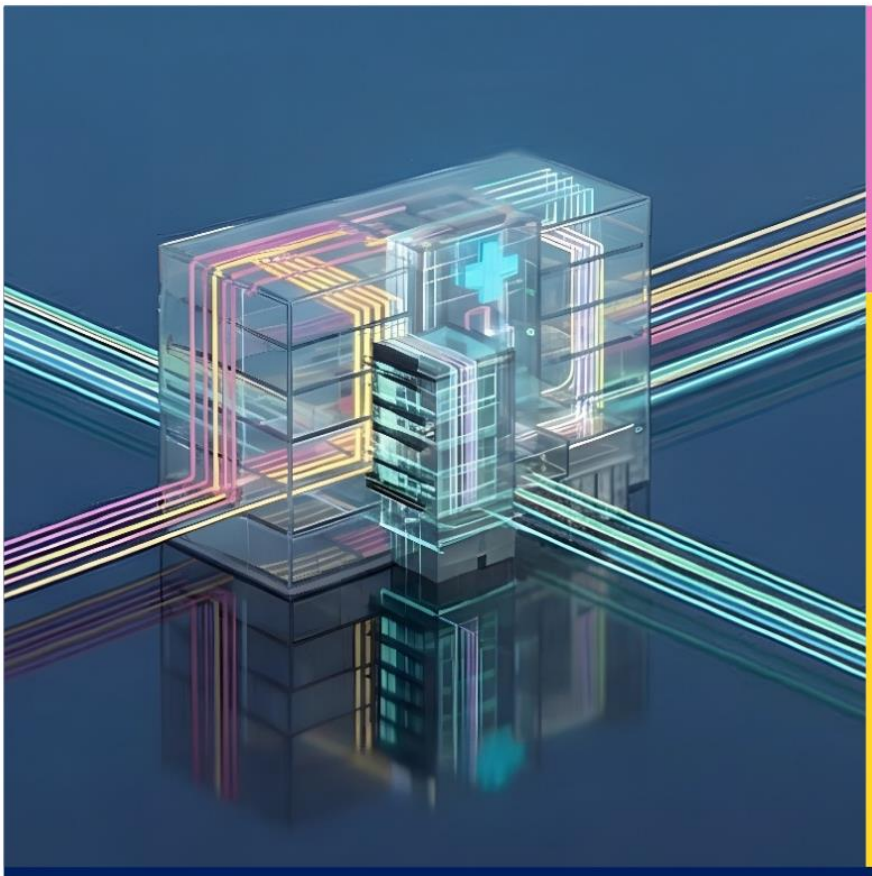

Centre for Digital Transformation of Health

THE UNIVERSITY OF MELBOURNE

Consumer & Community Involvement (CCI) Toolkit

Centre for Digital Transformation of Health

2026

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1.0 Consumer and Community Involvement (CCI) Capability Statement

The Centre for Digital Transformation of Health aspires to be a national leader in the practice of consumer (patient, carer) and community involvement applied to research and education on AI, data analytics and digital health.

To realise this mission, CDTH has developed a *Framework for Involvement* and invested in the capability of Ms Leslie Arnott, a *Consumer Engagement Specialist,* which both serve to embed and evaluate CCI practice across all CDTH digital health innovation projects.

Our co-designed *Framework for Involvement* (Figure 1) is employed in all digital health innovation projects [1]. Based on best-practice CCI literature and guidance, this framework continues to be co-reviewed and developed by consumers, communities and researchers, and it highlights key elements necessary to achieve Consumer Engagement Excellence in digital health research. At its core, it emphasises four interdependent areas: People, Consumer Roles, Principles, and Ways of Working. A successful consumer engagement model relies on fostering an independent and diverse network of consumer representatives who bring lived experiences, fast feedback, system level expertise and are engaged as CDTH team members.

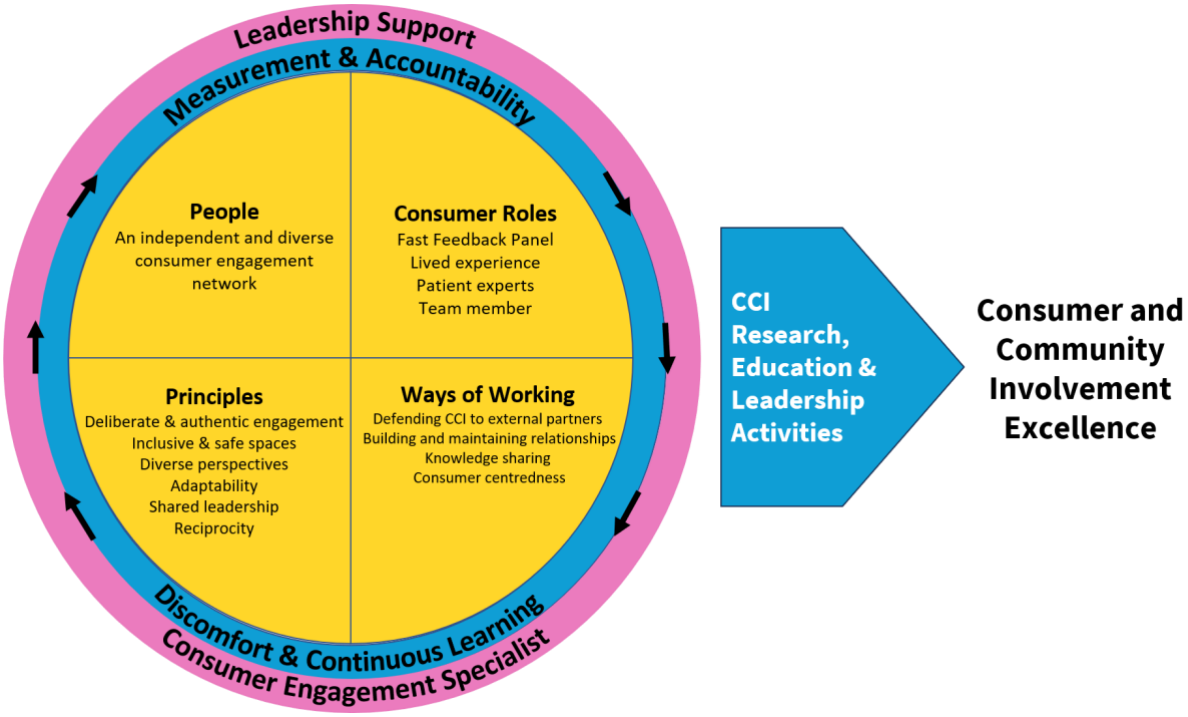


Figure 1: Framework for Involvement

Surrounding these core areas are essential enablers: Leadership Support, Measurement & Accountability, and Discomfort & Continuous Learning, all of which are championed by a Consumer Engagement Specialist. This framework also serves as a baseline, enabling both researchers and consumers to be reflexive of CCI practice in the context of CDTH. Each year Ms Arnott conducts interviews with both researchers and consumers to evaluate if the framework is being utilised in practice. Conversely when new concepts emerge in practice, the framework is adapted. This process ensures that consumer engagement is not just a tokenistic effort but a structured, reflexive and evolving practice that can be evaluated for excellence.

Leslie Arnott is an expert consumer, specialising in embedding consumer engagement principles across the research lifecycle. With a strong background in facilitating partnerships between researchers and communities, she provides tailored support to digital health researchers, ensuring best-practice consumer engagement in research design, implementation, and dissemination. Ms Arnott has played a pivotal role in developing consumer engagement strategies, overseeing consumer recruitment and reimbursement processes, and co-authoring research publications. Her expertise extends to advising on funding applications, training researchers and postgraduate students in CCI principles, and fostering reciprocal, responsive relationships with consumers. Leslie's leadership at the Centre for Digital Transformation of Health and Monash Centre for Health Research Implementation has established herself as a trusted advisor and educator in consumer engagement, co-design, and community-based participatory research.

