. I was very impressed with how quickly we were connected with a consumer with relevant experience. Thank you for this very worthwhile service”

“I was a bit sceptical before inviting consumers but now am convinced their input enhances the comprehensiveness and credibility of our research

“I had been led to believe by other researchers that consumer involvement was something to be resented or at best tolerated, however my experience has been overwhelmingly positive”

Consumer Involvement in Research (CIR): Does it work?

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ABSTRACT

Cancer Voices (CV) recognises the value of consumer involvement in both research and research funding decisions. In recognition of this value, CV developed a Consumer Involvement in Research (CIR) program which matches trained consumers to interested researchers, and it is believed to be the first program of its kind in Australia. This paper aims to evaluate the effectiveness of the Consumer Involvement in Research Program after ten years of implementation, and to briefly examine the current landscape of consumer involvement in cancer research funding in Australia. The results of both will inform the fine-tuning of CV's future direction in its continual efforts to increase consumer involvement in research and its funding.

Method

Consumers and researchers who have participated in the CIR program were surveyed separately about their experiences, views and recommendations regarding the program. The online surveys were created, and the results were analysed, by Survey Monkey (<http://www.surveymonkey.com>) in April 2016. CV also wrote to seven major cancer research funders seeking information about their degree of consumer involvement in research

Key Results

Of the 80 consumers and 70 researchers surveyed, 49 (61%) consumers and 44 (63%) researchers responded. Almost all researchers (95%) regarded the contribution made by the consumers to the research project as highly valuable. A majority of the researchers (60%) noted that consumers played a significant role in shaping research direction and helped researchers gain a deeper understanding of the consumer perspective. In particular, 80% of researchers agreed that the consumer provided insight into issues that were important to the community. Several researchers indicated that consumer involvement enhanced the comprehensiveness and credibility of their research. Some commented that they would like access to a broader range of consumers

Similarly, most consumers (80%) felt they were able to offer advice to ensure the research project would benefit consumers. Some consumers (19%) did not feel valued because they had received little feedback from the researchers as to the value of their contribution and the research's progress. In regards to the training course, 88% of the consumers felt that the CIR training course prepared them for their role in research. Their comments included a need for more time to share experiences

with other consumers, an annual refresher course, and more opportunity to network with other consumers.

Responses were received from five of the seven cancer research funders contacted. Only three of the five have the requirement that grant applicants show evidence that they had engaged with consumers and would continue to do so if funded. Four funders include at least two consumers on their Grant Review Panels, one of which, the CCNSW, has a Consumer Review Panel which provides 50% of the total rating.

Conclusions

CV's CIR Program is highly valued by both researchers and consumers. The high response rate to the surveys of over sixty percent supports the importance of the program to both parties, and to the benefit of the research itself. The results of the two surveys will help CV refine the matching process and its associated training course.

Further, CV recommends that a more in depth study be made of cancer research funders' practices regarding meaningful involvement with consumers, both within Australia and internationally, to encourage more cancer research funders to appreciate the benefits of consumer involvement in research.

BACKGROUND

Cancer Voices NSW provides the independent voice of people affected by cancer in NSW to improve the cancer experience of the over 40,000 people who are diagnosed each year. Established in 2000, we are active in the areas of diagnosis, information, treatment, research, support and care. To achieve this we work in partnership with decision makers and providers of these services, ensuring the patient perspective is heard from planning to delivery.

Since establishment Cancer Voices has recognised the value of, and need for, a process whereby informed, preferably trained cancer consumers can add value to cancer research. This recognition is based on the core principle that those affected by the research have a right to have their say on what and how research is conducted, which is reflected in international best practice in this area. In Australia, especially in New South Wales, this is now a free service to cancer researchers which can be accessed via our website www.cancervoices.org.au. The service, originally developed in collaboration with Cancer Council NSW (CCNSW), facilitates access by researchers to informed, trained consumers. The process has been documented by four peer reviewed publications [1,2,3,4].

Evidence shows that consumer involvement in research is beneficial, and there has been increasing requirements for consumer involvement from research funders [5]. Yet, there is little or no evidence of the benefits of a process for facilitating such direct consumer involvement with researchers. Anne Mackenzie et al [6] reported in their study the benefits of providing training workshops for researchers to increase awareness of the value of consumer involvement. This UK influenced program takes a different approach to our Consumer Involvement in Research Program, as it does not offer a process for connecting researchers to informed consumers, nor prioritises the need for consumer training to enable their effective involvement. Cancer Voices believes that the CIR

Program addresses these gaps, by evaluating the benefits of the CIR matching process and its lessons for training.

To implement our policy outlined above, the Cancer Voices Consumer Involvement in Research (CIR) Program was developed to enable informed consumer input into cancer research. Cancer Voices worked in collaboration with the CCNSW to develop an annual face-to-face training course. Following this one to two day course, trained consumers may be matched with requesting researchers, and also participate on Grant Review Panels. This study has not evaluated experiences of the latter. Cancer Voices provides a free service to researchers through the “*Request a Consumer Representative*” electronic form on its website, <http://www.cancervoices.org.au>. The form seeks all the necessary information to enable Cancer Voices to nominate suitable consumers to meet the researchers' requests. Matched consumers and researchers each receive a Guide which outlines their respective roles and responsibilities, as an aide memoire.

Our principal objective was to gauge the value of the CIR Program for both consumers and researchers, through an online survey of experiences, both positive and negative. All survey recipients had used our matching service. This is the first formal evaluation of the program after a decade of implementation.

Our second objective was to collate information on the requirements of consumer involvement from major cancer funding organisations in Australia, including what level of evidence of consumer involvement is required, and what weight, if any, is given to consumer involvement in final grant approval processes.

The outcome of both investigations will shape future interactions with consumers and researchers, fine tune the existing CIR process and its associated training course, and hopefully encourage those research funders who have yet to understand the value of partnering with consumers to rethink their approach.

We see substantial transitional potential for the CIR Program and process to be implemented beyond NSW, and indeed beyond cancer. Cancer Voices' CIR Program is a positive and practical example of implementing the best practice principles of the now well accepted “Partnering with Consumers” concept.

