

Beyond scientific rigour: Funding cancer research of public value

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Abstract

Objective: To identify the values deemed by cancer consumers and community members to be important in judging research, and develop an appraisal instrument for the inclusion of consumer and community values in cancer research funding decisions in an independent review process.

Background: Improvement in the level and quality of consumer involvement in research processes is becoming increasingly recognised as an important area of development in research governance. It was identified that while the current practice of selecting research based on scientific merit satisfies the need to fund research with the best scientific quality and potential for success, this may not necessarily satisfy all the needs and expectations of cancer consumers and the wider community.

Methods: A research team was established to undertake the qualitative study. A combination of focus groups and semi-structured in-depth telephone interviews were conducted to collect and verify information about the values held by cancer consumers and the wider community with regard to research.

Results: Consumer review criteria to guide consumers in judging the value of research, optimal rating scales to use with these criteria and views on how consumer needs should be incorporated into the process of judging and allocating research grants (e.g. the relative weight that should be given to scientific and consumer review) have been formally identified by this research.

Conclusions: The findings of this study clarify consumer and community values regarding cancer research funding and offer a means to evaluate research that address these values.

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1. Introduction

Consumer involvement in cancer research is becoming more established with an increasing number of cancer research funding organisations in the US, UK and Australia making this involvement a requirement of research grant applications [1–5]. Regulatory change is further driving the trend for consumer involvement in cancer research the US [6]. A growing number of researchers and advocates for greater consumer involvement argue that research which effectively involves consumers will better serve the needs of society [7–12]. On becoming involved in research, consumers want ongoing meaningful involvement, which is supported by objective useful information to help them contribute [13].

Most progress in consumer involvement in cancer research has been made in consumers being given an ‘advisory role’, largely through membership on research project planning committees [2,7,14]. There are a number of opportunities where people affected by cancer are involved in the scientific peer review of cancer research applications [2,15–18]. Responsibilities of consumers on these review panels varies but can include providing advice on areas such as the expected willingness of patients to participate in the research and the readability of participant information [17], where it has been evaluated, consumer involvement on scientific review panels has not been shown to alter which research gets funded [14,19].

While a selection of research based on scientific peer review satisfies the need to fund research with the best scientific quality and potential for success, it may not necessarily satisfy all the needs of cancer consumers (cancer patients/survivors) and community members (general public). To date, there have been no published studies that determine the viewpoint of cancer consumers and community members on what is important to them with regard to making cancer research funding decisions. Consequently, this study seeks to identify aspects that are important to cancer consumers and community members that may not be routinely considered in scientific peer review. The aim of the study is to develop an objective research appraisal tool for use by cancer consumers in an independent review process designed to follow scientific peer review, for a major cancer research funding organisation in Australia—the Cancer Council of New South Wales (NSW).

2. Methods

2.1. Sample

Self-selected participants were drawn from three sources: (1) *Cancer Voices NSW*, the peak independent cancer consumer advocacy organisation in New South Wales, Australia, (2) a list of non-commercial financial donors to the Cancer Council NSW and (3) the general community. Eligibility criteria included being aged 18 years or over, resident of NSW and having sufficient command of the English language to allow comprehension and completion of the study materials.

2.2. Procedure

A research advisory committee of 14 people was formed to set the direction of the overall project. This was chaired by an experienced consumer representative and included researchers with behavioural, psychosocial and basic science expertise as well as consumers and members of the general public. The project research team included two researchers with a significant track record in behavioural and psychosocial research, one consumer (chair of the advisory committee), and a senior staff member of the Cancer Council NSW with experience in policy development. Community participants were recruited through newspaper advertisements. Members of the other two groups were invited through newsletter articles and letters mailed directly to them on behalf of the researchers by the organisations who held their lists (*Cancer Voices NSW* and *The Cancer Council NSW*). Self-selection was judged to be appropriate since consumers judging future research funding applications for the Cancer Council NSW would also self select, and it was thought that these individuals might have more considered views about research and research funding priorities. Consenting participants were invited to participate in either phase 1 or 2 of the study. Phase 1 involved gathering consumer and community views and perceived priorities for judging research through structured focus group discussions. In phase 2, draft review criteria and rating scales, to be used by consumers to rate research grant applications, were developed and pilot tested through two discrete rounds of semi-structured telephone interviews.

