

# **Consumer and Community Involvement Audit and Needs Analysis**

Findings Report 2022  
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## Document Controls

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## Executive Summary

Health Translation Queensland is committed to supporting a collaborative approach, to strengthening capacity of stakeholders across the partnership, and to enriching consumer and community involvement (CCI) activities. An external consumer and community engagement consultant worked with the Health Translation Queensland Communications and Engagement Manager to undertake a consumer and community engagement audit and needs analysis across Health Translation Queensland's partnership, involving three main activities:

- A workshop with partners to discuss current practices and inform an environmental scan, survey and interviews as well as identifying recommendations for strengthening participation in consumer and community engagement
- An environmental scan through desktop analysis of relevant resources, tools and activities relating to consumer and community engagement in health research, health service design and research translation
- A partnership wide survey to capture lived experiences, barriers and opportunities for Health Translation Queensland partners and community health consumers
- Individual interviews with key stakeholders to better understand their consumer and community engagement capacity, activities, and opportunities for Health Translation Queensland to support consumer and community engagement.

### Key Findings:

- **Growing interest in consumer and community engagement:** there has been a marked increase in consumer and community engagement participation across the partnership and recent changes to grant criteria are top of mind.
- **Barriers to consumer and community engagement and management:** partner representatives are aware of the importance of effective consumer and community engagement however struggle to engage and manage effective consumer relationships with little to no funding or resource capability.
- **No shortage of resources, effectiveness unknown:** although Australia and abroad offer easily accessible resources, frameworks and tools, partners often develop their own internal frameworks and resources. Further a wide library of resources was referred to, but less often utilised in practice.
- **Training requires reconsideration:** 87% of the cohort reported the ineffectiveness of assigned full day training days and reported peer mentoring supported by “bite sized” learnings fed through their current communication channels would be far more effective and reach further.
- **Capacity barriers:** the majority of consumer and community engagement activities reported were unfunded and rely on resources with already limited capacity to meet the demand. Where a role to support consumer and community engagement exists, duties are out-prioritised due to other demands. Where roles are funded, the role is temporary.
- **Tokenistic engagement:** participants were aware of tokenistic consumer and community engagement and the negative impacts on their grant applications, however lacked support and guidance to improve engagement.
- **Misunderstanding:** participants reported misunderstanding on what co-design, consumer and community engagement or involvement aims to achieve, often contributing to poor engagement.



## Recommendations:

As a result of the desktop analysis, survey, interviews and workshop, the following recommendations in order of priority are proposed for Health Translation Queensland to progress consumer and community involvement.

### Recommendation 1: Leadership

Health Translation Queensland could lead consumer and community involvement in defining language, standards of good practice, management, and support across the partnership.

Consider the following areas for leadership:

- Clarify language to define consumer engagement and consumer and community involvement and other commonly used engagement terms and techniques
- Offer guidance on how to involve consumers and community in all stages of a research project; from identifying priorities to understanding and implementing the project itself.

### Recommendation 2: Centralised Consumer Service

To reduce duplication of resources across the partnership, establish a central coordinated consumer service where consumers are educated, recruited, managed, and upskilled.

A network of consumers could be managed within Health Translation Queensland and provided to partners. It is recommended to resource this service with dedicated personnel, estimated starting requirement at 0.2FTE. The role could manage relationships, resourcing and ongoing support for consumers and researchers. Further, this role could support engagement and co-design with consumers and researchers at the project design stage and act as a central knowledge hub for consumer and community involvement in research and health service activities occurring across the partnership (to identify opportunities for further collaboration).

Consider the following as part of the service:

- Access for early career researchers
- Manage pool of consumers and upskill / build their capacity
- Remuneration pathways
- Connect consumer organisations with researchers
- Centralised consumer and community involvement credentialing framework and develop supported education and training material (consider credentialing scope of clinical practice framework via QHEPS)
- Centralised credentialed consumer mentors
- Consumer registry
- Relationship development with peak consumer bodies

### Recommendation 3: Partnership Development

Involve partners, consumers, researchers, and clinicians to develop and understand research priority areas, key research and clinical questions i.e. the Top 10 priorities for future research agreed by patients, carers, and health professionals. Further, this report recommends Health Translation Queensland builds stronger relationships into health services. Note that this research priority setting process is an opportunity not only to identify research priorities, but also to gain buy in and commitment from a range of stakeholder groups.

### Recommendation 4: Central Funding Pool

To allow effective and diverse consumer and community involvement, Health Translation Queensland could develop and manage a central funding pool, potentially with support from its partners. Partner representatives could apply to the central funding pool to fund initiatives to



support consumer involvement. It is suggested that this initiative could be used to support priority setting work with consumers.

### Recommendation 5: Network or Community of Practice

To drive strategy, generate new lines of collaboration, discuss current problems, and promote the awareness of best practice, the establishment of a network, consumer and community involvement community of practice or similar is recommended. Membership of the group would be open to all partners. The group could deliver coordinated quarterly networking events and peer mentoring opportunities. This initiative would support building capacity and provide resources and case studies to promote across the network.

### Recommendation 6: Education & Capacity Building

Facilitate the sharing of information, existing resources, and expertise to the network or community of practice.