Beyond her institutional roles, Ms Arnott has led national initiatives to enhance consumer involvement in health research. As the inaugural Chair of the Consumer & Community Involvement Sub-committee for the Women's Health Research Translation and Impact Network (WHRTN), she co-developed a national CCI strategy, recruited and mentored consumer advocates, and guided research priority-setting projects. Her work spans diverse health domains, from women's health and perinatal mental health to rural healthcare services and racial and gender equity in maternity care. Through extensive training, resource development, and advocacy, Ms Arnott continues to strengthen consumer partnerships, ensuring that lived experience is central to health research. Outcomes of her work include:

- Consumer values prioritised and co-designed through a national priority-setting project that now underpin nine MRFF-funded WHRTN research projects
- Co-designed Victorian state policy on the framework for gradual strategic change to guide Victorian maternity service; development that was released in 2012 and provides ongoing guidance on the development and roll-out of evidence-based models of maternity care (www.health.vic.gov.au/publications/future-directions-for-victorias-maternity-service)
- Published paper (Paxino, J., Bolton, J., Dushyanthen, S., Arnott, L., Burns, K., & Denniston, C. (2025). Embedding Patient and Public Involvement in Health Professions Education: Bridging Novelty and Normalisation. *The Clinical Teacher*, *22*(6), e70226.
- Published paper (Madill, R. L., Arnott, L. D., Pascuzzi, L., Allen, K., Todd, A. L., Perz, J., ... & Boyle, J. A. (2023). Developing a national strategy of consumer and community involvement (CCI) for women's health research. *Research Involvement and Engagement*, *9*(1), 96.).
- Published paper (Teede, H. J., Hill, B., Boyle, J., Arnott, L., Baber, R., Byles, J., ... & Makrides, M. (2019). Women's Health: Research and translation activities needed. *InSight+*, (21).
- Published paper (Merner, B., Schonfeld, L., Virgona, A., Lowe, D., Walsh, L., Wardrope, C., ... & Hill, S. (2023). Consumers' and health providers' views and perceptions of partnering to improve health services design, delivery and evaluation: a co-produced qualitative evidence synthesis. *Cochrane Database of Systematic Reviews*, (3).
- Published paper (Levett, K. M., Lord, S. J., Dahlen, H. G., Smith, C. A., Girosi, F., Downe, S., ... & Askie, L. (2020). The AEDUCATE Collaboration. Comprehensive antenatal education birth preparation programmes to reduce the rates of caesarean section in nulliparous women. Protocol for an individual participant data prospective meta-analysis. *BMJ open*, *10*(9), e037175.
- Published paper (Roberts, L. J., Jayasena, R., Khanna, S., Arnott, L., Lane, P., Bain, C. (2025). Challenges for implementing generative artificial intelligence (Gen AI) into clinical healthcare. *Internal Medicine Journal*, (1-7).
- Training and capacity-building webinars for EMCRs on CCI, diversity and inclusion viewed 627 times (e.g. https://www.youtube.com/watch?v=qqdxOeJLDBk)

2.0 Before Consumer Engagement

2.1 Process for Consumer Recruitment

Requestor has a research project for which consumer recruitment assistance may be required.

1. Requestor emails the Consumer Engagement Specialist (CES) to ask for help.
2. The CES emails a reply to requestor to advise:
    a. Use the Toolkit V3 to familiarise yourself with the Centre's consumer recruitment processes, specifically Section 1, *BEFORE (*found in this document*)*
    b. CES asks requestor to complete Consumer Recruitment Questionnaire as best they can (found in this document), before first meeting and send it back to CES
    c. CES to send working days and ask them to book a suitable time for the first meeting
3. Requestor indicates a time they would like to meet to discuss the project for which consumers are to be recruited.
4. Email standard reply: 'We can meet for 30 mins to discuss your project and consumer engagement needs (suggest day and time)
5. Discussion is held covering the following points:
    a. Before the meeting, you review the questionnaire
    b. Scope of recruitment, including purpose, time, remuneration, experience, diversity, consumer needs
    c. Discuss funding
    d. Who is the project lead and designated contact for consumers?
    e. Will CCI be conducted online or in person?
6. At conclusion the CES indicates the request will be assessed; advises when the requestor can expect a written response i.e. within how many days
7. CES assesses whether the search is within their own capacity or within Research Support's capacity vis-à-vis the requestor's desired timeframe
8. Assessment is emailed to requestor. Options are to:
    a. Decline the request for consumer recruitment assistance, refer alternative options
    b. Agree to provide guidance and support for requestor to conduct recruitment processes. This could include providing links to condition-specific health peak bodies with contact details, link to CDTH consumer database, etc. If CES is to conduct the recruitment, they advise the requestor of approximate time required to conduct the recruitment
    c. Accept the consumer recruitment request and advise requestor: "CES will conduct the recruitment process with your assistance for capacity-building and training." Estimate key milestones capability of the recruitment process.
    d. If the request is accepted for either guidance or to conduct the consumer recruitment process, finalise the Consumer Recruitment Questionnaire to ensure essential details are given, including:
        i. Project Title
        ii. Description of project
        iii. Main contact for consumers
        iv. Ethics (submitted/approved)
        v. Is submitted, estimated time of ethics approval
        vi. Any obstacles affecting consumer recruitment (e.g. funding, disease rarity, etc)
        vii. Is there a disease or condition focus?
        viii. Level of consumer experience required
        ix. Number of consumers required
        x. Equity and diversity of consumers
        xi. Accessibility issues for consumers
        xii. Approx hours that consumers are required

xiii. Remuneration available for consumers
xiv. Minimum time of 2 weeks required for CES response
xv. When are consumers required?
xvi. Any additional comments

9. Key Milestones are:
    a. Consumer recruitment; share updates with research team and finalised recruitment
    b. Orientation packs sent to consumers
    c. EOIs and/or Consent forms sent to consumers
    d. Signed EOIs and consent forms uploaded to project folder
    e. Consumer details added to project folder
    f. If required, introductory meeting scheduled and held with project contact and/or CES and consumers
    g. If required, check-in meetings scheduled for consumers
    h. At conclusion of project, remuneration issued to consumers
    i. Follow up with consumers re: consumer feedback, receipt of remuneration, joining our database for future projects
    j. If project ongoing, keep consumers informed of the project's progress
10. Reporting
    a. Hours extracted from calendar
    b. Excel spreadsheet population
    c. Report percentage of over hours (process, person, project)

2.2 Questionnaire Template

The following questions have been provided to help you fine-tune your consumer recruitment process. A number of consumers and researchers contributed to the list of questions below. Feel free to suggest additional questions/comments.

Project Title & Project Code (use Tron project tracker)	
Briefly describe your research project/activity in a few sentences	
Based on the Validitron Leads guide, who is the Project Manager? Is this the main contact for all consumers associated with this project? (See DURING Section of this document)	
Has ethics for this project been submitted or approved?	
If submitted to ethics, what is the anticipated date of ethics approval?	
Are there any obstacles affecting recruitment (e.g. funding, etc)	
Is there a disease or condition focus?	
Describe the level of consumer experience required: experienced / non-experienced; (See BEFORE Section of this document)	
How many consumers are required?	
What equity and diversity is required (gender, CALD, Indigenous, LGBQIA+, rural/urban, age, disability, disease/condition focus). List all required	
Are there any accessibility issues related to the consumers you require? (e.g. location, computer skills, hearing, seeing, other sensitivity requirements)	
Approx how many hours are the consumers required?	
Based on payment schedule what remuneration is available for consumers? (See DURING Section under Remuneration in this document)	
A minimum time of two weeks is required for a response. When are consumers required by?	
Additional comments	

2.3 Guidelines for recruiting consumers as partners in research projects and activities

Purpose

To enable CDTH team members to effectively recruit, and ultimately embed, CCI principles and practices when working with consumers in research-related activities.