METHOD

Part 1: Consumers in Research Survey

Two parallel questionnaires, one for researchers (Appendix A) and one for consumers (Appendix B), were developed by Cancer Voices to elicit answers to five questions each about experiences, views, and recommendations. The online surveys, created using Survey Monkey (<http://www.surveymonkey.com>) in April 2016, were sent to participants by email with three further reminders. A list of researchers and consumers was compiled using data from the CIR matching service database of trained CIR consumers. It included all consumers and researchers who had been matched throughout 2015 and 2016, and who were actively engaged in the CIR program during this period. A total of 80 consumers and 70 researchers were identified to be familiar with the matching service and had all worked with either a research project and/or on a grant review panel. These

researchers and consumers were contacted by email through Survey Monkey. The data were collated by Survey Monkey and formatted as graphs and written comments.

Part 2: Consumer in Research Funding

Cancer Voices also wrote to seven cancer research funders in Australia outlining the CIR Program and noting that we were principally looking at NSW which is where our service has been primarily focussed. Five of these are major national funders. We advised research funders of the information we wished to collect via two questions and that this would be analysed and presented publicly.

RESULTS

Part 1: Consumers in Research Survey

Of the 80 consumers and 70 researchers surveyed, a total of 49 (61%) consumers and 44 (63%) researchers responded. The time of response was staggered, with a response to the first email being 24 consumers and 19 researchers. Following two further email reminders, a further 9 consumers and 6 researchers completed the survey. Finally individually addressed web link emails were sent to those who had not completed the survey. 16 consumers and 19 researchers completed the web link reminder.

The survey was undertaken by both new and more experienced consumers and researchers. Thirty-eight percent (38%) of researchers had worked with consumers on three or more projects (see Appendix A - Question 5). Similarly, thirty-eight percent (38%) of consumers had worked on three or more projects (see Appendix B - Question 5).

Views on the value of CIR

Almost all researchers (95%) regarded the contribution made by the consumers to the research project as highly valuable, with only 5% of researchers believing there was little input to the project due to the difficulty of finding roles for consumers in the early stages of complex research. They found interacting with consumers to be inspiring and motivating as the consumer confirmed the positives about their research. Seventy-two percent (72%) of researchers stressed that consumers played a major role in their research, citing the value of a personal connection with cancer, and that they were well informed and highly committed. Consumers' input helped researchers to refocus key clinical metrics for their projects (Appendix A - Question 1). One researcher reflected that it is difficult for consumers to contribute to basic science projects. (Appendix A - Question 6)

Consumers emphasised that the amount of value they could bring to the project depended on the type of project and the inclusivity of the projects' leaders. There was a strong consensus that their contribution was valuable, with 60% of consumers ranking their contribution from highly valuable to extremely valuable. The consumers brought to the project an awareness of the patient and the wider world, and their input was welcomed and integrated. Only 19% of consumers questioned their value to the projects as they had received little feedback from the researchers as to their contribution and how the research was progressing (Appendix B - Question 1). Less than half of the

consumers (42%) were kept informed about the progress of the project. Some researchers failed to communicate with their consumer at all (Figure 2, and Appendix B - Question 3).

The majority of researchers (60%) stated that the consumer's discussions and suggestions helped them to focus their research direction (Appendix A - Question 2). They helped align the project aims with clinical outcomes of value to the patients and their personal experiences helped the research teams to have a deeper understanding of the study from the consumer perspective. In one project the consumers' input was regarded as essential as to how information would be provided to the public.

Most consumers (80%) felt they were able to offer advice to ensure the research project would benefit consumers (Appendix B - Question 2). Their contribution was varied. Some felt they were able to ensure the broad views and priorities of people affected by cancer were addressed by the project. Others felt they made contributions so that the project was more useful for meeting patients' needs. Other contributions mentioned were the ability to give the perspective of consumers in rural and regional areas and the associated issues and allowing younger researchers to actually talk to someone who had experienced cancer. Two consumers believed their contribution was only sought so that the researcher could 'tick the box' to show that they had engaged with consumers to receive funding or that the researcher didn't seem to consider the views offered relevant. A suggestion was made that projects might be monitored to ensure the consumer perspective continues to be used by the researcher.

Most researchers (89%) confirmed that the consumer provided insight into issues that were important to the community and patients, whilst only 38% of researchers believed the consumer was valuable in identifying and prioritising research issues. The majority of researchers (60%) agreed that the consumer exposed aspects in their research that needed further thought and development (Figure 1, and Appendix A - Question 3). The majority of consumers (70%) indicated that the researchers were responsive to their suggestions and 80% believed the researchers respected their skills, knowledge and experiences (Figure 2, and Appendix B- Question 3).

Figure 1. Distribution of responses to Question 3 of researchers' survey.

