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Engaging Australian healthcare consumers to determine priorities and consensus for precision medicine approaches to detect non-communicable disease in early life: a modified Delphi study

Tegan Grace ,[1,2,3] Samantha Hoskins,[1,2,3] Kirsty Pringle,[2,4] Gillian Mason,[5] Melinda Cruz Turner,[6,7] Keren Ludski,[8] Leila Usher,[1] Nafiseh Ghafournia,[9] Craig Pennell [1,2,3]

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For numbered affiliations see end of article.

Correspondence to
Dr Tegan Grace;
tegan.grace@newcastle.edu.au

ABSTRACT

Objectives Research to develop early screening tools to determine an individual's risk of developing adult-onset disease is a growing field. Expectant parents may find themselves with an option in the future to undergo screening to determine not only genetic abnormalities in their child but also their risk of developing adult-onset non-communicable diseases (NCD) such as hypertension, obesity or hypercholesterolaemia. To ensure acceptability and feasibility of new screening tools researchers must work in partnership with healthcare consumers to discern consumers' current understanding and acceptance of these technologies in research and the potential for clinical applications. We sought to engage with healthcare consumers to develop a consensus, using a modified Delphi study design, for the acceptability of (1) screening tools for use within pregnancy that would indicate a child's risk for developing NCD, and (2) targeted early interventions for those identified at a higher risk of developing NCD using precision medicine approaches. The acceptability of future research design and conduct as well as the implications for implementation into routine healthcare were discussed. In addition, participants were asked to rank the non-communicable diseases they believed were of most importance for precision medicine research focus, in line with recent calls for better involvement of healthcare consumers in setting research questions and defining priority areas.

Design A modified two-stage Delphi study design including an in-person consumer workshop (stage 1) and online follow-up survey (stage 2), was used to evaluate consumer consensus for research to develop precision medicine tools for early detection and potential intervention to reduce onset of NCDs. The acceptability of research design and conduct and future implications for the implementation of newly developed tools into routine healthcare was also addressed.

Setting and participants We engaged 76 healthcare consumers in 2020, in the Hunter New England Region, New South Wales, Australia. Participants were recruited from existing healthcare consumer organisations, research programmes and healthcare networks through purposeful selection, with a focus on participants having a broad range of experiences and backgrounds to ensure adequate representativeness.

Results and conclusions Our findings indicate the majority (98%) of participants in our study believe early screening for risk of NCD in their children was acceptable, provided it was equitable and clear pathways for referral and support were available.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ Purposeful recruitment strategy and involvement of Aboriginal, culturally and linguistically diverse, first-time parents, both mothers and fathers, and parents with previous pregnancy complications allowed a consensus to be reached that involved a wide range of relevant healthcare consumers.
⇒ Workshop format did not allow complete anonymity, as recommended for Delphi studies; however, this was mitigated as much as possible by the facilitator's use of purposeful language to invite open-ended answers to questions.
⇒ Due to the nature of precision medicine having a strong genetic component, families who rely on egg or sperm donation in order to conceive may have differing views than the families involved.

INTRODUCTION

Worldwide, non-communicable diseases (NCDs) accounted for 7 out of the top 10 leading causes of death in 2019 (73.6%), and up to 85% of deaths in some high-income countries.[1] NCDs are one of the largest challenges we face in healthcare on a global and national level. The impact of chronic conditions on health-related quality of life and

productivity is significant, placing an ongoing burden on individuals and the healthcare system.[2] There has been a dramatic paradigm shift in how we conceptualise NCD due to research in animal and human models across the last thirty years demonstrating that antenatal and early life environments modify life course health and the development of adult disease.[3–6] Cardiovascular disease,[6] stroke,[6 7] asthma,[8] allergies,[9] neurodevelopmental disorders,[10] mental health conditions[11] and cancer[12] have their roots in the early developmental phases of human life. Originally focused on birth weight as a rudimentary proxy for intrauterine health and exposures, the Developmental Origins of Health and Disease field of research has rapidly developed to encompass complex gene-environment interactions that impact life course health outcomes.[13 14] For example, recent research reports the increased benefit of breastfeeding and early nutrition on BMI and cardio-metabolic outcomes in adolescents[15] and adults,[16] who had a higher genetic propensity for obesity.

