

Consumer Engagement

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Summary: The aim of this policy statement is to provide a description of the different types of consumer engagement within TROG.

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1. INTRODUCTION

Until relatively recently, the main role consumers played in health and medical research was as 'subjects' in research studies¹. Researchers are now however encouraged to involve consumers in a different kind of participation, where they work in partnership with one another to shape decisions about research priorities, policies and practices.

TROG has welcomed this initiative and complies with the Core Principles of Consumer Engagement in Cancer Control outlined in the National Framework for Consumer Involvement in Cancer Control (The National Framework)² by:

1. Integrating a consumer into the TROG Board and involving the consumer transparently in strategic planning and decisions about resource allocation.
2. Preparing and informing consumers through Duty Statements on order to optimise their involvement and advocacy for all people affected by cancer
3. Engaging consumers from Aboriginal and Torres Strait Islander, culturally and linguistically diverse and regional, rural and remote communities in an appropriate and culturally safe manner.
4. Ensuring the TROG membership engage with consumers respectfully and as equals
5. Implementing measurable outcomes, agreed with the TROG consumer expert, to build the evidence of meaningful and sustained consumer engagement.
6. Practicing ethically accountable behaviour.

2. CONSUMER CATEGORIES

TROG utilises the experience of a number of capable consumers' who fall into the following consumer categories as defined by the National Framework.

1. Personal Engagement
2. The Advocate
3. The Advisor
4. The Expert
5. The Partner

TROG has also acted on the recommendation of the National Framework to identify the approach best suited for each circumstance and to articulate the role required for the purpose by clearly defining each consumer category and by providing clear objectives in Duty Statements to assist consumers and researchers to understand the role requirements and the context within which they are invited to participate.

2.1 Personal Engagement

This would include past participants who accept the invitation from TROG to share their personal experiences with potential participants through podcasts and written stories on the TROG website. This may help raise awareness of the benefits of participating in TROG clinical trials.

These consumers are also invited to provide feedback on the information provided on the community pages of the TROG website.

2.2 The Advocate

Consumer Advocates represent the broad views and experiences of a range of people affected by cancer. This may include persons or groups that are unable to represent themselves such as people whose outcomes are poorer, rural, remote and regional consumers, Aboriginal and Torres Strait Islander people and culturally and linguistically diverse communities. Consumer Advocates may however have two-way links with others in the community through cancer consumer advocacy groups so that they are not left in isolation to represent the whole community's beliefs and expectations.

2.3 The Advisor

Consumer Advisors participate in TROG Trial Management Committees ensuring that the proposed methods are consumer friendly and that the research does not impose undue burdens on any participants. Consumer Advisors can warn of approaches which may be regarded as unethical, insensitive or inappropriate.

Consumer Advisors may also keep research participants and the wider community informed of the progress of the research through the provision of a newsletter to participants at the end of the trial or at key points throughout it. Consumer Advisors may also be involved in the review of lay summaries and the provision of trial updates to the community via community radio, presentations to community groups and through the press. Research teams or organisations could also publish lay summaries on their own websites.

TROG also supports the initiative of the NHMRC to include, where possible, a minimum of two consumers on a TMC to enable consumers to support each other and represent potentially different consumer viewpoints (e.g. carers and survivors).

Consumer Advisors may be required to undertake specialised training in order to optimise their contribution.

2.4 The Expert

Consumer experts are people who are called upon regularly by organisations due to their longstanding experience in consumer involvement and their ability to engage a diverse range of consumers to assist them in presenting the consumer perspective.

A Consumer Expert is involved in the TROG Scientific Committee (TSC), a high-level advisory committee as defined by the National Framework.²

In the words of TROGs current Consumer Expert their involvement brings to the TSC a combination of patient, health researcher and consumer experiences and contributes towards a patient-centred approach in radiotherapy care, collaborating with novel and inclusive ways towards improved radiotherapy patient care.