Definition of 'consumer'; Background / Context / Clarification

The term 'consumer' can tend to be ambiguous, especially in the context of health research and health service delivery. Whilst members of the public with a non-clinical background were originally named 'consumers' when involved in health research and health service activities (e.g. strategic planning committees, research steering committees, service design focus groups, etc) there are now others acknowledged as consumers, such as researchers or clinicians, when in the context of an 'end-user' (e.g. co-designing a digital health tool for use by clinicians only, a clinician enrolled in an educational course as a student etc). It is recommended at the beginning of each project that the context is well defined to support the assignment of the term 'consumer' to the relevant person/group. For the purposes of this Toolkit, the term 'consumer' will refer to a member of the general public without a clinical background and one who has or does not have, experience representing the community or a group.

Why does CDTH need to involve consumers?

In seeking to embed Consumer and Community Involvement (CCI) across the Centre, CDTH recognises and supports the importance of advancing the Australian Commission on Safety & Quality in Health Care's Standard 2: Partnering with Consumers. As part of its goal, the standard states that:

"*Consumers and consumer representatives are full members of key organisational governance committees in areas such as patient safety, facility design, quality improvement, patient or family education, ethics and research. This level can also involve partnerships with local community organisations and members of local communities.*[1]

CDTH sees value in ensuring CCI is an essential part of our research activities. With this in mind, the following guideline will provide assistance in the processes of successfully recruiting and supporting consumers as valued contributing partners.

2.3.1 Step 1: Identify the number and diversity of consumers required for your project/activity

The NHMRC states that "As each research project is unique, the development of plans for consumer and community involvement will be required for each research project"[2]

For grant application writing you will have had the opportunity to engage with appropriate consumer advocates to include them as partners in your proposed research project[3]. During this process you will have allocated part of the funds to cover consumer remuneration for their time (including, if successful, the time consumers spend during grant-writing stage), expertise and any possible out-of-pocket expenses to be incurred. Hourly rates should therefore match consumer experience/expertise[4]. (https://www.remtribunal.gov.au/sites/default/files/2024-03/FTO%202023%20No.%202%20-%20Compilation%20No.%204).

There is no hard and fast rule on the ideal number of consumers required for each activity, but you will be guided by the type of activity (e.g. research project, symposium, etc.), available funding, and the level of experience and expertise you require from consumers (e.g. for research steering committees, focus groups, online surveys, etc.).

Essential requirements across all types of activities, however – and those that are championed by CDTH – are equity, diversity and inclusion (DEI). By starting with DEI, we enable capacity-building in social inclusion and

fairness for both researchers and consumers, while developing skills in producing activities and projects that are more community-relevant.

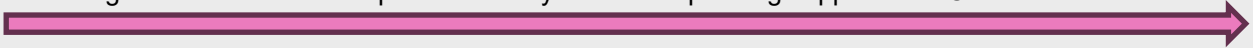
In consideration of the above your starting point for recruiting consumers therefore begins with engaging a variety of populations, cultures and experiences, such as:

- Indigenous
- Culturally & linguistically diverse (CALD)
- Disability
- LGBTQIA+
- Gender specific
- Older Adult
- Rural & remote
- Lived experience related to your work
- No clinical / no related research background
- Experienced consumers, linked into networks

2.3.2 Step 2: Identify consumer experiences and/or expertise required for your project/activity

The table below illustrates the types of varied roles consumers can have in research projects and related activities. It also provides a guide to varying remuneration levels commensurate with length of time, expertise and commitment to a project by consumers. The table is based on discussions and feedback received from CDTH researchers during a series of workshops in 2023 and was endorsed by consumers during a Centre review of the Consumer Engagement Framework in 2024.

CONSUMER ROLES

	The Fast Feedback Panel	The Lived Experience	Experts in the Patients Perspective in the System	The Team Member
Consumer Role Description	Provide fast feedback on brief documents or visual communication within 3 days	Provide project-level advice, and participation based on 1) their own experiences or 2) experiences of consumers like them	Provide program and strategy-level advice, based on experiences working in healthcare systems and organisational structures. They may also have lived experience.	Provide paid or volunteer hours to significant long-term projects or efforts to effect change for digital health transformation
Primary Capability / Expertise	Ability to quickly review documents for feedback	Experience of an illness and /or receiving healthcare services	Experience working in consumer advocacy roles in healthcare services, government or with NGOs.	A genuine passion or expertise aligned to the long-term project or effort to effect change.
Suggested Commitment	Ad hoc work < 30 minutes in length	Work is done in 2-hour blocks, 4 hour and full day blocks	Work is paid per hour with a minimum of 2 hours work for < 6 months but a casual contract for more than 6 months they should be come a team member	Negotiated as per project or hired on a contract.
Suggested Remuneration	Unpaid	Remunerated at the rate set by CHF or the Health Issues Centre or volunteer	Remunerated at the rate set by CHF or the Health Issues Centre or provided with a University of Melbourne per diem or volunteer	Member paid at a staff rate or given an honorary position at the University with CDTH for period of project.
Consumer Support Requirements provided by CDTH	An email explaining type of feedback sought, by whom, when feedback is due and a contact person	Pre-briefing and education, support during activity and closing the loop on the results of their participation. (We asked, you said, we did)	Pre-reading, pre-briefing, support during activity and closing the loop on the results of their participation. (We asked, you said, we did)	Pre-reading, pre-briefing, education, support during project, regular meetings to track progress, support to finalise and close the project and closing the loop with the public (We asked, you said, we did).
Increasing levels of consumer input into activity and corresponding support from CDTH 				

Variations in your projects/activities will deem both the level at which you engage or involve consumers and the required level of their experience and expertise. Keep in mind, the diversity in CCI can be achieved through intersectionality of individual consumers within a group. A further breakdown of the above is contained in the table below to further assist you in recruiting appropriate consumers for your research projects and activities.

Project/Activity	Consumer experience/expertise	Number of consumers
Research team	Lived/carer experience (if project or activity pertains to a specific health issue or condition) Health systems knowledge Demonstrated linkages to community networks Advocacy experience / linkages to consumer-led orgs Previous research team experience	Equal number of consumers to researchers
Governing steering committee	Lived/carer experience (if project or activity pertains to a specific health issue or condition) Health systems knowledge Demonstrated linkages to community networks Advocacy experience / linkages to consumer-led orgs 3+ years committee and/or research team experience	Minimum of 3 (there are often many more clinicians and researchers on a committee) 1 consumer is vulnerable, 2 consumers are self-supporting 3 are empowered
Forum/symposium panel	Lived experience of health condition or issue Advocacy experience / linkages to consumer-led orgs	Varied
Focus groups	Lived/carer experience	Varied
Digital testing	Lived/carer experience	Varied
Online surveys	Lived/carer experience	As many as possible
Conference presenter	Lived/carer experience	n/a

N.B.

1) In the mental health sector, consumer advocates do not consider carers as eligible consumer representatives;
2) Consumers should not have a clinical or research-related background.

2.3.3 Step 3: Using a number of resources for consumer recruitment

CII is currently developing a database to help you recruit consumers more efficiently and appropriately. This database will enable you to identify consumers who may possess one or more of the following characteristics/experiences you're looking for:

- Lived experience/carer experience of a health condition or issue
- Research team experience
- Linkages to community or consumer-led groups/organisations
- Cultural background/Intersectionality
- Health systems knowledge
- Research team experience

The first sheet of the database contains consumers who have worked with us before and are interested in partnering with CDTH in more research projects and activities.

The second sheet of the database contains a list of health peak bodies that may be aligned to the health condition or issue you're researching. Health peak bodies (e.g. Juvenile Diabetes Foundation) are often linked into consumer-led groups made up of lived-experience experts and carers, and they are often helpful in sourcing consumer partners for research projects and activities.