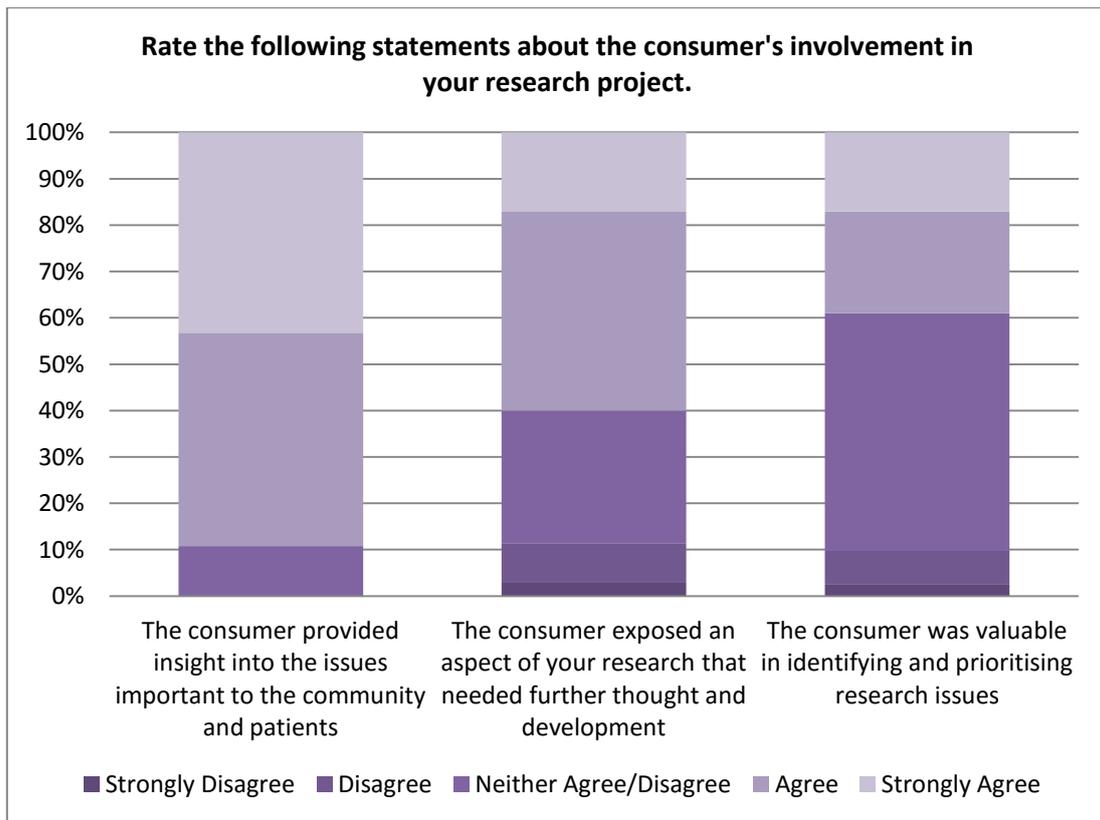
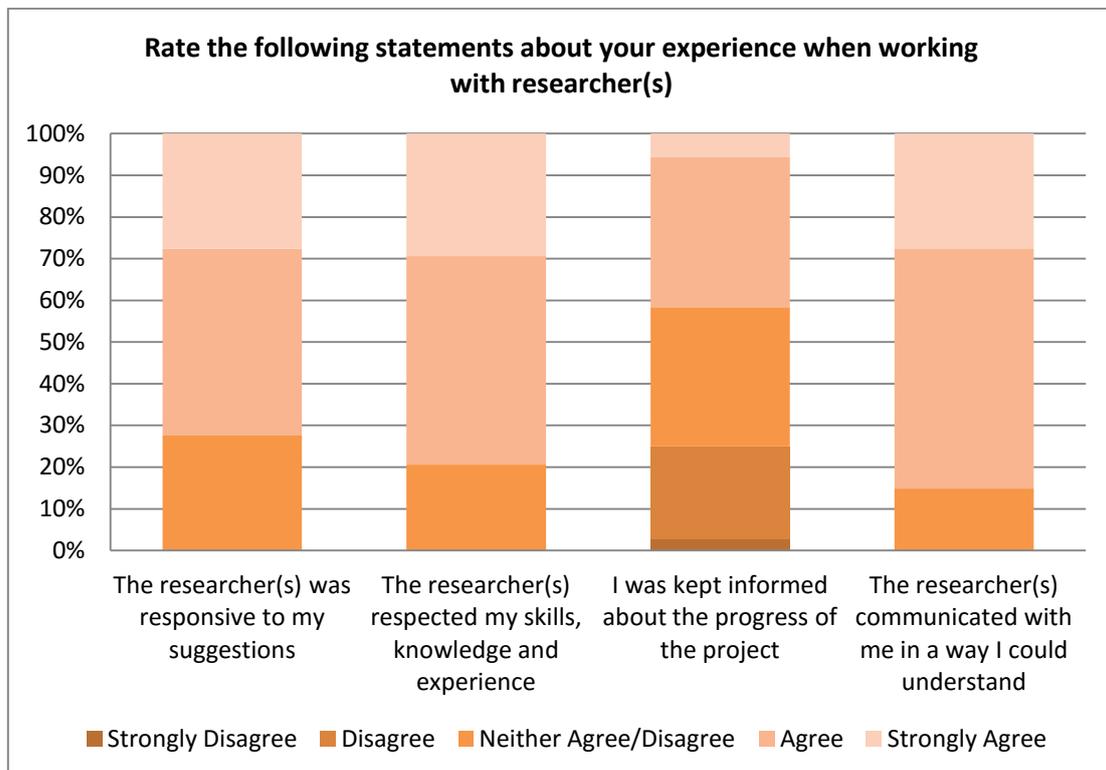


Figure 2. Distribution of responses to Question 3 of consumers' survey.



There were many positive written comments from researchers indicating that the consumers' involvement enhanced the comprehensiveness and credibility of their research. Some of these comments include:

The consumers ensured that important issues were not overlooked. They assisted the researcher to focus on research that benefited cancer patients and prioritise what was most relevant to do, not what was more easily do-able. Prior to working with consumers some researchers were sceptical, and others were told by colleagues that consumer involvement was something to be tolerated. However, their experiences have been overwhelmingly positive and they would make sure they include consumers in all future projects. One researcher believed that practising clinicians, who deal with cancer patients on a daily basis, do not need to involve consumers in their research, as their research is fashioned by their experience.

Views on the CIR Training

Eighty-eight percent (88%) of consumers believed that the training courses run by the CCNSW prepared them for the role (Appendix B - Question 4). They commented that the course covered all aspects of research and utilised very good strategies that were workshopped to ensure the consumer could work in a collaborative way with the researchers. Others felt that the one day version of the course was inadequate as there was no sharing of experiences with other consumers. Several consumers undertook the training several years ago and are now involved in projects where the research style has changed. They feel it is now more genetics based and as a result, understanding the language and terms used can be difficult. Overall, there were many consumers who would like to undertake a refresher course, update their knowledge, and share their experiences with other consumers. It was suggested that the training also includes examples of grant proposals that were outstanding and were successful in obtaining funding. One consumer felt training was too late in the year.

While all the researchers felt they did not need further Cancer Voices support to ensure productive involvement of the consumer in their research, 12 researchers qualified their answers with comments. (Appendix A - Question 6) One felt it would be good to identify a role for consumers in the very early stages of research where the idea is very new and technical. Another asked for help in establishing a focus group and to establish dialogue with the target audience. Some researchers reported that they would like access to a broader range of consumers, namely those identifying as Aboriginal/Torres Strait, the LGBTI community and those living in remote rural, and regional communities. Many researchers commented that they appreciated the CIR service and the speed at which consumers are matched to their research project.

When consumers were asked whether they would like more support or training for future research involvement, 33% of consumers agreed (Appendix B - question 6). They requested suggestions on how to assist researchers other than when they are writing applications. Of all consumers who provided comments, 11 consumers indicated that they would like a refresher course where they could share ideas and experiences with other trained consumers annually (Appendix B – Questions 6 & 7). It was suggested that consumers could have an update on the latest research trends, compare notes and offer suggestions about how to work with researchers on a variety of projects.

Part 2: Consumers in research funding

A total of seven cancer research funders (“funders”) were contacted by email or letter. Five funders responded, namely Cancer Council NSW, Cancer Australia, National Breast Cancer Foundation, National Health & Medical Research Council, and Cancer Institute NSW. Two funders, namely the Prostate Cancer Foundation of Australia and the Cancer Research Foundation, did not respond.

