Supplementary file 3

EXPERIENCES ACCESSING AND RECEIVING TUMOUR GENETIC PROFILING IN VICTORIA: A CONSUMER-LED CROSS-SECTIONAL SURVEY STUDY

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Supplementary file 3. GRIPP2 reporting as per examples in Staniszewska (1)

Section and topic	Item
Aim Report the aim of the study	To inform the equitable and ethical roll out of tumour genetic profiling in Victoria, Australia. To empower consumers to conduct and lead research,
Methods Provide a clear description of the methods used for PPI in the study	The consumer-led research process is described in detail within the manuscript, with additional information provided in supplementary file 1 and via the study's open science framework page https://osf.io/uc9t4/
Results Outcomes—Report the results of PPI in the study, including both positive and negative outcomes Include how was the development of the research question and outcome measures informed by patients' priorities, experience, and preferences?	-Developing the research question: • Consumers reflected on the status quo from their experience, highlighting inequalities with access to testing and the fact that people are getting unnecessary treatment that could be avoided with tumour genetic testing. • Consumers reflected on what they want in the future (equitable access, adequate information sharing with patients, shared-decision making, a health system that learns –with future patients benefiting from learnings from past patients) and provided innovative ideas for what needs to happen from now to achieve the desired future. • Consumers reflected on what research questions would help go from the status quo to the future we

Section and topic	Item
	hope for, submitted ideas and then with researcher support, developed the final questions. The different perspectives in the consumer group resulted in robust research questions that would look at consumer experiences in a multi-faceted way. - Research methods Recruitment • Contacts were shared on an excel spreadsheet and each team member (consumers, Uni of Melbourne researchers, VCCC Alliance staff) took responsibility for passing on study details to their contacts and / or networks. This resulted in a diverse recruitment strategy. We successfully recruited both carers and patients from across Victoria, with people who had experienced a range of diagnoses and treatment options. This resulted in a sufficient sample size, though we did anticipate our networks resulting in higher participant numbers than we achieved. Questionnaire • Consumers reviewed the questionnaire composed by the researcher based on former research and the workshop findings. The selection of predictors and outcomes was directly informed by discussions around the status quo and ideals for the future (see workshop summary document for more information https://osf.io/uc9t4/). • Consumers identified questions that seemed personal (e.g., anxiety and depression) and were too far removed from the purpose of the study. These were deemed unnecessary by the CRG and were removed. -Discussion of results • Each consumer provided reflections on what the key take away point of the results were for them. This ensured that the discussion (drafted by the research team) was centred around what was considered most important to consumers. It also allows for a comparison in perspectives, as VCCC Alliance staff also provided reflections (both available in supplementary file 5). Impact of conducting research on consumers

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	• Increased awareness, newfound appreciation for the research process and outcomes • Sense of empowerment, by contributing to advocacy and hopefully policy changes that lead to increased consumer choice options that can have better health outcomes • Felt well supported by the research team and VCCC staff from start to end. Impact of conducting research on researchers • Working with the consumer group was rewarding. It was a useful learning experience and helped to keep the research team energised. There was a strong sense of accountability and responsibility, as we did not want to disappoint the consumers we were supporting and had a more immediate sense of the importance of the study throughout the whole research process.
Discussion Outcomes—Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects	This is a consumer-led study, with the CRG contributing to and influencing all aspects of the study. The research questions were co-created with consumers, the methodology was refined by consumers, recruitment was co-conducted with consumers, interpretation of results was discussed with consumers and refined based on those discussions, and the discussion was framed based on key reflections of the consumer team. There were no negative effects.
Reflections Critical perspective—Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience	The process put into place by the VCCC Alliance in collaboration with the CRG and University of Melbourne researchers was effective. Facilitators included: • Consumers received training on research methods, consumer representation and precision medicine • Clear frameworks were put in place to establish roles and responsibilities from the outset. • The responsible researcher, selected by the VCCC Alliance to support the consumers, was experienced in partnering with consumers and had formal training in co-design. • Dedicated VCCC Alliance support staff to co-ordinate the project and act as a liaison between all parties (internally and externally). • Appointment of a CRG chair The process could be improved in the future by

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	• Further funding to support face to face interactions/workshops • dedicated ongoing training modules in research methodologies etc to support other consumer led research of this nature, • Ensuring length of research process from onset to outcome isn't drawn out too much as fatigue can set in at a particular point in time, engagement and commitment to project from consumers can waiver, survey participants curious about what has been done with the information they provided etc
How will the results be disseminated to study participants?	We will email study participants a summary of findings. We would also like to host a webinar to report back study findings to participants and facilitate further discussion.

1. Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S, et al. GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. Research Involvement and Engagement. 2017;3(1):13.