2.2.1. Phase 1: Focus groups

A trained moderator conducted each of the three focus groups comprising seven to ten individuals with nearly equal representation from each of the cancer consumer and community member groups. Participants were provided background information on the goals of research and the range of different research disciplines that commonly sought funding from the Cancer Council NSW i.e. basic, epidemiological, behavioural, clinical and psychosocial. A purpose designed focus group protocol was used in all three groups to guide questioning. The protocol included specific probes for example: “What do you want from cancer research?” “What do you think makes a good research project?” “Should research focus on the most urgent and serious health problems or any (all) health problems?” “Is the best research able to be immediately applied or will produce change in the long run?” “Is the best research cost-effective (small cost for big outcome) or should cost not be an issue?” “How should we incorporate consumer views into decisions about what research to fund?” For each area of agreement, participants were asked to identify ways each might be met by a research application and what scale they would like to apply e.g. 1–5 or 1–3 or good/bad. The focus groups were audiotaped and transcribed. One investigator (CS) took detailed notes of discussions.

2.2.2. Phase 2: Development and pilot testing of review criteria and rating form

An independent trained focus group moderator and a chief investigator (CS) conducted the content analysis of all focus group data to evaluate preliminary concepts, explore judgments and feelings in-depth, and identify recurring themes. Categories identified in the preliminary interpretation and a final agreed list of important themes were achieved iteratively through independently and then collectively re-reading, re-linking and re-segmenting transcript data. The themes and priorities generated from this process informed the development of the initial review criteria and rating scale.

Phone interview participants were mailed the 6-page project description from three de-identified research grant applications previously funded by The Cancer Council NSW, with the consent of the chief investigators; a lay summary of each grant, developed by the researchers, the draft review criteria and the draft

rating scale. The grants covered a range of research types: laboratory-based, psychosocial and a clinical trial. After completing the rating scales for the three grants, participants were asked to comment on the completeness, utility, content validity, acceptability and feasibility of the criteria and to provide general feedback about how they found the review process. Phone interviews were audiotaped, transcribed and content analysed. After one round of interviews, the criteria and rating scales were modified to include more detailed descriptors for each criterion and an expansion of options within the rating scales, and the process was repeated.

The study received ethics approval from the University of Newcastle’s Human Research Ethics Committee.

3. Results

Sixty-two people across NSW responded to the initial invitation to participate, with fifty-three people returning written consents. Unavailability and a ‘change of mind’ were the reasons given by non-responders on follow up. Twenty-seven participants were involved in phase 1 and twenty-six in phase 2. The number of participants from each sample group and their demographic characteristics are shown in Table 1.

3.1. Phase 1: Identifying consumer and community values to judge the value and merit of research

All focus group participants felt the identification of consumer and community values to support research funding decisions was a valuable initiative. The majority felt that medical researchers performed a necessary and important function. They were aware of the challenges that researchers face such as the need to continually seek funding. Most were aware that important scientific discoveries are sometimes made serendipitously. The majority felt inadequately informed about cancer research or the results of recent research.