The third sheet of the database contains a list of NFP consumer-led organisations and associations, again, that may align with your research topic or health issue. These can vary from highly organised not-for-profits (NFP) who are active in lobbying and advocacy work to associated groups who provide social support to individuals with the lived-experience of a health condition.

The fourth sheet of the database contains a list of councils in Melbourne University's catchment. Local councils are responsible for supporting and improving the health of their communities and are often a rich source of information on how to engage and work with various priority populations and/or groups from diverse communities or with those who have specific health conditions.

The consumer recruitment database will continue to grow over time. You are encouraged to add to this database and seek out the Centre's Consumer Engagement Manager for further assistance in finding suitable consumers for your projects.

2.3.4 Step 4: Recruitment - working with organisations to help you find consumers

Once again, consider priority populations and the intersectionality of our communities when recruiting consumers for your activities (see Step 3). This includes a combination of varied cultural backgrounds, lived-experiences, advocacy, linkages to community networks, health systems knowledge and research committee expertise.

After you've considered what you require from consumers and at what level you require them (e.g. research team member, focus group participant, etc), you're now ready to recruit. This process will vary, given differing project needs and the diversity of consumer experiences required.

Some research projects, especially those which are long term, may require the development of Terms of Reference (TORs). Depending on the project these can be co-designed with consumers after the recruitment process takes place or developed prior to consumers coming on board.

Below is a list of ways you can engage and involve consumers, based on the level of engagement/involvement required:

Activity/Project	Engagement Method
Online surveys	Social media Public engagement orgs (who specialise in accessing the general public to participate in various online questionnaires, etc) Your own networks / colleagues' networks
Focus groups	Social media Related health peak bodies Consumer-led orgs and support groups – if related to a specific health issue Local councils Consumer advocacy organisations (e.g. Health Issues Centre at Deakin University) Hospital Consumer Advisory Committees (CACs)
Validitron digital testing	Social media Related health peak bodies Consumer-led orgs and support groups – if related to a specific health issue
Research team member	Related health peak bodies and Alliances (e.g. Harmony Alliance) Consumer-led orgs and support groups – if related to a specific health issue Consumer advocacy organisations (e.g. HIC) Tapping the shoulder of experienced consumers you know
Steering Committees	Related health peak bodies and Alliances Consumer-led orgs and support groups – if related to a specific health issue Consumer advocacy organisations

Once you have received responses from consumers who are interested in being involved in your project/activities, you're now ready to provide consumers with recruitment documentation (Expressions of Interest – EOI) to identify suitable candidates as consumer partners. After reviewing the EOIs, you may wish to conduct interviews for consumer candidacy or simply rely on the information contained in the EOI to guide your selection. The size, complexity and type of project will deem the appropriate recruitment processes required. Remember to consider the combination of characteristics/experiences listed above (see Stage 3).

Once you've selected consumers for your project an 'offer of engagement/welcome letter' email can be sent. This should include a reiteration of the timeline, commencement date, duration of engagement and remuneration processes.

At the end of this document is an example of a template for recruitment to help guide your selection process.

This is one of several documents contained in the 'BEFORE' folder of your CDTH CCI Toolkit. The folders are entitled BEFORE, DURING and AFTER to coincide with the 3 stages of consumer engagement that take place in any of your research projects.

Examples of case studies and their 1-page summary, illustrating good engagement with consumers and the community can be found in the Appendices.

2.4 Expression of Interest (EOI) Template

The Centre for Digital Transformation of Health (CDTH) at the University of Melbourne embraces diversity and equity. We welcome expressions of interest from consumers with a broad range of lived experiences, varied cultural backgrounds, expertise and linkages to consumer networks.

Position details

Survey participant, Research team member, Steering Committee member, Course guest presenter, Webinar presenter, User experience activity, etc	

Contact details

Name		
Email address		
Phone No		

About you (Please use the sections below to tell us about yourself)

What motivated you to apply for the position?

Please provide examples of any skills, knowledge and/or experience you may have that would lend themselves to this position?

Have you been involved in other health/research committees/working groups or relevant activities before?

Do you have any experiences in working with consumer-led organisations, support groups or related networks?

Feel free to include any additional comments you'd like to share

☐ I, *<insert centre name>*, agree that this form may be shared with relevant research team members for the purposes of recruiting consumers to this project. (please select checkbox).

2.5 Intersectionality Checklist

The two tables below are for internal use only and for your own personal use as a guide and/or a reference to the lived experience or relevant expertise identified in your consumer group. Ensure consumers have consented to providing their personal information and are informed that their information will be stored securely in CDTH's database which is only available to staff within the Centre.

This information is also useful for future reporting and evaluation of CCI development in our projects to help reflect on our approaches and effectiveness of consumer recruitment. They are not an exhaustive list but they are helpful in helping us to reflect on the importance of diversity and intersectionality in any recruited group.

Task/activity (e.g. focus group, research committee, etc)	
Number of consumers required	
Population-specific	
Health specific	

LGBT QIA+	Indigenous	CALD	Rural	Older Adult	Disability	Experienced	Non-Experienced	Consumer Name or # (e.g. 01, 02….)

The third table below is useful for populating the consumer database CRM that will continue to grow as we work with more and more consumers.

The aim is to have these Toolkit templates and others like it available in an online digital format to streamline the populating of relevant databases.

Personal Details		
Full name		
Postal address		
Contact number		
Email address		
Occupation		
Gender		
Do you identify yourself as Aboriginal or Torres Strait Islander?	☐ Yes ☐ No	Please specify:
Do you identify yourself from a Culturally and/or Linguistically Diverse background (CALD)?	☐ Yes ☐ No	Please specify:
Your Experience	Please indicate your experience by marking **X on** all that apply	
Which applies to your experience?	☐ I am a consumer representative ☐ I am a carer ☐ I am linked into a specific health issue network ☐ I am part of a consumer-led organisation	
Your Experience		
Please list health areas, health sectors or health issues to which you identify (if any). E.g. Diabetes, Maternal and child health, Mental health, etc		
What is your experience with the above? If comfortable answering		

Personal Details

Your Availability

Are you available to meet with your research team when required? *These may be face-to-face or online meetings*	☐ Yes ☐ No

Consumer Training and Involvement

Have you undertaken any formal consumer training? If Yes, please list what you have done and where.	☐ Yes ☐ No
Are you currently involved with a consumer organisation and/or acted as a consumer representative on a committee or board? *If yes, please name the organisation, describe your role and include recent activities you have carried out.*	☐ Yes ☐ No
Do you or have you worked for any health or research institutions? If Yes, where?	☐ Yes ☐ No
What qualities, life skills or other expertise would you contribute that you feel may be useful to this project?	

2.6 BEFORE – Checklist

No	Details	Done
1	Identify level of assistance required from the CES (consult, mentor, collaborate)	
2	Read and follow Processes for Consumer Recruitment guide	
3	Fill out questionnaire for CES Send questionnaire to CES Discuss project details with CES Finalise level of assistance required from CES	
4	For consult and mentor levels of assistance: Identify number and diversity of consumers require for your project Identify consumer experience/expertise required (see table in 'Guidelines for recruiting consumers) Use an internal database to recruit consumers: (2nd tab), and/or contact CES if further support is required Work with health peak bodies (if applicable) to find consumers (use link above) Define activities, roles and responsibilities of consumers	
5	Send EOI form to relevant people/organisations listed in the database (related health peak bodies and/or consumers). Should contain project overview, timeline and duration of engagement, commencement date, remuneration rates N.B. This will eventually be electronic	
6	Use Intersectionality checklist (if required) after reviewing EOI responses to ensure group diversity	
7	Send offer of engagement/welcome letter to consumers chosen. Should include: timeline and duration of engagement, commencement date, remuneration rates Consent form (researchers to provide) Plain Language Statement (PLS) Primary point of contact to provide support and guidance	

These are not listed in the Consumer Recruitment Guidelines but they are options you may wish to consider, depending on the type of your research project:

- if interviewing consumers for their role, develop standard interview questions and a grading category for candidates responses
- advertise the position across social media

3.0 DURING CONSUMER ENGAGEMENT

3.1 During your project: Involving Consumers

Consider the following items for an orientation pack that may include information such as:

- welcome letter with contact details of the Consumer Engagement Specialist (CES) and Lead Researcher so support is always at hand
- background information on the project they are joining
- Consumer Charter and Principles
- information on meeting locations, dates and times
- how and when they will be paid (you may need to include tax file declaration, police check, superannuation choice)
- conflict of interest declarations
- confidentiality requirements – including consent for consumer details to be shared with research team

This is a time when the Lead Researcher can nominate themselves or other researcher from their team as the main contact for consumers. In addition, the CES can be available to provide CCI support for both researchers and consumers. Be sure it is articulated clearly in your orientation pack who the main point of contact is for consumers and ensure they have the capacity (time and ability) to support consumers in all aspects of their involvement.