The first question asked each funder about the existence of requirements of grant applicants to show evidence that they have engaged with consumers in developing their grant applications and would continue to do so if funded. It was answered in the positive by The CCNSW, Cancer Australia and the National Breast Cancer Foundation. The National Health & Medical Research Council asks for such evidence but it is not a mandatory part of the grant application, that is, a lack of response will not impact assessment.

The second question asked if the funder had initiated consumer review of potential grant recipients as part of the decision-making process. It was answered positively by the CCNSW, National Breast Cancer Foundation, Cancer Australia and the Cancer Institute NSW. These included at least two consumers on their Review Panels, with the CCNSW standing alone in having a Consumer Review Panel (consumers only) which provides 50% of the total final rating scores.

Table 1. Summary of responses by cancer research funders re CIR.

Funder	Require evidence of consumer engagement?	Consumer review of grant applications?
Cancer Council NSW	Yes, mandatory	Consumer Review Panel (50% of total rating)
Cancer Institute NSW	No	At least 2 consumers on Review Panel
National Breast Cancer Foundation	Yes, mandatory	At least 2 consumers on Review Panel
Cancer Australia	Yes, mandatory	Yes
National Health & Medical Research Council	Yes, not mandatory	No
Prostate Cancer Foundation of Australia	No response	No response
Cancer Research Foundation	No response	No response

DISCUSSION

Cancer Voices NSW recognises the benefits of consumer involvement in research and funding decisions, and that there is increasing evidence that researchers and research funders are of the same view and are interested in accessing them. In support of this, Cancer Voices NSW in collaboration CCNSW developed the CIR program a decade ago to facilitate consumer involvement in research by providing training to consumers and matching interested researchers with them.

The evaluation of this CIR program as well as the comparison of the level of consumer involvement in research funding decisions by some of the major Australian cancer research funders is very informative. We understand that this is the first time the experiences of CIR in practice have been evaluated. While the CIR program has received positive feedback from both researchers and

consumers, the overall response received from cancer funders was somewhat disappointing. This project identified some of the benefits of consumer involvement in research and areas for improvement and expansion in both areas.

The following comments received from the survey will help the fine-tuning of the CIR program, in particular, and will influence future interactions with researchers and consumers:

Researchers' comments:

- Researchers value the CIR matching process run by Cancer Voices and are impressed by the speed with which they were connected with a consumer with relevant experience.
- They emphasised that consumers provided valuable input and they look forward to working with consumers in all future projects.
- One requested consumers who represent the issues and values of the socially disadvantaged patients, another asked for those who identify as LGBTI and two researchers requested consumers who have an understanding of the difficulties of living in remote rural locations.
- Two researchers indicated that they needed access to trained consumers who identify as of Aboriginal or Torres Strait heritage.
- One would also like help in organising a focus group for consumers.

Consumers' comments:

- Many consumers reflected how much they enjoy working with the researchers and believe researchers need support for keeping a focus on the end result.
- They enjoy the opportunity to make a contribution to cancer research.
- Several have seen the CIR program grow throughout the ten years from being a good concept to a very well regarded and accepted service to connect researchers to informed consumers to add value to their research.
- There were requests to have more opportunities to work with researchers.
- Consumers were not always kept in the loop of what was happening in the research project.
- Consumers would like to be updated on research developments, share suggestions and ideas as a group and to be able to network with each other.

The results from the cancer research funders, although somewhat disappointing, do show awareness of the value in varying degrees of consumer involvement in decision making about which grant applications will be funded. Only the CCNSW has developed the implementation of true consumer involvement in research through its Consumer Grant Review Panel to the level that Cancer Voices would regard as best practice to date. This may be due to the partnership, initiated by consumers, enjoyed by the CCNSW and Cancer Voices NSW since the early 2000's in this area.

RECOMMENDATIONS

The recommendations made by researchers and consumers in the surveys, as well as responses received from cancer research funders, will help to shape Cancer Voices' future direction in its efforts to increase consumer involvement in research and research funding in the following ways:

- In collaboration with CCNSW, consider additional content for future training courses for consumers.
- Increase communication with researchers throughout the CIR matching process to ensure that they keep in contact with their matched consumers throughout the length of the project.
- Offer consumers more opportunities as requested, Cancer Voices will also enhance awareness of how they can be involved in other areas of CV advocacy as an adjunct to the CIR program.
- Run a refresher workshop for consumers to be updated on research developments, for sharing of suggestions and ideas and for consumer networking.
- Work with CCNSW to ensure a broad cross section of interested consumers undertake future training courses.
- Seek ways to enable trained consumers to attend cancer research related conferences to update their knowledge base.
- Conduct a more in depth study of cancer research funders' practises regarding meaningful involvement with consumers.

CONCLUSIONS

Cancer Voices' Consumer Involvement in Research (CIR) Program is highly valued by both researchers and consumers. The very high response rate to the surveys, over 60%, indicates the importance placed on the program by both researchers and consumers who have been involved with the CIR program. Researchers commented that *'they know the valuable input consumers can have on research and have always worked with consumers'*. Others who are new to CIR stated that *'the feedback from consumers was extremely valuable and they will ensure they get consumer involvement for all future projects'*. The consumers enjoy working with the researchers and *'hope they can continue to contribute in a positive way'*.

The results of the two surveys will help Cancer Voices refine the matching process and its associated training course, and will shape future interactions. They may also assist other CIR Programs and processes to become established and accepted throughout the research community..