Four main themes concerning criteria for judging research emerged from the discussion. Participants considered the different types of research from laboratory through to clinical and psychosocial, and were

Table 1
Demographic characteristic of the research participants

	Focus groups (n = 27)			Interviews (n = 26)			All (n = 53)
	*1	*2	*3	1	2	3	
Gender							
Male	4	2	3	2	1	1	25% (n = 13)
Female	7	3	8	10	5	7	75% (n = 40)
Age ranges (years)							
Male		39–73			44–70		39–73 \bar{x} = 49
Female		32–74			39–78		32–78 \bar{x} = 54
All		32–74			39–78		32–78 \bar{x} = 51
Current marital status							
Married		10			14		45% (n = 24)
De facto or living with a partner		3			2		9% (n = 5)
Separated or divorced		5			2		13% (n = 7)
Widowed		2			3		9% (n = 5)
Never married or single		8			5		24% (n = 13)
Highest level of education							
Secondary school		8			5		24% (n = 13)
Certificate or diploma		8			7		28% (n = 15)
University degree		12			14		49% (n = 26)
Employment status							
Paid full-time employment		9			8		32% (n = 17)
Paid part-time employment		3			4		13% (n = 7)
Self-employed		9			12		
Retired, not working							40% (n = 21)
Household duties							
Student		1			1		
Volunteer		2			1		4% (n = 2)
Not employed—disabled							6% (n = 3)
Unemployed, looking for work							
Unemployed, not looking for work							
Country of birth							
Australia		24			25		92% (n = 49)
Other		3			1		8% (n = 4)

* (1) Consumers, (2) non-commercial financial donors of the CCNSW (a large proportion of financial donors have family/friends affected by cancer (*Cancer Council NSW Donor Information Database.*)) and (3) general public.

satisfied that the points raised in discussions were important across all types.

3.1.1. Extent of benefit

Participant support was greatest for research that could lead to tangible, long-term, sustainable and substantial benefits to people. Participants felt that these benefits could reasonably be derived from research that targeted any of, prevention, causation, treatment or alleviating suffering and that the more benefits to be had from any research, the better. It was strongly agreed that

research should lead to realistic solutions to problems that have an important impact on human lives (physical and mental health, welfare, dignity, social issues etc.). The number of people who might benefit from the research was seen as less important than the size of benefit.

“it (research) must improve lives, whether that is mental wellness, physical health or how a person is left to deal with the problem . . . like making sure treatment does not cause financial strife or more suffering”

3.1.2. Timeframe of and pathway to benefit

While tangible benefits of research was viewed as extremely important, the imminence of the benefit was seen as less critical, although many participants felt that the pace of progress in cancer research was often not rapid enough. Research closer to being clinically implemented was generally felt to be of higher priority than research that was years from application, but participants also felt that if any research could be shown to potentially lead to great benefit then it should be rated high. Of concern to participants was whether the steps to applying research represented significant constraints to achieving the actual benefits of the research. It was felt that researchers should identify this in research proposals.

“... one other question would be, what would be needed to go from the point that you’re hoping to reach, to application”[sounds of agreement]

3.1.3. Equity

Participants felt that everyone who could potentially benefit from research should be able to benefit and that no one group (gender, racial, ethnic, rural or socioeconomic group etc.) should miss out on the benefits of research if it is relevant to them. Unequal benefit of research was considered to be both unnecessary and unfair. Understudied groups and groups who carried a high burden of illness (such as spinal cancer sufferers) were also important equity issues for participants.

“... being available to rich and poor, country and city”

3.1.4. Consumer involvement

Another common view of participants was that consumers should be involved in the design and conduct of research.

“... the community must be in agreement with it, rather than just being the brainchild of one particular scientist”

It was also considered necessary that the results were communicated to consumers and community members in understandable language. This, it was felt, would also aid personal decision-making on health matters and boost support for cancer research.

Table 2
Preliminary criteria and rating scales

Preliminary criteria	Rating scale
1. Extent of benefit	Minor = 1 Moderate = 2 Substantial = 3
2. Timeframe for realising the benefit	No = 0, Yes = 1
3. Potential for application of findings	No = 0, Yes = 1
4. Equity	No = 0, Yes = 1
5. Consumer involvement	
(a) Development phase	No = 0, Yes = 0.5
(b) Ongoing involvement	No = 0, Yes = 0.5

Participants felt it was important that researchers were given plenty of opportunity to articulate how they think their research does contribute to satisfying consumer needs.