Depending on the type of research project or activity, you may wish to consider a formal induction or some form of professional development for consumers. Some projects work well with consumers being trained 'on the job', while other projects require pre-project learning or an induction, especially when consumers are joining a team as research partners. For projects utilising focus group formats, there is little to no training required.

It's important to connect your consumers. Introductions are essential to help them feel comfortable and safe in a team environment, and it exercises one of our most important principles in coproducing research – building and maintaining relationships. It's good practice for the CES to provide an orientation meeting to ensure all consumers understand what will be required of them and to discuss any queries they may have prior to the work commencement.

3.2 Expectations

An explanation of consumers' roles and responsibilities sets the scene for clear expectations. Also, providing consumers with the Centre's and NIHR's Principles for Co-producing Research[1] will help guide expectations as well. These principles underpin CDTH research project to provide support, guidance and a sense of security to all related activities.

With research projects that utilise consumers as research partners, taking them through a Project Logic session can further assist them in understanding the necessary steps required to realise the project, as well as help them understand more fully, their involvement in it. The Murdoch Children's Research Institute has an excellent template for a Project Logic and it can be found here.

Consider any type of training or induction required and consult with the CES to determine what is needed.

3.3 Welcome Pack

You will find templates for the welcome email and accompanying documents in the Appendices. The type of project you're conducting will determine what is appropriate to send your consumers. Consider including some or all of those points listed above as well as the following:

- An introductory email letter
- Code of Conduct
- A copy of the Plain Language Statement (PLS)
- Terms of Reference-ToRs, if required; (these ideally should be co-developed with consumers or with the CES prior to recruitment, especially when consumers are co-producing projects with you in partnership). Consult with the CES if you are unsure of what to include.

3.4 Meeting with consumers

Arrange an induction meeting (online or in person) to discuss likely activities, expectations, and any queries consumers may have. Accommodate for special needs when required. Points of discussion include (but are not limited to):

- Team/project activities and expectations
- Duration of involvement and remuneration processes
- Self-identification of any learning or knowledge gaps that may require additional support from the Consumer Engagement Manager or team/project members
- Other consumer needs
- Further understanding of CDTH's work (include NIHR's Principles of Co-produced Research)
- Meeting times / communication methods
- Sharing contact details (only with consent)
- Scheduled check-ins – these can be determined and set by the group

3.5 Ongoing support

When required, it is good practice for Research leads and/or the CES (depending on the size, complexity and duration of your project/activities) to follow up and respond to any queries or concerns raised during check-in sessions. This helps to support and monitor consumer wellbeing, commitment and participation and illustrates our commitment to championing the principles for co-producing research.

Be sure to keep your consumers informed of the project's progression on a regular basis and ensure they are remunerated in a timely manner if the project is long term.

3.6 Remuneration Guidelines

Gift Card payments

These are payments for consumers who are involved in 'one-off' activities and are not required in an ongoing capacity (e.g. participating in a focus group, attendance at a workshop, etc). However, it is possible for you to pay a consumer with one Gift Card for a number of activities in one lump sum (e.g. 3 x 2-hour co-designing sessions for a workshop).

You can assign Gift Cards through THEMIS, using this link: https://unimelbcloud-my.sharepoint.com/personal/heather_morris_unimelb_edu_au/Lists/Giftcards?env=WebViewList

Follow the prompts and notify Heather Morris of the people for whom you have generated the Gift Card(s). Heather can be contacted on: heather.morris@unimelb.edu.au

Please refer to the Remuneration Cost Comparison table following in this section for indicative hourly rates.

N.B. If you are generating Gift Cards for clinicians (or consumers who are employed by institutions), please obtain the recipient's private email and have the Gift Card sent there. Professional emails have often been sent to spam folders due to security systems in some institutions and have not been retrievable.

Independent Contractors

Engaging individuals as independent contractors – different steps may apply for those with / without ABNs

This option enables engaging individuals as independent contractors but needs to go through the Finance Team. More information on engaging independent contractors can be found here.

- For those with an ABN, an engagement request needs to be submitted to the Finance Team (one request per person) so they can initiate the independent contractor engagement process. Once individuals have been fully onboarded, a purchase order (PO) will be raised. The individuals can then add the PO number to their invoices and submit them for payment.
  - As these engagements are for 'research' services (not professional services) there is no requirement for individuals to provide Insurance as they are covered by UoM's Insurance.
  - Payments are made in lump sum payments (for an outcome rather than hours/days worked so there is no Superannuation requirement). **You may need to check for GST.
- For those without an ABN, their engagement may need to be handled by People 2.0** (an external contracted company that costs extra), unless they meet any one of the criteria set out in the Statement By Supplier Form, in which case Finance may also be able to handle their engagement. In many cases this is possible if the following criteria is satisfied; when "the supply [of services by the relevant working group member] is made by an individual or partnership without a reasonable expectation of profit or gain".
  - Here is the link to submit an Independent Contractor request:
  - Independent Contractor Engagement Request - Finance and Commercial Services (service-now.com)
- You can submit a single request to Finance via this Service Now Form. As part of this request:
  - Provide a summary of the engagement and details of the individuals you wish to engage as independent contractors on the project.
  - If you have consumers that don't have ABNs and it looks like they would meet at least one of the criteria in the Statement By Supplier Form, i.e., that 'the supply is made by an individual or partnership without a reasonable expectation of profit or gain', it is probably helpful to liaise with the Finance dept generally to see if this could be an ongoing process. Double check with Finance to make sure they are satisfied with generally using this process.
- For consumers it means:
  - sending UoM a copy of Australian Work Rights (for example copies of a birth/citizenship certificate and driver's licence)
  - providing bank details for payment

- signing the service agreement
- Invoices need to be in PDF format and emailed to finance-invoices@unimelb.edu.au
- If you want to submit an invoice on behalf OR

Whoever is listed as the contact will receive a notification to approve the invoice in Themis. Once approved it is in the cycle for payment. You can email or use Finance chat function to check on payment status (the name and PO number are required).

ADVICE RE: Statement by Supplier

This is not a well-known option to UoM Finance however Karen Davies, Independent Contract Advisor (kjdavies@unimelb.edu.au) can make processing this option a possibility. It seems to be an option known to some consumers.

Casual Contracts

Staff Services Knowledge Base articles and guides on the Staff Hub will assist you with Casual Contracts:

1. Casual Contract - Choosing the right payment type for casuals
2. Casual Employment - Hiring a casual
3. How to Bulk Upload Casual Contracts into MCC
4. Casual Employment - Creating/editing casual engagements

In addition, more information is available for the following:

1. Casual Employment - Costings
2. Casual contract - How to enter the costing in Manage Casual Contracts
3. Manage Casual Contracts - Attachments
4. Casual Employment - Approvals
5. Manage Casual Contracts - Setting up Delegations
6. Casual Contract - Person search in Manage Casual Contracts
7. Checking the status of casual contracts
8. Casual Employment - Casual Engagement issues
9. MCC - Your Guide to the New Department Admin View
10. Casual Contracts - Approval Process
11. How to Bulk Upload Casual Contracts into MCC
12. Using the "Additional Approver" field in Manage Casual Contracts

HR Assist can help you every step of the way and they have a live chat function.