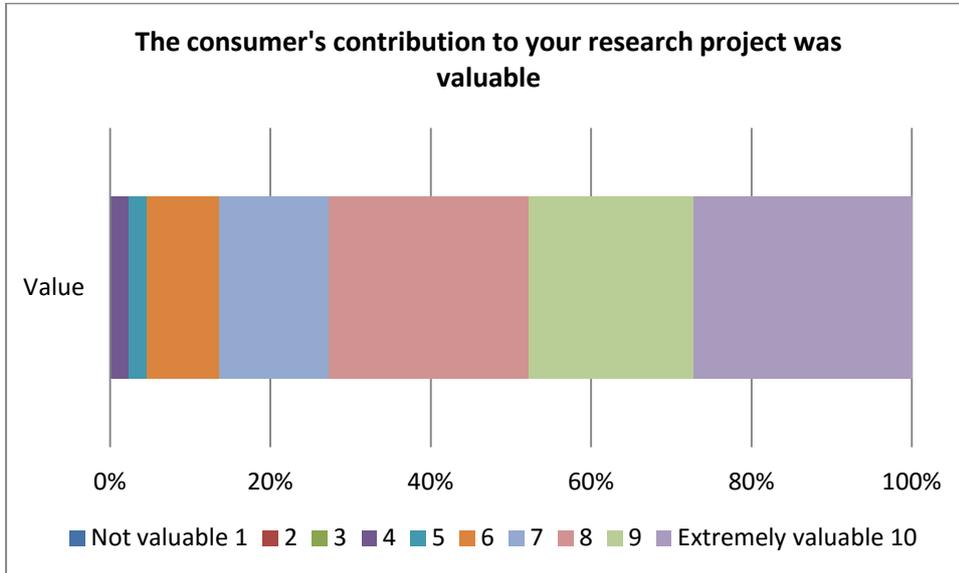
REFERENCES

1. Saunders C, Crossing S. *Towards meeting the research needs of Australian cancer consumers*. BMC Res Notes. 2012 Dec 3;5:667. DOI: 10.1186/1756-0500-5-667.
2. Saunders C, Girgis A, Butow P, Crossing S, Penman A. *From inclusion to independence--training consumers to review research*. Health research policy and systems / BioMed Central 6: 3, 2008.
3. Saunders C, Girgis A, Butow P, Crossing S, Penman A. *Beyond scientific rigour: Funding cancer research of public value*. Health Policy 84: 234-242, 2007.
4. Saunders C, Crossing S, Girgis A, Butow P, Penman A. *Operationalising a model framework for consumer and community participation in health and medical research*. Australia and New Zealand health policy 4: 13, 2007.
5. Staley K. Exploring Impact: Public involvement in NHS, public health and social care research. 2009. INVOLVE, Eastleigh. Viewed at http://www.invo.org.uk/wp-content/uploads/2011/11/Involve_Exploring_Impactfinal28.10.09.pdf
6. McKenzie A, Alpers K, Heyworth J, Phuong C, Hanley B. *Consumer and community involvement in health and medical research: evaluation by online survey of Australian training workshops for researchers*. BMC (2016) 2:16 DOI 10.1186/s40900-016-0030-2