The importance of both genetic and environmental factors in the first 1000 days of life from conception on the development of adult-onset disease presents health researchers a unique opportunity to develop screening tools that may be used as early as the antenatal period to identify those at a higher risk of developing NCDs. By identifying higher risk individuals very early in life it may be possible to develop interventions aimed at reducing or preventing disease onset in those most vulnerable. This is possible due to developmental plasticity, which is at its greatest in the first 1000 days of life from conception, and precision medicine. Developmental plasticity refers to the ability of people with similar genetics (genotype) to develop different traits (phenotype) due to environmental influences (for example nutrition). Precision medicine involves the use of a person's genes, environment, lifestyle factors, clinical information and biomarkers to enable healthcare providers to obtain information beyond observable 'signs and symptoms'[17] to provide individualised and targeted preventative measures. Of particular relevance to this research is the potential for early-life interventions, targeted at individuals with a genetic propensity for adult-onset NCD.

To ensure acceptability and feasibility of new screening tools, capable of detecting the risk of a child developing adult-onset NCD researchers must work in partnership with healthcare consumers, as per current Australian policy which highlights the importance of meaningful engagement throughout all stages of research (design, conduct and translation).[18] As precision medicine is a rapidly growing field, there is a need to undertake ongoing consumer engagement to gain an understanding of the current Australian healthcare consumer understanding and acceptance of precision medicine. The aim of this study was to engage with healthcare consumers to develop consensus, using a modified Delphi study design, for (1) screening tools for use within pregnancy that would indicate a child's risk for developing NCD and (2) targeted early interventions for those which a higher risk of developing NCD. The acceptability of research design and conduct, as well as the future implications for implementation of screening tools into routine healthcare, as well as the development of interventions, were discussed. In addition, participants were asked to rank the NCD they believed were of the most importance for precision medicine research focus, in line with recent calls for better involvement of healthcare consumers in setting research questions and defining priority areas.[19]

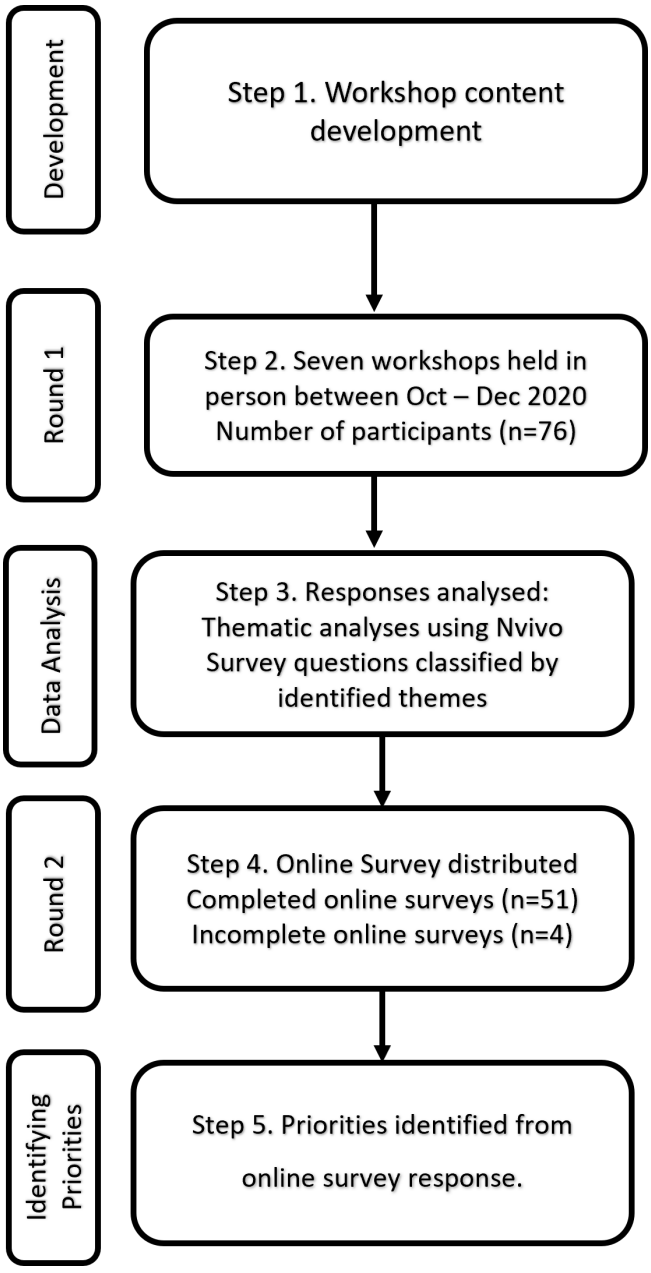

Figure 1 Study design.