Volunteer Agreements and Letters of Agreement

Volunteer agreements are drawn up by HR. Note: having a Deed of Understanding (Conflict of Interest) document for expert and/or working groups simplifies some of the Volunteer Agreement content.

Letters of Agreement (for remuneration via organisation) come through the Research Innovation Commercialisation (RIC) department.

Engaging individuals via UoM casual payroll

This option is to engage the individuals as employees on short term casual contracts. This will involve putting them on the payroll and the fortnightly casual payment cycle (applicable to long projects where consumers are engaged semi-regularly and/or involved in research activities. E.g. interviewing research participants)

If you decide to pursue this option, your next step is to get in touch with the MDHS HR team to discuss employment processes. Rates need to be confirmed by HR as to which UoM level a project participation equates to. (Casual also attracts 25% loading):

a. Involves completion of timecards and HR training requirements (e.g. workplace safety modules)
b. Remuneration is in 3-hour blocks. E.g. attendance at project meetings attracts remuneration for a minimum of 3 hours (even if meeting goes for 1 hour). Completion of timecards is required for weeks when meetings are occurring (e.g. 1 hour meeting attendance, 1 hour pre-reading, 1 hour administration tasks).
c. Consumers are remunerated for the required HR training (minimum 3 hours); this includes loading and preparation time
d. Timecards need to be filled out for payment.

KEY PEOPLE WHO CAN HELP YOU THROUGH THE PROCESS:

Letters of Agreement between Organisations

Jennifer Zheng
Contracts Officer – Research Grants, Contracts & Finance
Research, Innovation & Commercialisation (RIC)

Casual Contracts and Volunteer Agreements They can check if any consumers have pre-existing contracts with UoM (e,g, one person does a small amount of other casual work for the Uni and has already done the training and are familiar with timecards, or if they hold another contract in a different capacity)

Janita Westbury | Manager, Casual Workforce Compliance
Faculty of Medicine, Dentistry and Health Sciences
janitaw@unimelb.edu.au

Sophie De Bavay (legal)
HR Business Partner
Faculty of Medicine, Dentistry and Health Sciences
sophie.debavay@unimelb.edu.au

Stephanie Beckett (legal)
stephanie.beckett@unimelb.edu.au

Independent Contracts are processed by the Finance team, led by Karen Davies. They are keen to get contracts in place before the work commences (though it is possible to process during/after). This can be done as a separate process AFTER the contract has been accepted (via a manual process HR26 form).

Karen Davies
Independent Contractor Advisor
Finance Service Practice Team)
kjdavies@unimelb.edu.au

Recommendation: Make contact with your respective HR, Finance, contracts teams at CDTH.

3.7 Remuneration for Validitron projects

Validitron CCI Activities		
Participant	Hourly Rate	Comments / Other
A Adult consumers	$100	
A Adult actors as consumers	$80	
C Child/Adolescent consumers	$50	
C Clinician	$100	
C Consumers as research team members	$60	
E External Partner consumers in person	$200	
E External Partner consumers online	$100	

3.8 Remuneration Comparisons

	Details	Remuneration	Rates	CDTH Rate
VCCC		**Sitting Fee**	**Monash Partners (MP) Hourly Rates**	
Committee Chair	Strategic advice / Policy / program / research priorities / Leadership / evaluation	$272 ≥ 4 hrs $136 < 4 hrs	MP $60 hr rate: 5-8 hrs = $300 - $480 MP $60 hr rate: 1-3 hrs = $60 - $180 CHF day rate = $616 (based on Remuneration Tribunal for Offices, not specified, Pg 6, 2024)	5-8 hrs = $300 - $480 1-3 hrs = $60 - $180 (hr rate also applies to pre-reading/prep work)
Committee Member	" " "	$234 ≥ 4 hrs $117 < 4 hrs	MP $55 hr rate: 5-8 hrs = $275 - $440 MP $55 hr rate: 1-3 hrs = $55 - $165 CHF day rate = $464 (based on Remuneration Tribunal for Offices, not specified, Pg 6, 2024)	5-8 hrs = $275 - $440 1-3 hrs = $55 - $165 (hr rate also applies to pre-reading/prep work)
Committee Chair	Consumer perspective on working grps, interview panels, project involvement, project governance	$234 ≥ 4 hrs $117 < 4 hrs	5-8 hrs = $275 - $440 ($55, MP) 1-3 hrs = $55 - $165 ($55, MP)	5-8 hrs = $275 - $440 1-3 hrs = $55 - $165 (hr rate also applies to pre-reading/prep work)
Committee Member	" " "	$202 ≥ 4 hrs $101 < 4 hrs	5-8 hrs = $250 - $400 ($50, MP) 1-3 hrs = $50 - $150 ($50, MP)	5-8 hrs = $250 - $400 1-3 hrs = $50 - $150 (hr rate also applies to pre-reading/prep work)
Involvement	Speaking engagement, reviewer role, education, training, panel member at events	$50 per hour		$60 per hour (hr rate also applies to prep work)
Consulting	Focus groups & workshops, interviews, writing, story-telling, program delivery	$40 per hour		$50 per hour (hr rate also applies to prep work)
Informing	Attendance at events etc	$0		

	Details	Remuneration	Rates	CDTH Rate
TANDEM / VMIAC		**Sitting Fee**	**Monash Partners (MP) Hourly Rates**	
Collaborate/ Empower (in line with IAP2 Spectrum description)	Advisory & steering groups, Co-chairing, co-production, policy & service design, brd members, shared authority, etc	$239.80, 1-4 hrs $478 50, 4-8 hrs (incl. GST)	1-4 hrs = $60 - $240 ($60, MP) 5-8 hrs = $300 - $480 ($60, MP)	$239.80, 1-4 hrs $478 50, 4-8 hrs (hr rate also applies to pre-reading/prep work)
Involvement (in line with IAP2 Spectrum)	Workshops, focus groups, interviews, committees, appearances, working groups, storytelling, etc	$192.50, 1-4 hrs $385, 4-8 hrs	1-4 hrs = $40 - $160 ($40, MP) 5-8 hrs = $200 - $320 ($40, MP)	$192.50, 1-4 hrs $385.00, 4-8 hrs
Monash Partners				
Lead or Committee Chair	Council governance, strategic advice, policy & evaluation, providing researcher/consumer training	$60 per hour		
Committee Member	“ “ “	$55 per hour		
Collaborate	Project presentation at conference, project co-lead, working group	$50 per hour		
Involve	Engaging in a project or speaking engagement, co-design workshops, interview panel	$40 per hour		
Consumer Health Forum	**Based on Remuneration Tribunal for Offices not specified, pg 6**			
Chair		$616 per day	$71.50 p.h. x 8 ($60, MP)	
Member		$464 per day	$53.75 p.h. x 8 ($55, MP)	

3.9 Out of Pocket Expenses Reimbursement

New procedure for out-of-pocket reimbursements

A request for Out-of-Pocket reimbursement for Visitors and Honorary staff, previously known as F07, can now be raised by selecting the Out of Pocket option to Visitor or Honorary payee type in the new form.

Please ensure legible scanned copies of tax invoices/receipts and other relevant materials (for example email correspondence) are attached as supporting documentation for the request, including evidence of currency conversion (if applicable) for foreign currency tax invoices/receipts.

Please ensure the correct approver (last section of the form) is selected using **Fetch Financial Approver** function before submitting your request, noting that financial delegation your nominated approver must suffice to cover the reimbursement amount for the corresponding budget unit.

