Policy Statement

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Consumer Engagement Charter

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Summary:	The purpose of this policy is to outline TROG's framework for incorporating consumer input at all stages of the research cycle.
Applies to:	This policy should be followed by: a) TROG Cancer Research employees
Approved by:	TROG Board of Directors
Revision Chronology:	Vs 1 Original document

Contents

1. Introduction

TROG Cancer Research (TROG) is committed to embedding the voices of those affected by cancer; patients, survivors, carers, and community members, into our research. Consumer perspectives improve the relevance, quality, and impact of our work by shaping priorities, informing study design, and guiding the dissemination of findings. This Charter sets out TROG's principles, objectives, and approach to meaningful, sustained consumer engagement.

2. Purpose

This Charter formalises TROG's framework for incorporating consumer input at all stages of the research cycle. It ensures that our research reflects community needs and priorities, supports translation into clinical practice, and aligns with national best practice principles for consumer involvement in research.

3. Guiding Principles

i. Respect – We recognise and value lived experience and uphold the right of consumers to contribute to research decisions.
ii. Inclusiveness – We strive for diversity in background, geography, and cancer experience, including under-represented groups.
iii. Connectivity – We work with tumour-specific networks and advocacy organisations to recruit and engage relevant consumer partners.
iv. Relevance – We ensure engagement opportunities are meaningful, accessible, and aligned with TROG's multidisciplinary research scope.
v. Transparency – We communicate clearly about roles, expectations, and the impact of consumer contributions; and align our practices with recognised national guidelines, including those of NSW Health, NHMRC, and the Australian Clinical Trials Alliance (ACTA).
vi. Partnership – We collaborate with consumers as equal partners in research, governance, and knowledge translation.
vii. Equity – We remove barriers to participation, including accessibility, language, and cost considerations.
viii. Cultural Safety – Engage with consumers from Aboriginal and Torres Strait Islander, culturally and linguistically diverse, and rural/remote communities in ways that are culturally safe, respectful, and responsive.

4. Objectives

- Embed consumer perspectives across the research lifecycle, from concept generation to post-study dissemination.
- Empower consumers to contribute to TROG's strategic direction and research priorities.

- Provide training, resources, and ongoing support for consumers and researchers to work effectively together.
- Build sustainable relationships with consumer representatives and advocacy groups.
- Promote awareness of consumer engagement value across the TROG community.

5. Scope of Involvement

Consumers will contribute to:

- Research Prioritisation – Identifying priorities through TROG Scientific committee, working party and/or special interest group representation as well as workshops, forums, and surveys.
- Proposal Review – Assessing new research proposals and subsequent grant applications for relevance, feasibility, and potential impact.
- Study Design & Development – Trial management committee membership, reviewing protocols, participant information and consent forms, and other participant information for clarity and relevance.
- Dissemination & Outreach – Assisting in translating findings into accessible formats and promoting public awareness.

6. Consumer Roles

- Personal Engagement – Sharing personal experiences to raise awareness and providing feedback on TROG's public-facing materials.
- Advocate – Representing broader community perspectives, particularly under-represented groups, including those from rural/remote areas, Aboriginal and Torres Strait Islander peoples, and culturally and linguistically diverse communities.
- Advisor – Reviewing trial processes and participant materials for clarity, feasibility, and appropriateness; providing updates to the community.
- Expert – Bringing high-level consumer expertise to TROG Board, TROG Scientific Committee, working parties and/or special interest groups and contributing to patient-centred research planning.
- Partner – Working in co-design roles as equal decision-making partners in research development.

7. Consumer Advisory Network

TROG will maintain a diverse pool of consumers for short-term, project-specific, or ongoing involvement. This will operate as a Consumer Advisory Network, providing a platform for peer support, mentoring, training, and succession planning, ensuring TROG has a sustainable pool of skilled and diverse consumers ready to contribute. This will be facilitated by:

- Active recruitment through advocacy groups and clinical networks.
- Induction and training resources.
- Reimbursement of reasonable expenses.
- Mentoring opportunities for new consumer representatives.

8. Remuneration, Reimbursement, and Recognition

TROG acknowledges that consumers contribute their time, expertise, and lived experience on a largely voluntary basis. We are committed to ensuring this contribution is valued, supported, and sustainable. TROG applies the principles of Remuneration, Reimbursement, and Recognition (RRR) as outlined by NSW Health, and aligns with the expectations of the NHMRC Statement on Consumer and Community Involvement in Health and Medical Research and the Australian Clinical Trials Alliance (ACTA) consumer engagement resources.

- Remuneration – Honoraria or sitting fees may be offered for substantive contributions, guided by available resources and consistent with national best practice.
- Reimbursement – Consumers will be reimbursed for reasonable out-of-pocket expenses (e.g. travel, accommodation, childcare, parking) incurred through participation. Clear and accessible processes will be provided to support timely reimbursement.
- Recognition – Consumer contributions will be acknowledged through authorship or acknowledgement in publications, opportunities to present or co-present at TROG meetings, consumer awards, and acknowledgement across TROG communications.

By adopting the RRR principles and aligning with national guidelines, TROG aims to create a fair, equitable, and respectful framework that both acknowledges the diversity of consumer expectations and ensures participation is accessible and valued.

9. Roles and Responsibilities

- **Board & Executive** – Embed consumer engagement in strategic and governance frameworks.
- **Researchers & Project Teams** – Collaborate with consumers at design, implementation, and reporting stages.
- **Consumer Representatives** – Contribute perspectives, participate in discussions, and review materials.
- **Central Operations Office** – Recruit, support, and coordinate consumer involvement across TROG activities.

10. Monitoring & Evaluation

- Annual reporting to the Board on consumer engagement activities, reach, and outcomes.
- Use of agreed metrics (e.g., number of projects with consumer review, diversity of consumer pool).
- Feedback collection from both consumers and researchers to inform continuous improvement.

11. Review

Approved by the TROG Board of Directors. Reviewed biennially to ensure alignment with strategic goals and evolving best practice.

12. Conclusion

TROG Cancer Research values the perspectives of those affected by cancer as essential to ethical, relevant, and impactful research. This Charter commits us to partnership, equity, and excellence in consumer engagement.