METHODS

Study design

As the aim of this study was to develop consumer consensus a two-stage modified Delphi study design was used (figure 1). Delphi studies are designed to formally

achieve consensus within a group who have a range of expertise or experience in a particular topic. This technique has been used widely in areas of emerging technologies, interventions or knowledge in order to anticipate issues, facilitate appropriate governance, and set priorities.[20] As this was a consumer engagement study we modified the Delphi design to include a workshop in stage one. While this did not allow for anonymity as per the traditional Delphi study design this format was considered appropriate to allow healthcare consumers to openly engage in discussions, share ideas and knowledge, and voice questions and concerns. Participants were asked open-ended questions, following established guidelines,[21] to generate discussion and allow respondents freedom to give their opinions and ask questions if needing further clarification (online supplemental appendix 1). Australian research into meaningful engagement with healthcare consumers reported training for researchers as a key factor to success.[22] Workshops were therefore co-facilitated by researchers with formal training in consumer engagement (TG, trained by GM) and experience engaging with healthcare consumer organisations (CP).

Previous research has also indicated healthcare consumer involvement in research would be improved if the research was understood more through clear explanation[20] and improved health literacy.[22] Workshops therefore began with a short informative presentation about precision medicine. The content of the presentation included current applications, technologies, the use of genetics in determining risk of disease and how precision medicine approaches could be used to develop targeted interventions. Participants were asked if they would approve of research to develop genomic screening in pregnancy to screen for the risk of NCDs later in life using maternal, paternal and fetal cell-free DNA. Participants were then asked to think of as many potential advantages or disadvantages of such research. Further questions related to the participant's views on early life interventions, based on tools developed from such research, and whether they would agree or disagree with this type of technology becoming available as part of routine healthcare. Consumers were also asked what they thought were the most important NCDs for researchers to be focusing on for prevention and treatment in the general population.

Two scribes recorded workshop participants' answers during each workshop. Data were entered into NQivo and thematically analysed. In order to avoid the potential pitfalls of the Delphi technique, the most commonly cited being a debate on what levels of agreement constitute a 'consensus' we analysed data according to Dupras et al's[20] predetermined cut-offs for 'perfect consensus (100%), 'consensus' (90%), 'wide agreement' (70.0–89.9%), 'majority' (50.1–69.9%), and 'large minority' (25.0–50.0%). The first stage of this study involved seven in-person workshops with participants (n=76), followed by an online survey based on the results of the workshop (n=51). The second stage of this study was an online survey, which enabled individual and anonymous input from participants.

Participants

Guided by previous Delphi studies and recent Australian research regarding consumer engagement,[22] recruitment of participants was through purposeful selection, with a focus on participants having a broad range of experiences and backgrounds to ensure adequate representativeness, rather than a focus on sample size.[23] Six workshops were held in Newcastle, New South Wales, with one workshop run with women enrolled in an existing Aboriginal pregnancy study in a regional area. Workshops were held with healthcare consumers (n=76) including Aboriginal women from the regional town of Tamworth, New South Wales (n=5) and the Awabakal Mums and Bubs Programme, a Newcastle Aboriginal antenatal health service (n=14), culturally and linguistically diverse (CALD) women (n=10), first-time parents (n=12), women who had experienced pregnancy loss (n=13), women who had experienced preterm birth (n=9) and fathers from diverse cultural backgrounds who had experienced a range of pregnancy outcomes (n=13). Participants were approached through appropriate consumer networks. The Steering Committee of the Gomeroi Gaaynggal Aboriginal cohort study[24] which includes Elders from the Tamworth community were approached by the study manager. An Aboriginal research officer facilitated recruitment and co-facilitated the workshop. An Aboriginal obstetrician from Awabakal Mums and Bubs Programme approached Aboriginal mothers and fathers and co-facilitated workshops for these participants in Newcastle. Consumer advocacy organisations Red Nose and Miracle Babies Foundation facilitated recruitment of women and their partners, with representatives from the organisations co-facilitating the workshops. CALD women were approached to be part of the study by the Multicultural Health Liaison Officer within the Mothers, Obstetrics and Multicultural Support programme at the John Hunter Hospital in Newcastle, who also co-facilitated the workshop. Translation of information and consent forms and in-person healthcare interpreters (Arabic, Vietnamese, Farsi, Russian) were provided for the workshops by the Hunter New England Healthcare Interpreter Service.