“... include a section in the application form ... and say, in assessing your submissions, as well as looking at the scientific merit, from this year they’ll also be looked at from the point of view and ... perspective of the layman”

3.2. Phase 2: Developing and piloting the review criteria and rating scale from identified consumer and community values

Ultimately, five categories, which served as the initial set of criteria, were identified from the focus group data (see Table 2).

Pilot study participants thought the draft criteria set reasonable expectations and could be easily met by researchers. Consumer involvement was considered less feasible for some types of research, such as laboratory-based, and it was recommended that allowance be made for this within the rating scales. On exploring the issue of communicating research results to consumers and community members, which had been identified from focus group data as an important aspect of consumer involvement, all participants felt that the transmission of research results should become a sixth criterion. It was suggested by several participants that a manual defining each criterion and providing examples would greatly assist the review process.

Participants felt that judgements against the identified criteria were not black and white and simple

Table 3
Final consumer review criteria and rating scales

Criteria	Range of scores ^a
<i>Extent of benefit:</i>	Nil (no information provided) = 0
Will the findings potentially have an important positive impact on human lives, including any of the following aspects: disease causation (identifying the biology of cancer and the fundamental mechanisms by which cancers arise), prevention, diagnosis; treatment; physical and/or mental and/or social wellbeing; quality of life, dignity, survival? When assessing this criterion, trained consumer reviewers may want to consider some or all of the following:	Minor = 1
• Has the researcher explained how the research will generate tangible benefit/s to human life?	Moderate = 2
• Has the researcher indicated the probability, magnitude, and/or duration of these potential benefits? • Does the research provide a number of benefits?	Substantial = 3
<i>Pathway for realising the benefit:</i>	Nil = 0
Is there a clear description of the steps required to reach the stated benefits of the research? When assessing this criterion, trained consumer reviewers may want to consider some or all of the following:	Moderate = 1
• Has the researcher provided a brief description of the broad steps or stages required to reach the stated benefits of the research?	Substantial = 2
• Do the steps or stages appear reasonable? • Are the steps or stages achievable?	
• Do the steps or stages represent significant constraints to achieving the actual benefits of the research?	
<i>Potential for application of findings:</i>	Nil = 0
Is there potential for real-world application of findings in the long-term? When assessing this criterion, trained consumer reviewers may want to consider some or all of the following: • Is it likely that the research findings will be able to be put into practice (in either the short, medium or long term)?	Moderate = 1
• Are there likely to be significant barriers to putting the research findings into practice?	Substantial = 2
• How compatible are the research findings likely to be with existing laws, public policy, resources etc.?	
• Where relevant, does the researcher include the groups they will work with to overcome barriers to applying research findings?	
<i>Equity:</i>	Nil = 0
Is there adequate justification for the selection of the study sample that demonstrates potential for equity, e.g. the research does not exclude groups who could potentially benefit from its outcomes, and/or it addresses an under-studied group and/or a group with a high burden of illness? When assessing this criterion, consumer reviewers may want to consider the following (the research is not required to meet all these expectations):	Moderate = 1
• Does the researcher explain how the findings could be generalised or applied to similar people outside the research?	Substantial = 2 (also includes if more than one option is addressed)
• Does the research have the potential to provide benefit across all relevant persons, groups and/or places?	
• Does the research address an under-studied group? • Does the research address a group with a considerable burden of illness?	
<i>Consumer involvement:</i>	No = 0, Yes = 1
(a) Development phase: have experienced consumers (e.g. from consumer or cancer groups) been involved during the development of the research proposal?	
(b) Ongoing involvement: is there a plan for ongoing consumer involvement in the research?	No = 0, Yes = 1
Is consumer involvement described? Have researchers identified the preferred approach of consumers for involvement in the research? Are there formal processes/structures in place that link the researchers with consumers?	
<i>Dissemination of results:</i>	No = 0
Is there a plan for circulating lay information about all research results to participants and/or the general community? Are there plans for consumers to be involved in the dissemination of research results?	Participants or the general community = 1 Participants and the general community (or community only where no human participants) = 2

^a Level of reasonable explanation given by the researcher in the funding proposal against each criterion.

