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Consumer Engagement Guide
FOR RESEARCHERS

2020



<u>HOW OUR COMMUNITY NETWORK CAN HELP YOU</u>	4
<u>ALIGNING CONSUMER ENGAGEMENT WITH FUNDING BODY EXPECTATIONS</u>	6
<u>Strong engagement with consumers/key stakeholders</u>	8
<u>Consumer engagement responses to funders</u>	10
<u>RENUMERATION</u>	11
<u>Cost model for consumer sitting fees and hourly rate remuneration</u>	12
<u>GUIDE FOR GOOD ENGAGEMENT</u>	14
<u>Concept Development</u>	14
<u>Trial materials</u>	14
<u>Steering committees</u>	15
<u>Dissemination</u>	15



HOW OUR COMMUNITY NETWORK CAN HELP YOU

PC4 works with our Community Advisory Group (CAG) and Community Network to help researchers develop their research concepts and grant applications.

At no cost to you, our community can assist you with:

- Designing your study intervention
- Providing feedback on study design and methods from a consumer perspective
- Joining your project as an Associate Investigator
- Joining your project steering committee as a consumer member
- Providing feedback on trial materials prior to recruitment
- Providing feedback on trial summary materials for participants or the general public
- Helping disseminate trial results through community networks



MONITORING & EVALUATION

- have continued involvement with the study to maintain focus & address issues as they arise
- collaborate with researchers to evaluate the research process
- reflect on their role & what they have learned

NEW PATHWAYS



IDENTIFYING & PRIORITISING

- through local user groups & organisations help inform research priorities
- be consulted about research topics & priorities important to them as service users
- collaborate with researchers to identify topics for research
- identify topics for research themselves.

SCIENTIFIC & ADVISORY COMMITTEES



IMPLEMENTATION

- increase the likelihood that results of research are implemented, by adding validity to the findings
- develop patient information for new services/interventions within hospitals, GPs, surgeries etc.

CLINICAL PRACTICE



DISSEMINATION

- advise on different avenues for disseminating results
- jointly present the findings with researchers
- write information for local patient groups/hospitals etc.
- assist in getting results/findings published on charities/voluntary organisations websites
- help distribute results within their informal networks
- produce summaries of findings

REPORTING RESULTS



ANALYSING & INTERPRETING

- assist the research team in developing themes from data
- be consulted to see if they understand/interpret data in the same way as the research team

HOW TO INVOLVE PATIENTS AND THE PUBLIC IN YOUR RESEARCH WITH PC4



DESIGN

- inform the design of the research study
- clarify the research question and affirm its importance
- ensure the methods selected are appropriate for patients
- assist in creating a recruitment strategy
- review & comment on proposed questionnaires & data collection methods

EMAIL REVIEWS



DEVELOPMENT OF THE GRANT PROPOSAL

- assist with ensuring that research proposed & chosen methods are ethical
- inform areas where patients/public could be involved
- provide ongoing advice on patients/public involvement
- define outcome measures
- advise on the appropriateness of the Lay Summary
- raise awareness about costs of involvement, expenses & prompt researchers to cost for involvement
- be named as co-applicants

CONCEPT DEVELOPMENT/PEER REVIEW WORKSHOPS



UNDERTAKING/MANAGING

Setting up a steering group to manage/monitor the research

- steer the project throughout the research process
- assist in writing the patient information and consent forms
- aid in designing the detailed protocol
- produce research updates that are patient friendly
- can assist in conducting interviews & surveys

PROJECT COMMENCEMENT: STEERING COMMITTEES, REVIEW PICF CONSENT INFO

ALIGNING CONSUMER ENGAGEMENT WITH FUNDING BODY EXPECTATIONS

The [NHMRC's Keep Research on Track II 2018](#) focuses on eight steps of research development where consumers should be engaged in the very early stages of planning. The NHMRC offers a suite of resources to help researchers consider consumer engagement that can be found [here](#).

In the strong engagement with consumers/ stakeholders section of grant applications, it's important that you demonstrate a higher level of consumer involvement in the development and conduct of your study. Here are Cancer Australia's levels of consumer participation in their [National Framework for Consumer Involvement in Cancer Control](#). Cancer Australia also provides a number of generic adaptable consumer engagement trial resources as part of their consumer involvement tool kit.