Remuneration

Health Consumers New South Wales remuneration guidelines[25] for healthcare consumers engaged in focus groups were adhered to, with each participant receiving a gift voucher equivalent to $42/hour for their participation in the half-day workshop and online survey. Parking and lunch were provided to all workshop participants.

Data analysis

Recorded results from the workshops were collated and entered into NVivo (QSR International). Participant answers to each question were grouped into positive,

negative and neutral responses (including those considered contingent on certain elements being met) prior to thematic analyses. The generated list of priority NCDs from the workshops formed the basis of the second-round online survey to determine consensus on research priorities and acceptability of precision medicine approaches for early detection and interventions. Non-communicable diseases were included in the second-round survey if they were mentioned by three out of the seven groups. Survey results were anonymous and sent via a link using the Research Data Capture platform. The results of the survey were analysed to determine healthcare consumers ranking of the top five research priorities for NCD and consensus regarding the acceptability of precision medicine approaches to early screening and intervention for NCDs. This survey consisted of ranking questions (1 = highest priority) to ascertain the participants' top five NCDs for future research focus. The final question asked the participants if they would approve of precision medicine approaches to early screening and development of interventions for NCD.

Patient and public involvement

This research was a healthcare consumer engagement study. Consumer research priorities, experiences and preferences reported in this research will form the basis of future research projects. Consumers involved in this study were recruited from healthcare consumer organisations and appropriate networks and the results of this study will be disseminated through those networks.

RESULTS

Participants

Fifty-seven (75%) females (M = 36.00 years, SD = 6.69 years) and 19 (25%) males (M = 37.07 years, SD = 3.12 years) participated in the half-day workshops. Over half (66.6%) had private health insurance, 88.9% were married or in a de facto relationship while 7.4% were single, 1.85% were divorced or separated and 1.85% reported a relationship status of 'other'. The second round online surveys were completed by 68% of participants (n=51).

Benefits

Qualitative analyses of workshop data indicated the key benefits identified by participants for the use of precision medicine approaches to early screening for NCDs were 'planning and preparation', 'knowledge and education', and 'better allocation of health resources'. Planning and preparation were particularly important for workshop participants who were living in country or rural areas to enable them to plan for things like specialist appointments if these were needed. Participants discussed the opportunity parents would have to seek education and information about health conditions to make informed decisions regarding actions they could take, such as dietary changes or physical activity, to improve their child's health outcomes. The potential for targeted intervention to prevent or reduce risk of disease was seen as the greatest benefit, particularly if the result was a reduction in NCDs in the population through early detection. Potential savings to the healthcare system were also identified as a benefit of earlier detection of risk, particularly if this led to a shift from treating disease to preventing progression or manifestation of disease.

> At the moment you go to the Dr when you're sick. If you start earlier it becomes routine to be preventative in healthcare (female, 35 years).

In addition to implementing interventions and improving their own knowledge of health conditions, participants highlighted the potential for precision medicine approaches to be valuable if they resulted in better allocation of healthcare resources to those who were most likely to benefit from them.

Disadvantages

Proposed disadvantages of early screening for NCD in healthcare settings included the potential for 'increased stress', and the development of a system of 'health inequality'. When discussing genomics and precision medicine in research settings participants expressed their main concern to be 'inadequate community engagement'. It was important to healthcare consumers that research involving genetic material (DNA, RNA, cell-free DNA) involved clear and upfront engagement with participants regarding how samples and information were collected, stored and kept secure. This was particularly important among Aboriginal and Torres Strait Islander participants. Ongoing engagement with researchers including the communication of results was also important to consumers.

The possibility for increased stress on parents was cited as the most common potential drawback to early screening and detection of NCDs if these tools became available as part of routine healthcare. Workshop participants noted screening could be particularly stressful if there was a lack of support from healthcare professionals or if parents were unfamiliar with a particular condition. Within a healthcare setting, parents wanted assurance that they would not be 'left on their own' after being given the results of their child's early risk screening. The costs of new technology or tools to parents were also of concern and were discussed in several workshops with participants noting it would be important to ensure all families were able to access and benefit from new screening tools. Current access to non-invasive prenatal testing at a cost was discussed as an example of how new technologies could become available only to those who could afford them, resulting in a two-tiered health system and 'health inequality'.