‘yes’, ‘no’ options were found to be largely inadequate. Most felt the scoring ranges for all criteria should be expanded as they felt differences in research applications could be better discriminated if more scoring options were available.

In response to feedback, the criteria and scoring ranges were revised (see Table 3) and a set of plain English guidelines, which included descriptors of each criterion and application examples was developed. Second round interviewees felt the guidelines provided essential information that better supported the understanding and application of the review criteria.

Pilot study participants were asked about the weighting that should be given to the consumer review of grants compared to the scientific review. It was felt that as long as the research had already been checked for adequate scientific rigour and ethical aspects, consumer judgements should be given at least equal weighting. Several participants suggested that any discordance between consumer and scientific review should be resolved in open discussion.

4. Discussion

This study succeeded in clarifying consumer and community values regarding research funding and in developing a set of criteria that can be used by consumers to evaluate research, which address these values. The lack of existing similar instruments indicates the difficulty of the task of assessing the values held by consumers and community members on a complex subject such as research.

While there is now a growing need for researchers to explain how their research will be translated into practice, traditionally the success of obtaining research funding has been largely dependent on satisfying scientific merit requirements. This familiar peer review model remains the corner stone of assessing the scientific credentials of the individuals and institutions involved and the technical quality of the planned research, but it has many shortcomings as a standard for public value aspects. As the US Center for Science Policy and Outcomes noted: “When a focus on peer review (or any other such procedural mechanism) displaces deliberation about public value, it constitutes a public failure” [20]. The findings of this study offer a means of choosing among various research projects those of

measured consumer and community value, subsequent to selection based on scientific peer review.

A number of common barriers and challenges to consumer involvement in research have been previously noted including how to involve consumers in generating research funding recommendations, how to reduce the level of subjectivity in consumer involvement in funding decisions, and how to develop consumer confidence in this area [21]. This research goes a long way towards addressing these challenges. Important obstacles yet to be dealt with include gaining broad support from cancer researchers for consumer involvement and further developing consumer understanding of science, medicine and medical research. Improving consumer discrimination of mass media published cancer research information is also an important challenge to be tackled in the future.

The selection criteria identified by the research have intuitive appeal. They appear to be valid on face value. Further to this, the criteria generate reasonable expectations of research, they resonate with consumer and community members who have since been introduced to them, they can be practically described and identified in terms of assessment, and they help communicate, in an understandable way, what is most important to the people affected by cancer and other community members of NSW. They are similar to a number of those articulated in a recent publication describing collective, overarching Australian values [22].

By providing a means to explicitly include consumer and community values in research funding decisions and allow non-scientists to have a significant say in public investment in science, the findings represent an important starting point in recognising and acknowledging social disquiet and preferences with respect to research. Consumer and community valuation of research may also encourage researchers to take greater care in communicating their objectives in terms of linking research efforts to desired social outcomes.

5. Limitations

While the qualitative methodology used in this study is likely to be the most appropriate to gather enough information to support a full understanding of the attitudes and perspective of the participants and identify complicated thought processes, it has several limita-

tions. The most important of these is a lack of ability to broadly generalise the findings. The criteria identified in this study may not be constant as, while being reasonably stable, social values can change over time. Likewise, they cannot be viewed as a universal or ultimate set of social measures, as social values may differ across states and nations.

Other limitations include the difficulty to completely rule out ‘social desirability bias’, which may have led participants, especially those in the focus groups who were subject to group processes, to repress particular views on the issue, if they felt they were outside the general mode of thinking of other participants. Discussing and confirming focus group findings in the pilot test phase is likely to have minimised this influence.

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