CONSUMER CAPABILITY

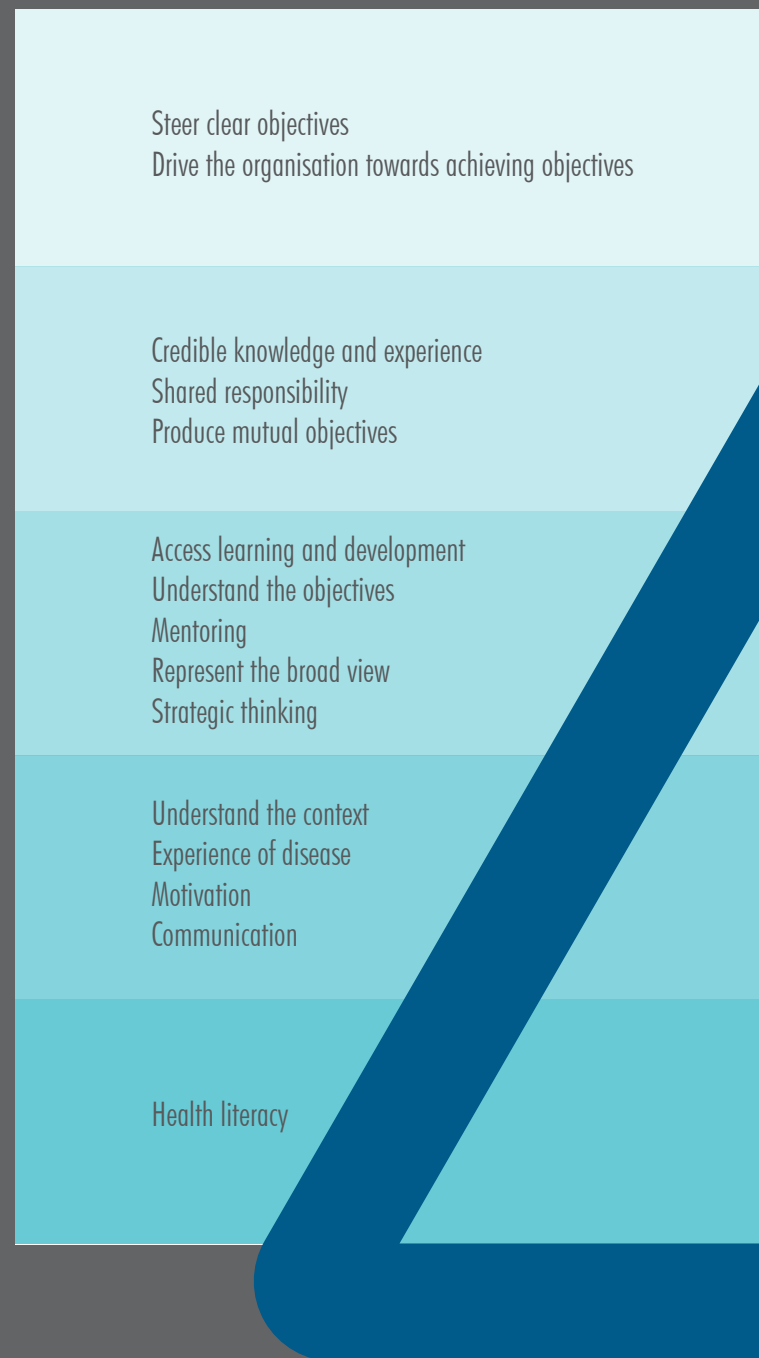


Figure 1. Cancer Australia's levels of participation of consumers engaged in cancer research development and conduct.

ORGANISATIONAL CAPABILITY

Set
priorities, lead
major activities
CONSUMER LED

Commits and organisational objective to consumers/
consumer organisations and acts on outcomes involves
consumers in setting policy and strategic directions

Work equally
with health professionals,
administrators, research, policy makers
PARTNERSHIP

Engages consumer organisations in partnerships
Consumers fully integrated in boards, working parties
and all aspects of the organisations, including
best practice improvements

Involved in information, support,
cancer services, policy, research
and spanning the patient pathway
INVOLVING

Provide education and training
Selection, Facilitation
Building consumer involvement into
all aspects of the organisation
Networking opportunities

Seek information, provide feedback
CONSULTING

Consult focus groups surveys
Consultative workshops

Provide information, seek feedback, build awareness,
improve health literacy
INFORMING

Feedback/forums
Newsletters/resources
(Oral, electronic,
print, web)

LEVELS OF PARTICIPATION

In terms of PC4 support, receiving concept reviews from our CAG meets the “involving” level of this pyramid. Engaging a consumer perspective on your project steering committee elevates engagement to partnership, while engaging in co-creation of your intervention and project design meets consumer-led participation.