Acceptability of precision medicine screening for NCD in clinical care

When discussing the application of genomics and precision medicine into routine healthcare for early screening

and intervention for NCDs participants stated their acceptance of any new tool would be contingent on how the screening was implemented and what (if anything) could be done if an increased risk was identified. Information about the time between screening and emergence of the disease, support from healthcare professionals to intervene and the allocation of resources and funding were discussed as factors likely to impact their final decision. Participants raised several questions that they would like answered before making a decision in a clinical setting. These included what specifically was being screened for, what interventions would be available, what support would be available and what was the risk-reward ratio (ie, what percentage of those identified as higher risk would the proposed intervention likely improve the outcome for). Participants were more likely to view early screening for NCD risk positively if there were proven interventions that worked to significantly reduce risk and if the process included clear pathways and referrals for support including specialists (eg, a lactation consultant or dietician for early dietary interventions). In addition, workshop participants noted the importance of any new technology or screening being available to all families, not only those who could afford additional screening or testing for a fee. Equity and availability of new healthcare technology were important to healthcare consumers. The potential increased cost of screening to the healthcare system was discussed, with several participants voicing the importance of balancing the cost of the new early screening and intervention with the existing cost of trying to treat NCDs in the community.

Healthcare consumer priorities for non-communicable disease research

The workshops yielded a list of 22 NCD of importance to healthcare consumers. Those that were mentioned by at least three of the seven groups were included in the online survey, with a list of ten health conditions presented in the second round. A total of 51 online surveys were completed (68%). Participants were asked to rank their top five health conditions in order of priority (figure 2). Mental health conditions and cancer were ranked as a top priority by 80% and 78% of participants, both constituting a 'wide agreement', high blood pressure and reproductive health were ranked as a top five priority by a 'majority' of participants (62% and 60%, respectively). Allergies and immune conditions also received a 'majority' consensus, with 58% of participants ranking it as a top five priority. Obesity (48%), lung health (38%), diabetes (40%) and high cholesterol (26%) reached a 'large minority' consensus. A final question in the online survey asked if participants would agree to the use of precision medicine approaches to provide early-life screening and interventions for NCD risk within the first 1000 days of life. A majority agreement (98%) was reached in affirmation, with 2% answering they were 'unsure'.

DISCUSSION

Current population health approaches have had limited success in reducing the rates of NCD. The emergence of new technologies enabling earlier screening and detection of risk for NCD has the potential to change the way we deliver healthcare. A paradigm shift from disease treatment to early screening and the application of precision medicine interventions to prevent or reduce disease may be key to tackling this global health problem. Our findings indicate the majority of participants in our study believe precision medicine approaches to early screening and intervention for NCD in their children were acceptable, provided it was equitable, and that clear pathways for referral and professional support were available. A key component for success in this area of precision medicine

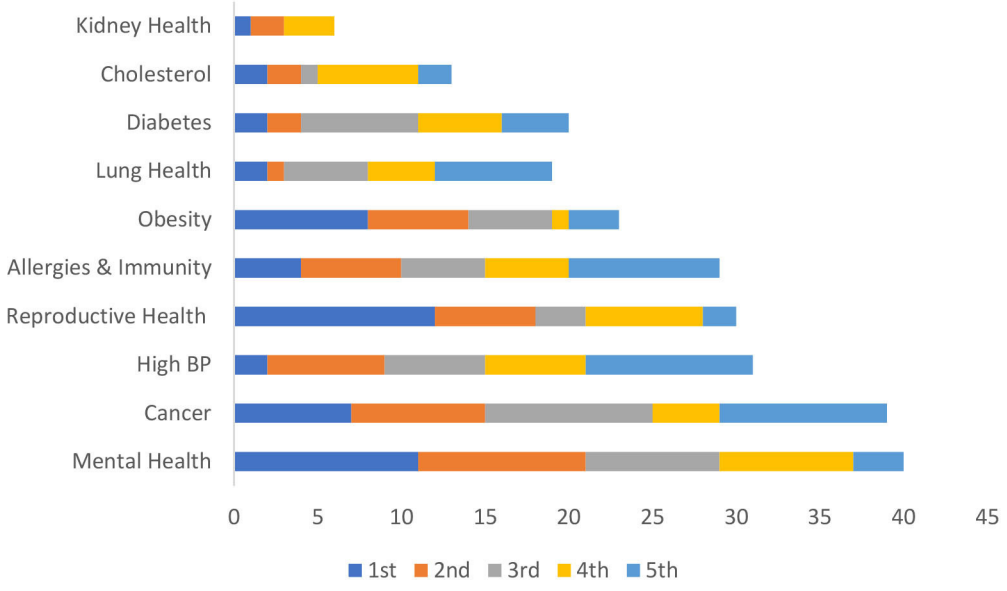

Figure 2 Healthcare consumer research priority ranking.