Payment requests below $2000 will not require workflow approval in the Readsoft - ProcessIT system and **an automated approval notification** will be sent to your nominated financial approver. Payment requests above $2000 requests will proceed through the ProcessIT workflow for approval per standard practice

Payment to suppliers without an official invoice should be raised using Payment request for Supplier with no Invoice and Royalties form. A Recipient Created Tax Invoice (RCTI) form is the recommended alternative for payments to suppliers without an official invoice where specific criteria are met.

Expense Claim Form – Consumer reimbursement

(Please attach copy of receipts)

DATE:

CLAIMANT NAME:

Details	Date	Project	Amount

Claimant: _____ Date:_____

Signature

Approval: _____ Date:_____

Signature

_____

Print Name

Reimbursement Payment Details – Australian Accounts:

Account Name: Account No.:

Bank: BSB:

3.10 DURING – Checklist

No	Details	Done
1	Involving Consumers; send orientation pack that includes: Primary contact person (Researcher or CES) Consumer charter and/or principles Meeting dates/times/place Remuneration processes Code of Conduct Consent for contact details to be shared with research team members (templates for the above found in Appendices)	
2	Proceeding: Induction (only if required) Orientation meeting by CES for introductions and relationship-building (when required)	
3	Expectations: Define consumer roles and responsibilities (use Consumer Roles table – found in Appendices) Provide Centre & NIHR principles Consider taking consumers through a project logic session (if required)	
4	Meeting with consumers: Schedule induction/introduction meeting for: Team- and relationship-building Identifying any learning gaps / needs Discuss importance of principles Activities/expectations Co-designing TORs (only if required) Sharing contact details (optional; seek endorsement from the group)	
5	Support Schedule check-ins (only if required)	

4.0 AFTER CONSUMER ENGAGEMENT

4.1 Closing the Loop

Once consumer involvement in your project comes to an end it is time to finalise outstanding processes. Check with the Consumer Engagement Specialist (CES) if you need support.

Depending on the project, The CES or the Lead Researcher will draft and distribute a thank you letter acknowledging consumers' involvement. The letter should contain details of final remuneration processing (if applicable) and an invitation for consumers to stay in touch, should they wish to be informed of the outcomes of the research activities and their impact.

A 1-2 page summary of the project's findings (written by the researcher and/or CES) should be drafted if any consumers express interest in hearing of the project's outcomes.

Consumers' consent will also be sought for their contact details to be stored in the CRM database for involvement in future projects. The CES can provide follow up for any queries, questions and feedback, and can assist to ensure all outstanding remuneration fees are finalised.

Whenever possible, and if requested, keep consumers abreast of the impact of the project so they are aware of the value of their contribution as research partners. Finally, if a published paper is an output for your project, be sure to notify the consumers with a link to the publication.

Templates for the thank-you letter, survey and consent form follow below.

4.2 Thank you Letter

<insert date here>

Centre for Digital Transformation of Health
University of Melbourne
Level 8 - Melbourne Connect,
700 Swanston Street
Carlton, 3056, VIC
Australia

Dear <insert consumer name here>,

On behalf of the Centre for Digital Transformation of Health (CDTH) I would like to thank you for your involvement in the <enter project or activity name here>. We're pleased to have partnered with you and we look forward to your continued connection with our Centre and our communities as we advance our work in the digital health solutions space.

<insert details of any outstanding remuneration here>

Please feel free to stay in contact with our Consumer Engagement Specialist, Leslie Arnott, if you're interested in hearing more about this project (leslie.arnott@unimelb.edu.au). We are always happy to keep our community informed of our projects, activities and progressions.

At CDTH we are committed to a consumer engagement framework that is characterised by authenticity, inclusivity, and impact. We hope your involvement in the work was structured, yet flexible, and that you felt supported and/or empowered to contribute your lived experience and wisdom in a meaningful way.

Your involvement supports CDTH's ongoing commitment to producing research that is community relevant. With this in mind, and with an ethos of continued improvement, we invite you to take part in a short survey (see attached) to share your experiences and insights, and to help us develop the Centre into a place where excellence in Consumer & Community Involvement (CCI) is 'business as usual' in our research projects and activities. Please see survey attached.

Once again, many thanks for your involvement.

Best wishes,

<enter name here>

<enter position name here>

4.3 Consumer Engagement Survey

At the Centre for Digital Transformation of Health (CDTH) we are always looking to improve our consumer engagement processes by using a continual improvement approach to our projects and activities. We invite you to take this short survey to help us better understand how we can make our Centre a place where consumers are empowered to have a say in the future of digital health, including how to access, understand and use their data.

Experience and Engagement

Overall Experience

How would you describe your overall experience participating in this research project or activity? What aspects of the research project did you find most engaging or rewarding?

Clarity of the Role

How clear were you about your role and responsibilities as a consumer in this project? Did you feel adequately prepared for your involvement? If not, what could have helped?

Support and Resources

Were the resources and materials provided useful in facilitating your participation? Did you receive sufficient support from the research team during the project?

Impact of Participation

Value of Contribution

Do you feel your input was valued and made a meaningful impact on the research outcomes? How do you think your participation influenced the research process or findings?

Personal Development

Did participating in this research project enhance your knowledge or skills related to healthcare or research? What personal and/or professional insights did you gain from this experience?

Communication and Collaboration

Communication

How effective was the communication between you and the research team? Where there any communication barriers? Did you feel comfortable raising your questions or concerns throughout the project?

Collaboration

How well did you collaborate with other participants and researchers? Were there opportunities for meaningful dialogue and interaction within the group?

Suggestions for Improvement

Feedback for Improvement

What suggestions do you have for improving consumer engagement in future research projects? Are there additional resources or training that you believe would enhance consumer involvement?

Future Participation

Based on your experience, would you be willing to participate in similar research projects in the future? Why or Why not? What would encourage you to participate again?

Additional Comments

Open Feedback

Is there anything else you would like to share about your experience that hasn't been covered by the questions above?

We would like to thank you for providing feedback for this project. Your insights will help us improve consumer engagement methods and ensure that Consumer & Community Involvement (CCI) is valued, impactful and at the forefront of our research projects and activities.

4.4 Consent Form for Future Involvement

At CDTH we are always keen to stay connected to consumers and communities who work with us on our research projects and activities. If you are interested in being involved in future activities, we invite you to fill out the Consent Form below so we can include your details in our consumer and community database.

Your personal information is important to us and we take care to ensure that it is kept in a secure space in our Centre. Only those working at CDTH on our research projects and activities have access to it. Your information will be stored securely on encrypted servers for a period of 5 years.

Contact details

Name	
Email address	
Phone no.	

Areas of interest (e.g. health conditions/illnesses, digital health solutions, women's health, Indigenous health, rural & remote health, disability, older adults, Culturally and Linguistically Diverse (CALD) health, cancer, heart disease, etc)

Additional aspects of yourself you feel free to share with us that are relevant to your interest(s). Example: lived experience, previous consumer representative experience, previous research activity experiences, organisations or groups with whom you are associated or represent, identifying intersectionality

Signature: _____ **Date**: _____

(By signing this consent form, you are agreeing for CDTH to place your personal information on our secure consumer and community database)

Please return this completed form to Leslie Arnott, Consumer Engagement Specialist, at: leslie.arnott@unimelb.edu.au, or to your relevant research team leader.