APPENDICES

Appendix A: Consumers in Research - Researchers' Survey

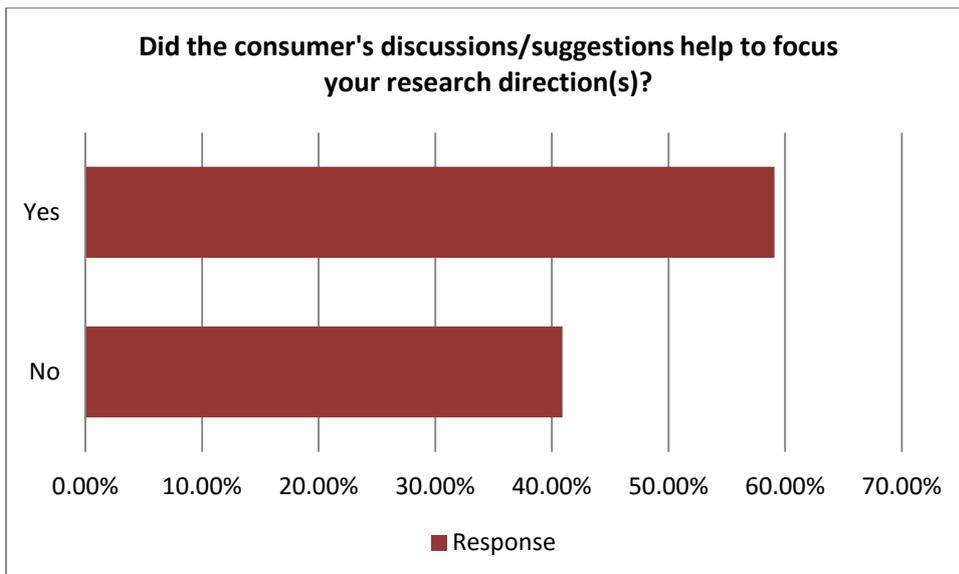
Question 1



Responses - 44

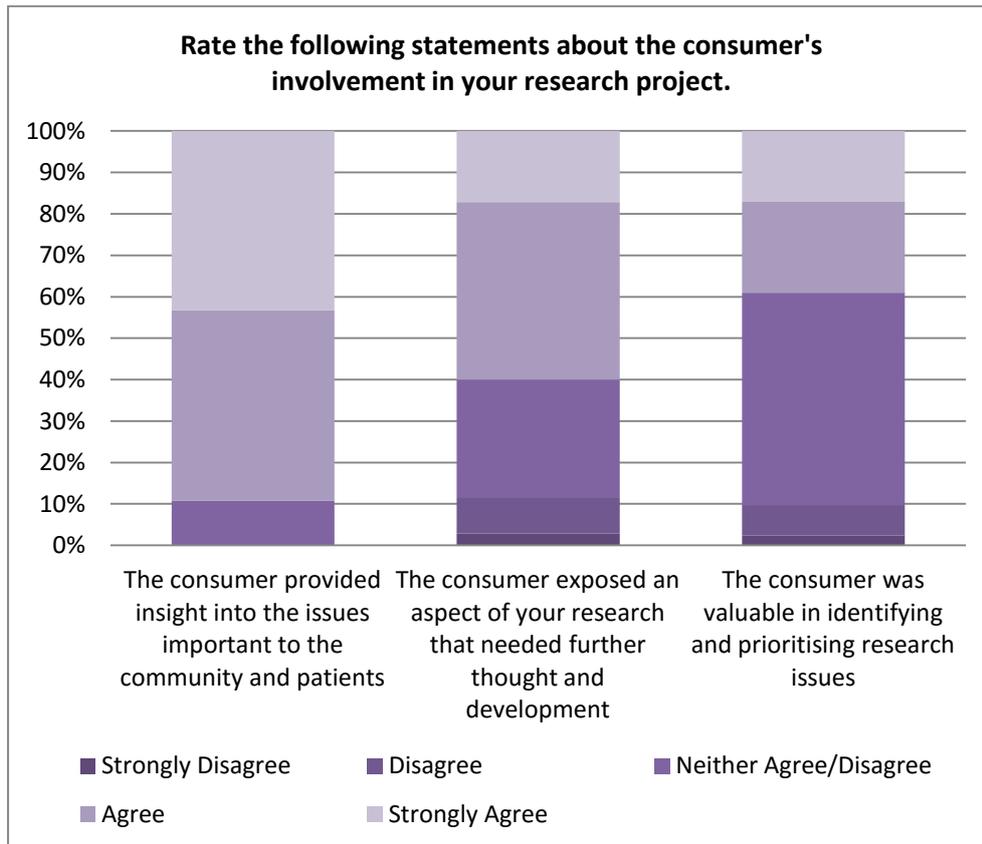
Comments – 16

Question 2



Responses - 44

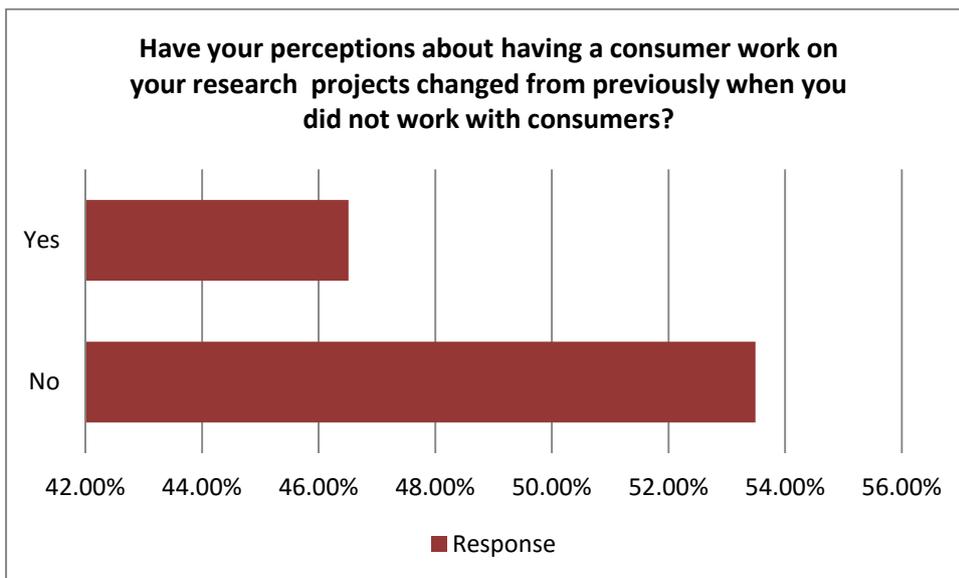
Question 3



Responses - 44

	Strongly Disagree	Disagree	Neither Agree/Disagree	Agree	Strongly Agree
The consumer provided insight into the issues important to the community and patients.	0%	0%	10.81%	45.95%	43.24%
The consumer exposed an aspect of your research that needed further thought and development.	2.86%	8.57%	28.57%	42.86%	17.14%
The consumer was valuable in identifying and prioritising research issues.	2.44%	7.32%	51.22%	21.95%	17.07%