research and development will therefore be the parallel development of technologies for early screening and detection alongside the development of evidence-based interventions and the ability for long-term follow-up to determine effectiveness. Importantly ongoing consumer engagement is needed to guide research protocol development and ensure acceptability of newly developed screening tools, and adherence and effectiveness of intervention protocols.

Results from this study indicate that research to develop early predictive and screening tools for NCD risk is acceptable to the Australian healthcare consumers we engaged with. Ongoing meaningful consumer engagement in the design and develop these new technologies and tools will play a vital role in the success of this research. Implementation of these tools into clinical care would necessitate further meaningful engagement with larger numbers of healthcare consumers to ensure concerns regarding intervention and support pathways are adequately addressed during translation. Health conditions of most concern to healthcare consumers for future research focus were mental health, cancers, hypertension, reproductive health, allergies and immune disorders, obesity, respiratory health, diabetes, dyslipidaemia, and kidney health.

Strengths and limitations

While we acknowledge that not every potential family structure was engaged in this study, the purposeful recruitment strategy and involvement of Aboriginal, CALD, first-time parents, both mothers and fathers, and parents with previous pregnancy complications allowed a consensus to be reached that involved a wide range of relevant healthcare consumers.

A potential limitation of the study was the structure of the workshops not allowing complete anonymity, which is recommended for Delphi studies to ensure participants do not feel under external pressure to answer a certain way. This was mitigated as much as possible by the facilitator's use of purposeful language to invite open-ended answers to questions, and assurances of there being no 'right or wrong' answer. We recognise that there are increasingly complex family structures in society and while every effort was made to include a broad range of healthcare consumers it is acknowledged that there were small numbers of some groups, such as LGBTIQ+families. Due to the nature of precision medicine having a strong genetic component, families who rely on egg or sperm donation in order to conceive may have differing views on the use of genetic screening, and the availability of such tools in the future for these families may need to be addressed in more detail.

Conclusion

Healthcare consumers in this study were supportive of research to develop new technologies and tools to detect risk of NCDs in early life. Ongoing consumer engagement during the research and development of these tools were a priority for consumers, as was equitable access to newly implemented tools in clinical care. Consumers were more likely to view screening tools positively if there were clear referral pathways and support.

Author affiliations
[1]School of Medicine and Public Health, The University of Newcastle, Callaghan, New South Wales, Australia
[2]Mothers and Babies Research Program, Hunter Medical Research Institute, New Lambton, New South Wales, Australia
[3]University of Newcastle, School of Medicine and Public Health, Callaghan, New South Wales, Australia
[4]School of Biosciences and Pharmacy, The University of Newcastle, Callaghan, New South Wales, Australia
[5]Community and Consumer Involvement, The University of Newcastle Hunter Medical Research Institute, New Lambton, New South Wales, Australia
[6]NICU Lived Network, Sydney, New South Wales, Australia
[7]NHMRC Clinical Trials Centre, The University of Sydney Faculty of Medicine and Health, Sydney, New South Wales, Australia
[8]Red Nose Australia, Hawthorn, Victoria, Australia
[9]School of Humanities, Creative Industries and Social Sciences, The University of Newcastle, Callaghan, New South Wales, Australia

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Contributors TG, KL, MCT, CP, LU, NG, KP contributed to the study design and were directly involved in facilitating the workshops, SH attended as a consumer. TG analysed the qualitative and quantitative data. TG, CP, KL, MCT, LU, NG, SH and KP contributed to the final manuscript. TG is the guarantor.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by the Hunter New England Human Research Ethics Committee (2020/ETH01175). Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. Data available upon reasonable request to the corresponding author.

ORCID iDs
Tegan Grace http://orcid.org/0000-0003-4208-0435
Craig Pennell http://orcid.org/0000-0002-0937-6165

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