The NHMRC suggest they require engagement in a minimum of four phases:

NHMRC CONSUMER ENGAGEMENT PHASES	PC4'S CONSUMER ENGAGEMENT SUPPORT EXAMPLES
<p>1 Determining research priorities.</p>	<p>If the study is part of PC4's research priorities; these were developed with both external community engagement as well as input from our Community Advisory Group.</p>
<p>2a Development of concept/hypothesis/ research question as well as the study design.</p>	<p>Participation in a Concept Development Workshop.</p>
<p>2b Research project consideration of partners, methodology and processes and budget development including cost of community/ consumer involvement.</p>	<p>Use of PC4's consumer remuneration guide.</p>
<p>3 Research including participant recruitment, consent and responsibility (ethics, governance) and oversight or governance of the conduct of the research.</p>	<p>A named consumer Associate Investigator and/or consumer project steering committee member. Feedback from CAG on trial recruitment and consent materials.</p>
<p>4 Reporting, communications and publication (including translation). This could include implementation strategies/activities or identification of subsequent research required.</p>	<p>CAG review of trial summaries and if appropriate study manuscripts. Use of CAG network to facilitate dissemination.</p>



Below is an example provided by the [Cancer Council of NSW](#) on questions consumers use to guide their scoring of grant applications. These may be useful as a checklist to review your consumer engagement description within a grant application.

- ✔ Has consumer consultation into the development of this specific project already been undertaken?
- ✔ Have the researchers clearly identified the nature of consumer consultation to date?
- ✔ Has an individual consumer, or a consumer organisation, agreed to act as the consumer representative on this project?
- ✔ Are the consumer(s) named?
- ✔ Have the researchers explained what experience or training the consumer(s) have undertaken or been provided which renders them 'qualified' to act as the consumer representative(s)?
- ✔ Are the consumer(s) networked as a member of a broader consumer organisation?
- ✔ Are there formal processes/structures in place that link the researchers with consumers? For example, is the consumer named as an Associate Investigator on the proposal, or is the consumer nominated as a member of the project Advisory Group?
- ✔ Given the nature of the research, are the extent and type/s of consumer involvement appropriate? For example, it would be expected that consumer involvement in a clinical trial would be more extensive than consumer involvement in a basic science study.
- ✔ Is there a plan for ongoing consumer involvement in the research?
- ✔ Is the nature of ongoing consumer involvement clearly described, including the matters on which consumers will be consulted and the mechanisms by which this consultation will occur, and is the involvement two-way?
- ✔ Have the researchers identified the preferred approach of consumers for ongoing involvement in the research?

REMUNERATION

Financial acknowledgment for consumer representation is accepted as best practice and many health consumer organisations across Australia recommend remuneration as part of any meaningful contribution. Your budget should aim to cover all out-of-pocket expenses as well as any sitting fees for consumers that are members of project steering committees. Out-of-pocket expenses include public transport costs, private transport and parking expenses, training costs, accommodation and other incidental costs. Claims for the use of private cars is calculated in accordance with the [Australian Taxation Office Claiming motor vehicle expenses](#) as a sole trader – cents per kilometre policy.

If you plan to engage with consumers in other activities during a research project an hourly rate remuneration can also be offered. When deciding on this hourly rate consider that it should be commensurate to their level of involvement/engagement.

Our CAG emphasises that payment for consumers should be framed around one on one discussions with each consumer member to discuss if and how they would like to be reimbursed for their involvement. Once agreed, this arrangement should be formalised and explained prior to the project's commencement. A consumer's preference may change during the project. So, don't forget to extend the offer again at a later stage.

For consumers who do not wish to be financially reimbursed for their involvement alternative forms of recognition could include registration for research symposia, conferences or other events which can help consumers continue to develop their capability as consumers; a key domain of Cancer Australia's framework for effective consumer engagement. The budget guide below has been adapted from the [Victorian Comprehensive Cancer Centre consumer cost model](#) and approved by PC4's CAG.