2.5 The Partner

The highest level of consumer involvement is partnering (also known as co-design) where consumer knowledge is valued equally. Consumer Partners are consumers considered as equal partners with essential knowledge necessary for health reform, research and policy development and system change.²

TROG has a Consumer Partner serving on the TROG Board of Directors. This consumer is a cancer survivor with a combined history of improving healthcare, policy and research, and chaired the project to develop the National Framework referred to throughout this document.

The TROG Board aims to bring consumers and professionals together to exploring advances that influence clinical practice.

3. CONSUMER LEARNING

A Consumer Learning website <http://consumerlearning.canceraustralia.gov.au/> has been developed by Cancer Australia to enhance the contribution of people affected by cancer to clinical trials research. Through this website, TROG consumers have access to a suite of learning and support initiatives to enhance their knowledge and skills in engaging with TROG and its researchers to conduct quality trials.

4. APPOINTING CONSUMERS

4.1 Personal Engagement

Consumers invited by TROG to share their personal stories are contacted through their treating Radiation Oncologist or Clinical Trial Coordinator. These consumers are fully informed about TROG and consent obtained prior to their personal stories being communicated to the public via the TROG website.

4.2 The Advocate

TROG engages consumer advocates through the National Indigenous Cancer Network (NICaN) - a national network that encourages and supports collaboration around Indigenous cancer research and delivery of services to Indigenous people with cancer including their carers and families. NICaN Consumer Advocates are invited to speak at TROG Annual Scientific Meetings to share their experiences and advice with the Australasian Radiation Therapy Community and to build support networks and collaborators. Advocates should have undergone advocacy training which is offered by a number of groups in each state often in collaboration with Cancer Councils. A number of cancer specific groups such as the Breast Cancer Network Australia (BCNA) also offer training at this level.

4.3 The Advisor

TROG recommends that Consumers Advisors for Trial Management Committees are selected from people nominated by state based cancer consumer advocacy groups and specific cancer groups, such as the Prostate Cancer Foundation of Australia (PCFA) and the BCNA. These groups are able to identify consumers who are adequately informed and who are able to provide a broad view of people affected by a particular kind of cancer. On-line training for these people is available through the Cancer Learning website of Cancer Australia (see section 3 above). A number of Clinical Trials Groups undertake training for their consumer advisors.

4.4 The Expert

The Commonwealth Consumer Affairs Advisory Council has developed six principles to assist government and industry in the appointment of consumer representatives. These principles are described in the Commonwealth of Australia (2005) *"Principles for the Appointment of Consumer Representatives: A Process For Governments And Industry"*³. TROG shall refer to these principles in the selection of a Consumer Expert.

4.5 The Partner

When appointing a Consumer Partner, TROG shall follow the *“Principles for the Appointment of Consumer Representatives: A Process For Governments And Industry”* as described in section 4.4 above.

5. TROG CONSUMER ADVISORY PANEL

TROG has formed a Consumer Advisory Panel (CAP) in order to increase consumer involvement, as recommended by the Core Principles of Consumer Engagement in Cancer Control outlined in the National Framework for Consumer Involvement in Cancer Control (The National Framework).

The purpose of the TROG CAP is to provide support, mentoring and training amongst TROG consumers whilst creating a platform for succession planning. This will result in TROG having available to it a group of trained consumers who shall advocate for TROG and advise its members of any approaches in research that may be regarded as unethical, insensitive or inappropriate together with suggestions on ways to better inform and/or include participants in research.

6. MENTORING

Consumers can make a valuable contribution towards TROG being that it is a relevant and patient centred organisation. They can best learn and develop confidence in their participation when supported and guided by their peers who have expert knowledge of TROG.

With this in mind new consumer participants will be mentored to assist their introduction into their new position. Mentoring will be facilitated to best fit with the role of the consumer. The mentor can most likely be an experienced TROG consumer but could also be a suitable other member with whom they will be working. Further ongoing support and assistance can be provided according to Cancer Australia’s Consumer Training and Mentoring Guide:

http://canceraustralia.gov.au/sites/default/files/publications/consumer_training_and_mentoring1_504af023a08ae.pdf

7. REFERENCES

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