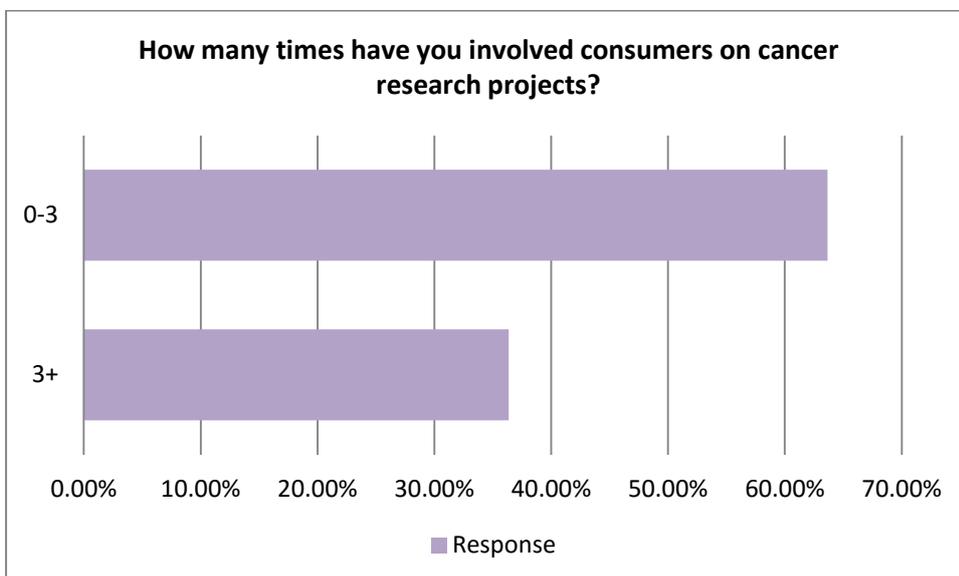
Question 4



Responses - 44

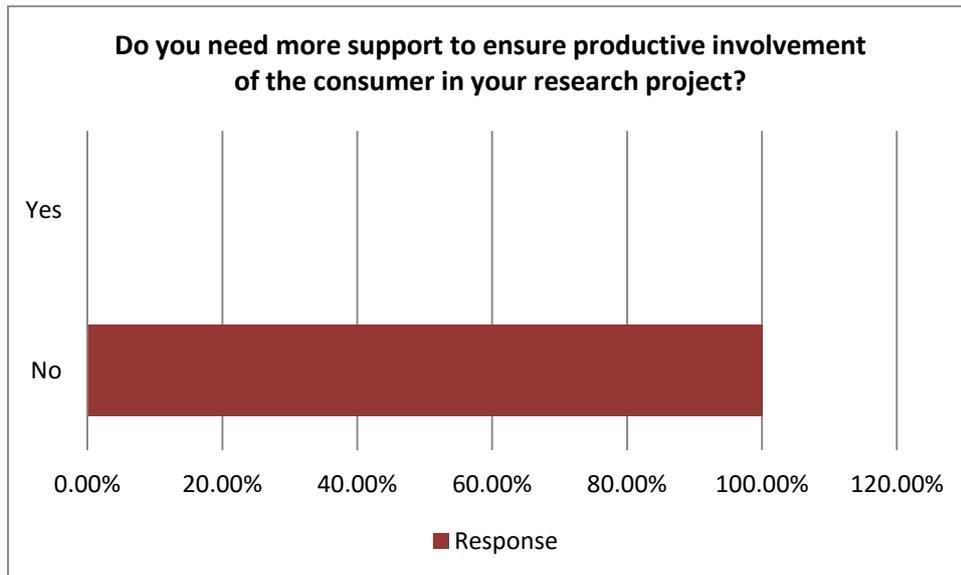
Comments - 22

Question 5



Responses - 44

Question 6



Responses - 44

Comments - 12

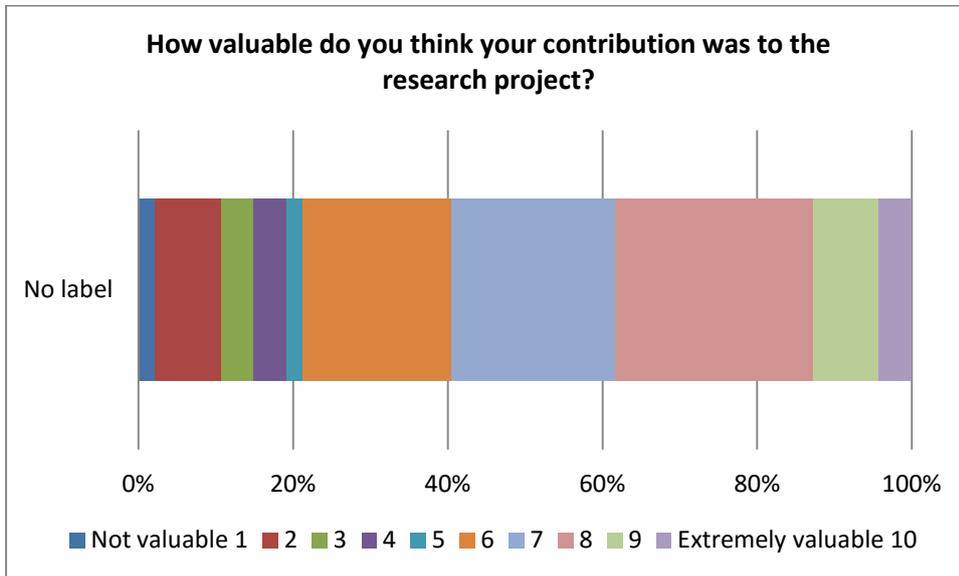
Question 7

Do you have any other comments, questions or concerns?