COST MODEL FOR CONSUMER SITTING FEES AND HOURLY RATE

LEVEL OF ENGAGEMENT	REMUNERATION TYPE	MECHANISMS OF ENGAGEMENT
Consumer-led	Sitting fee \pm	<ul style="list-style-type: none"> • Consumer engagement in organisational governance, strategy, policy and e • Advocacy, leadership, evaluation and continuous improvement of consumer • Provision of strategic advice on consumer engagement and consumer-led e • priorities/initiatives to the organisational leadership team. • Drive a program of consumer-led consultation processes to build relationship knowledge base.
Partnership	Sitting fee \pm	<ul style="list-style-type: none"> • Represent the consumer perspective on Steering Committees, Working Group • Program and project involvement – liaison, advisor, team member, project
Involving	Hourly rate	<ul style="list-style-type: none"> • Speaking engagements/panel member at events. • Reviewer roles in research, education, training and communications.
Consulting	Hourly rate	<ul style="list-style-type: none"> • Participate in consultation activities such as focus groups, consultative work • Storytelling to support communications, program development or delivery: i

¹ Amounts determined by Safer Care Victoria A guide to consumer remuneration citing Department of Premier and Cabinet Appointments and Remuneration Guidelines (2019). Schedule C: Classification criteria and remuneration schedule - Group C organisations (Section 3a) relates to advisory bodies to departments. The upper limit has been used for sitting fees to acknowledge the additional time required in pre- and post-meeting reading, preparation, and follow-up actions. The committee member rate is 85% of the Chair rate.

² Amounts apportioned for comparative complexity of consumer contribution to align with VCCC model of consumer engagement. The Chair rate is the same as the member rate for Consumer-led activities, and the member rate is 85% of the Chair rate.

*There is no separate sitting fee for a Deputy Chair. If a Deputy Chair is appointed, payment will be at the member's rate. If the Deputy Chair assumes the role of the Chair the Chair's fee will be payable for the period, the Deputy Chair acts as Chair.

\pm Sitting fees have been segmented into 4-hour blocks, with maximum payment capped at the full day rate.

+No hourly rate remuneration for participation in surveys.

	COMMITTEE CHAIR*	COMMITTEE MEMBER	PARTICIPATION
evaluation. engagement practice. education and research tips and the organisational	\$268 [\geq 4h] ¹ \$134 [$<$ 4h]	\$228 [\geq 4 h] ¹ \$114 [$<$ 4h]	
tips and interview panels. governance.	\$228 [\geq 4h] ² \$114 [$<$ 4h]	\$194 [\geq 4h] ² \$97 [$<$ 4h]	
			\$40/h
shops and interviews ₊ . interviews, writing, video-based.			\$50/h



GUIDE FOR G

Our CAG has a wealth of experience working with researchers. Many of our members have been with PC4 since it's inception in 2009.

Below are suggestions and tips from our CAG on how researchers can successfully engage with consumers involved in their research.

Concept Development

Consumers often find it easier to provide feedback when guided by specific questions researchers have about their concept/project. Below are some questions you could use to guide feedback by consumers:

- Would the burden on the patient in this intervention be acceptable?
- Do they have any concerns about the intervention design?
- Could the intervention be changed to reduce the burden on participants?
- Does this study address a question they feel is important for cancer patients?
- Are there any ways they feel consumers could be further engaged in the project?
- Are the outcomes in this project important from a consumer perspective?
- If you were approached to participate in this study, would you? Why/why not?
- From a consumer perspective, what is the greatest strength of this study?
- From a consumer perspective, does this study have any weaknesses?

Trial materials

- Consider working with consumers to develop trial recruitment materials including advertising materials, PLS and consent forms.



GOOD ENGAGEMENT

Steering committees

- Make sure you directly ask for consumer input during meetings.
- Think about the meeting papers for steering committee meetings – will these be easy for the consumer to understand?
- Are there any highly scientific areas being discussed i.e. statistics, health economics? If so, remember to try to summarise in appropriate language for consumers.
- Be aware of consumers' other commitments.
 - Find out what other research projects are they working on
 - Are there any days/times they can't attend meetings?
- Make sure you provide enough turnaround time for consumers to provide feedback.
- Consumers have a wealth of professional experience, not just their lived cancer experience. There may be ways this professional experience can also benefit the project.
- Take time to email consumers to thank them for their input but to also keep them up to date if it's been a while since the last progress update.



Dissemination

- How will you engage with consumers to disseminate your study results?
- Do consumers in your project have any networks that can be leveraged to share your results?
- Ensure any trial summaries have been reviewed by consumers.



CONNECT WITH US

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