4.5 AFTER – Checklist

No	Details	Done
1	Draft and send thank you letter to all consumers that includes: Remuneration payment steps Invitation for us to stay in touch if consumers are interested in the research outcomes after completion of the project Request to complete and return Consent Form for CDTH to retain their details and to be contacted for future projects Request to complete and return Feedback Form Draft 1-2 page plain language summary of the research project if consumers express interest in preliminary outcomes of the project	
2	Follow up on remuneration – ensure this has been processed and consumers have been contacted to verify receipt of payment. Investigate and resolve any outstanding issues (e.g. remuneration for out-of-pocket expenses, non-receipt of Gift Card, etc)	
3	Send Plain Language Summary of project to interested consumers (if required)	
4	Notify interested consumers of any published papers in relation to the project (if required)	

5.0 References

1. *https://www.safetyandquality.gov.au/standards/nsqhs-standards/partnering-consumers-standard*
2. Statement on consumer and community involvement in health and medical research | NHMRC
3. https://unimelbcloud.sharepoint.com/:w:/r/teams/CollectiveImpactIncubator/Shared%20Documents/CDTH%20Consumer%20engagement/02%20Consumer%20Engagement%20Pillar%20Support%20Activity/202311%20Consumer%20Engagement%20Grant%20Writing%20Tips/20230922%20Grant-writing%20TIPS_V1%20-%20Draft.docx?d=w9a9c6f55df344e0bb86d51f91f17f053&csf=1&web=1&e=ena4FC
4. CHF Remuneration guidelines: taken from the Remuneration Tribunal (Remuneration and Allowances for Holders of Part-Time Public Office) Determination (No.2)2024: https://www.remtribunal.gov.au/sites/default/files/2024-06/PTOH%20-%20RT%20Principal%20determination%202024.pdf
5. https://www.learningforinvolvement.org.uk/content/resource/nihr-guidance-on-co-producing-a-research-project/#:~:text=An%20emphasis%20on%20relationships%20is%20key%20to%20sharing%20power.,key%20to%20co%2Dproducing%20research

6.0 Appendices

CASE STUDIES

The following 1-page synopses of case studies are provided to illustrate what good co-productive and co-design practices look like when working with consumers and communities. References for the full paper can be found at the end of each synopsis.

Case Study 1: Fostering African American improvement in total health (FAITH! APP)

About the Case Study

Due to the under resourcing, marginalisation and structural racism in small and large metropolitan areas of Minnesota, disparities existed that exacerbated the prevalence of cardiovascular disease (CVD) amongst African American adults aged over 60. In Minnesota, African Americans experienced higher rates of CVD, and the mortality rate was double that of whites. A faith-based African American community requested that this growing health problem be addressed by local leaders and researchers to find a solution.

The Opportunity

Development of an easily accessible health education program on an App to do two things:

- Incentivise its members to be proactive in self-managed activities to improve their health and reduce the prevalence of CVD
- Provide social support

The Challenge

A history of ongoing structural racism created mistrust in the community, affecting the ability for the App to be successfully co-designed with the community and other stakeholders outside the community (researchers, app designers etc) in order for it to be developed and implemented.

The Approach

After the community-driven research topic was identified, funding secured and research project processes established, Church Champions, who were trusted members of the faith community, were involved in defining the research questions and study design for feasibility of the App. They were also active in building relationships and trust between the community and the researchers. As relationships grew and trust established, community members were comfortable to be involved in the iterative co-designing processes with the research team and other associated stakeholders. Researchers noted that Church Champions' input from the beginning of the project improved the design of the App. Notable aspects incorporated into the App included references to psychosocial needs and preferences, and regular spiritual messaging. Culturally and faith-relevant infographics were also co-developed with the community.

The Success

With co-design principles upheld throughout this project (the sharing of power; reciprocity; everyone was of equal value; contributions from stakeholders were respected; the building and maintaining of relationships) a culturally aligned intervention was developed, the results of which improved cardiovascular health in the study participants. Community involvement and trust-building (especially through the involvement of Church Champions) facilitated exceptional recruitment and retention rates of study participants (98-100% uptake). As a result, the co-production team was able to secure additional funding to expand the reach of the FAITH! App, including beyond faith communities to health centres. Relationship-building between academics and a marginalised community strengthened diversity and inclusion efforts led by the research institution which included revitalising its own strategy for patient accessibility. Relationship-building was therefore key to the overall success of this project.

Brewer, L. C., Fortuna, K. L., Jones, C., Walker, R., Hayes, S. N., Patten, C. A., & Cooper, L. A. (2020). Back to the Future: Achieving Health Equity Through Health Informatics and Digital Health. *JMIR mHealth and uHealth*, 8(1), e14512. https://doi.org/10.2196/14512

Case Study 2: Peer- and technology-supported self-management training tool (PeerTECH)

About the Case Study

Mental health Certified Peer Specialist (CPS) Leaders (trained in peer support, with lived experience) identified a lack of resources to engage older adults (60 years or older) with severe mental illness (SMI) such as bipolar disorder, major depressive disorder and schizophrenia. Their solution was to design an outreach tool that supported geriatric mental health.

The Opportunity

Development of a biopsychosocial digital tool that included tips such as how to make friends, what to do when you're lonely and how to stick up for yourself at the doctor's office.

The Challenge

Ability for older persons to confidently access digital tools is varied. User-specific design of the tool was required to ensure uptake.

The Approach

Researchers and scientists worked with CPSs to co-design an App that was transformed from something that could have been highly medicalised to one that emphasized recovery through self-management. Self-monitoring features were designed to address psychiatric distress, medication adherence and peer support. Peer TECH training was delivered by a trusted CPS leader, ensuring confidence and uptake by end-users.

The Success

Co-designing the App with lived experience CPSs was instrumental in developing a tool that was user relevant. As a result, the App was found to be feasible and acceptable by patients and CPS Leaders. Usage of the App was associated with statistically significant improvements in medical self-management, a sense of hope, quality of life and empowerment. Success of the App has led to foundation and federal funding to continue the work and to widen its availability to end-users.

Whiteman, Karen L., Matthew C. Lohman, and Stephen J. Bartels. "A peer-and technology-supported self-management intervention." *Psychiatric Services* 68.4 (2017): 420-420.

Case Study 3: Creative co-design of back pain education resources – “Talkback”

About the Case Study

Evidence-based guidelines form part of a suite of resources available to physiotherapists for educating and treating clients with back pain. These guidelines provide best practice recommendations; however, physiotherapists are often confronted with the difficulty of implementing them. With co-design quickly becoming recognised as a way of improving the implementation of services and treatment, this case study provides a detailed account of how a creative co-design approach helped to produce and implement prototype evidence-based back pain resources.

The Opportunity

Development and testing of end-user educational resources that are contextually sensitive, evidence-based and ready for implementation.

The Challenge

Ability for clinicians to e enabling clinicians to understand the importance of peer support in people’s recover journey; clinicians’ uncertainties about their ability to explain the complexities of back pain.

The Approach

Researchers and consumers worked together in two workshops to create visual tools that illustrated perceptions and descriptions around pain. Through this process workshop participants became aware of the way in which pain feels in different contexts by different people, enabling clinicians to gain a better understanding of how patients articulate their symptoms. Discussions and the illustrations created in the workshops provided data which was then co-synthesized by the workshop participants. The final output of the project was named ‘Talkback’ and is a package of interacting resources that form a complex intervention that patients and physiotherapists engage with throughout the healthcare journey. Resources for patients include leaflets, online information, an interactive education session, and a workbook that includes action planning and goal setting. Resources for physiotherapists include guidance on using Talkback and training on how to improve back pain communication.

The Success

The case study achieved several key outcomes, including the establishment of a flattened hierarchy that fostered a culture of trust among participants. By utilizing a creative setting, the project effectively encouraged innovative thinking, leading to increased articulation of ideas and deeper understandings among all stakeholders. Additionally, the implementation of the project was facilitated by a rapid adoption and usage of the tools developed, which were embraced by both patients and researchers alike.

Webber, R., Partridge, R., & Grindell, C. (2022). The creative co-design of low back pain education resources. Evidence & Policy, 18(2), 436-453. https://doi.org/10.1332/174426421X16437342906266

Centre for Digital Transformation of Health

The University of Melbourne

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health-informatics@unimelb.edu.au

mdhs.unimelb.edu.au/digitalhealth

Centre for Digital Transformation of Health

THE UNIVERSITY OF MELBOURNE