Comments - 19

Appendix B: Consumers in Research -Consumers' Survey

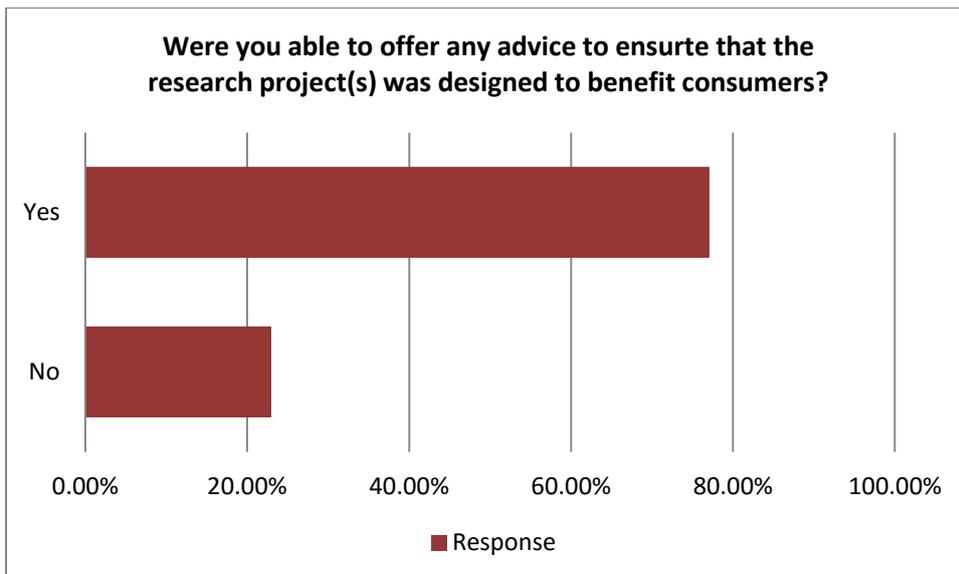
Question 1



Responses - 49

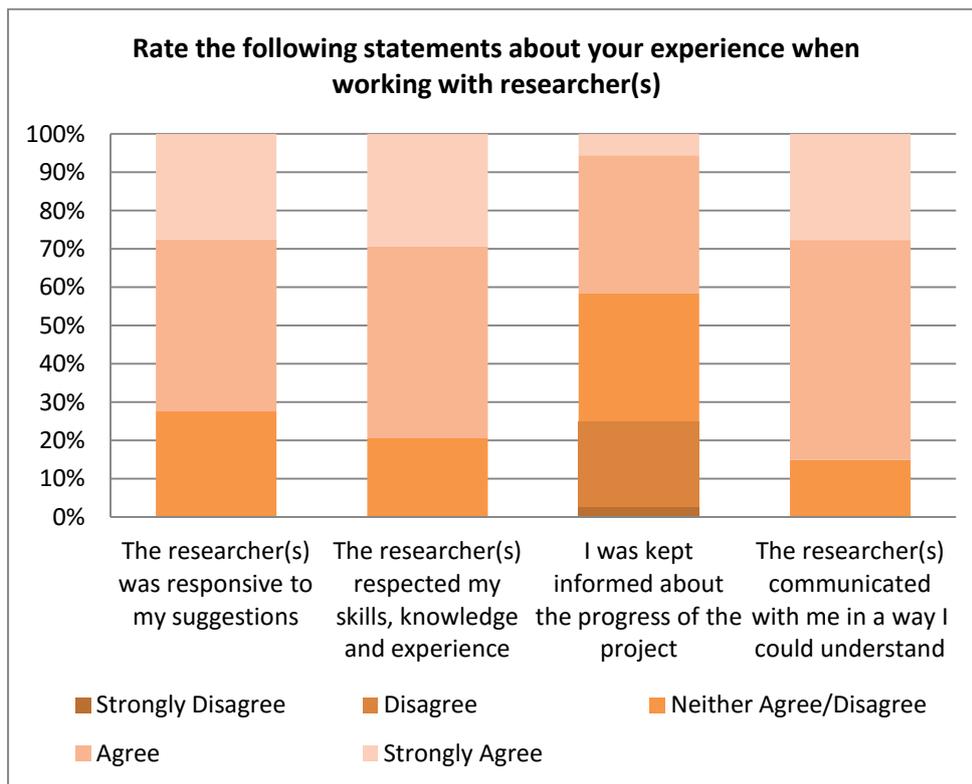
Comments - 24

Question 2



Responses - 49

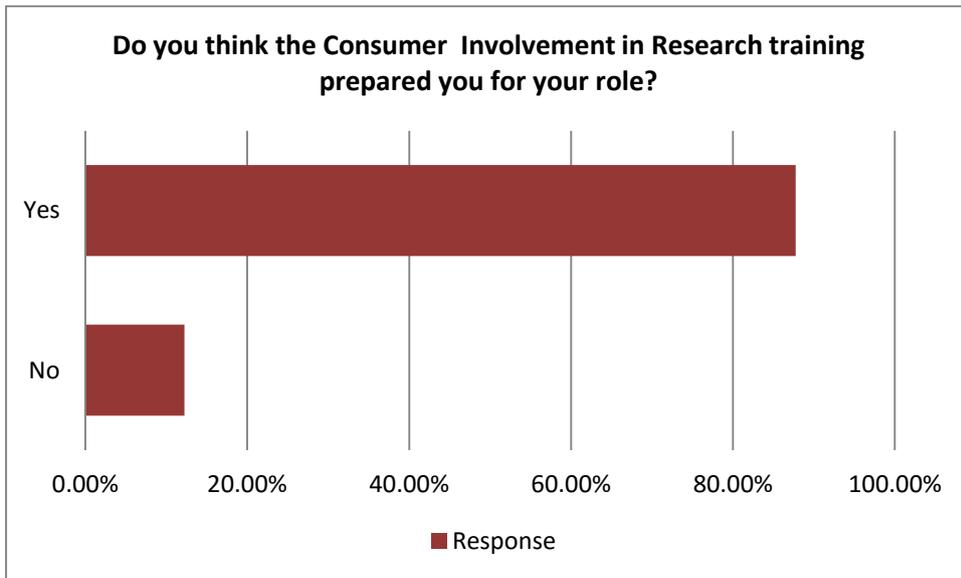
Question 3



Responses - 49

	Strongly Disagree	Disagree	Neither Agree/Disagree	Agree	Strongly Agree
The researcher(s) was responsive to my suggestions.	0%	0%	27.59%	44.83%	27.59%
The researcher(s) respected my skills, knowledge and experiences.	0%	0%	20.59%	50.00%	29.41%
I was kept informed about the progress of the project.	2.78%	22.22%	33.33%	36.11%	5.56%
The researcher(s) communicated with me in a way I could understand.	0%	0%	14.89%	57.45%	27.66%

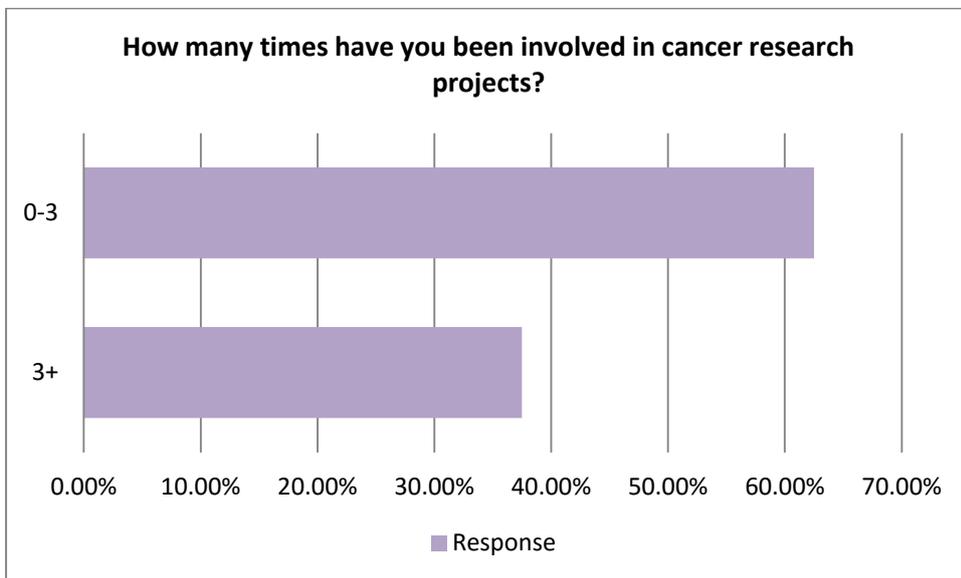
Question 4



Responses - 49

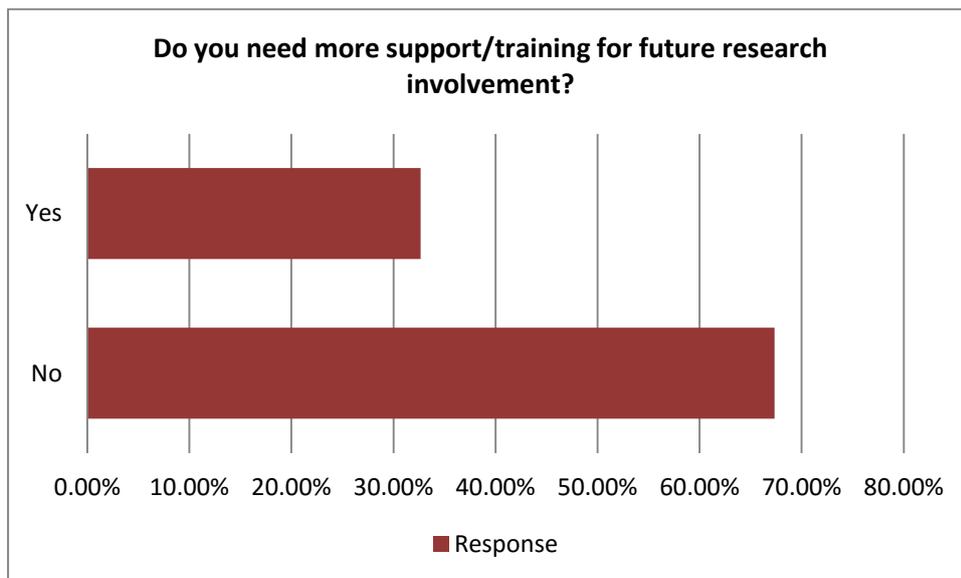
Comments - 6

Question 5



Responses - 49

Question 6



Responses - 49

Comments - 16

Question 7

Do you have any other comments, questions or concerns?

Comments - 28