- Repurpose and share information without duplicating resources
- Consider developing short “ted-talk” style videos (speakers could be drawn from the CCI network or pool of interviewees from this report) on topics regarding consumer and community involvement including:
  - Case studies
  - Engagement tips
  - Effective consumer and community involvement
  - Co-design training and development
  - How to support consumers
  - Establishing relationships with consumers
  - Advocating at the table for consumers”
  - Science communication training for researchers
  - Consumer partnering training
  - Co-authorship with consumers
  - Access to mentors
  - Management of existing resources and tools
  - Measuring the impact of consumer and community involvement



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## Project Summary

This report summarises the process, goals, participants and resulting recommendations for consumer and community involvement across the Health Translation Queensland partnership. This project was undertaken between September 2021 and February 2022. A review of the available literature, resources, courses, and practices provided insights into the current offering available to clinicians, researchers and consumers, and their translation into practice. Further, input from practitioners, researchers and health consumers was included to provide a deeper understanding.

### General Overview of the Project

This project aimed at understanding current consumer and community engagement resources across the Health Translation Queensland partnership and beyond. This objective was met by the resource list. The resource list provides an extensive directory of organisations, templates, guides, videos and tools for organisations, clinician, researchers, and consumers.

The second objective was to understand the barriers and areas of concern for partners, clinicians, researchers and consumers. This was met through individual interviews with representatives from Health Translation Queensland partners and other identified stakeholders.

This activity also supported the third objective; to identify areas of opportunity for Health Translation Queensland to support their partners.

### Participants, Communication and Engagement

This project was informed by hundreds of resources and individuals from across the partnership with experience or interest in consumer and community engagement. The individuals contributed their knowledge through interviews, surveys, and workshops. Their collective experience was shared willingly from their time served in research, workgroups, on subcommittees, advisory boards, health service initiatives, co-design activities, and grant applications.

The information presented in this report is based on a desktop review, conversational engagement, and an online survey. The report provides considerations and recommendations for establishing consumer and community engagement services and offerings to support Health Translation Queensland partners.

This report is prepared for Health Translation Queensland and aims to better understand the current landscape and considerations and provides recommendations to improve consumer and community engagement across the partnership.

### Purpose

The purpose of the project is to better understand key activities, barriers, and opportunities from Health Translation Queensland partners and to provide recommendations to strengthen consumer and community engagement across the partnership.

### Governance

The project was overseen by Katrina Cutler, Communications and Engagement Manager, Health Translation Queensland, who worked with consultant Jessica Taylor. The two met frequently through videoconferencing to provide oversight, stakeholder information and support project delivery.

### Report Distribution and Access

It is recommended that the final report executive summary including recommendations be made available to contacts identified on the stakeholder database.





## Deliverables

The agreed deliverables for this project were:

- Desktop research and review of current resources and services
- Resource database
- Development of stakeholder survey questionnaire based on desktop findings
- Delivery of stakeholder survey to Health Translation Queensland partners and wider networks
- Stakeholder interviews with consumers, clinicians, Health Translation Queensland partners
- Stakeholder contact database
- Delivery of findings report
- Recommendations from key findings



# Discovery

## Desktop Analysis Report

### Background

The profile and available resources for consumers, researchers and clinicians to engage has increased significantly over the past three years. Consumer and community engagement has moved from isolated activity to becoming more accepted and valued across research projects and health services. A key influence has been Medical Research Future Fund (MRFF) and National Health and Medical Research Council (NHMRC) updating their guidelines to include consumer and community engagement, often weighing heavily on applications. This change has forced universities and health services to engage with consumers to meet criteria. Further, researchers and clinicians are concerned about how to meet consumer and community involvement criteria effectively. Researchers and clinicians are under resourced and lack understanding of how to undertake consumer and community involvement effectively.

### Methodology

The landscape study was carried out as a desk study and field assessment. The literature and activity review and field sample were designed primarily as a description study to provide baseline information on existing activities involving health consumer and community engagement in research.

### Scope of the Report

Where the term “consumer” on its own is used, it is in reference to a healthcare or research consumer. The report focused on several key themes of the current consumer and community engagement landscape and is not a comprehensive account of all activities throughout Queensland or Australia. The engagement activities focused on current Health Translation Queensland partners. In this report the terms consumer engagement, consumer and community engagement and consumer and community involvement are used interchangeably.

### Key Activities - Resource list background and findings

The desktop analysis sourced recommended resources through feedback from stakeholders, independent desk analysis and review of partner resources available to the public. The resource list identifies types of resources, overview, and active links (Appendix 3). A total of 402 resources and publications relevant to consumer and community engagement in research, health service and translation were identified and reviewed in detail. Of the 402, 186 items were considered appropriate to include in the Resources & Services Library (attached).

The following key themes emerged from the accessed resources and literature:

- Benefits
  - Consumer and community engagement offers a diverse range of benefits.
- Tools and resources
  - There is no shortage of resources, training opportunities online however little opportunity to engage, digest the information and apply in practice.
- Consumer rights and access to support
  - The rights of consumers involvement in projects and inability to access similar internal support as health and researcher employees can access.
- Enablers and Barriers
  - Effective consumer and community engagement requires investment of time, resources, system review, policies, and practices at all levels of research and health services.
- Evaluation



- Consumer and community engagement is complex and application of consumer and community engagement is not consistent between research and health service groups, calling for improvement. Clinical trials and health services consumer and community engagement is slightly more considered compared to consumer and community engagement in research.
- Duplication
  - Organisations often develop and fund consumer and community engagement frameworks, guides and online resources but rarely offer ongoing support to implement the material.
- Eligibility Criteria
  - Updated grant eligibility criteria include significant weight in assessment for large grant opportunities and ineffective consumer and community engagement is adding additional barriers to funded projects successfully engaging consumers.

## Key findings to date

### *Key Finding One – Information Overload!*

There is no shortage of toolkits, case studies, resources for consumers, health professionals, researchers, or organisations. The desktop analysis discovered hundreds of resources readily available through an online search. The effectiveness of such resources is of concern with little evaluation. The analysis identified a common theme in which many organisations develop a framework internally however very few proceed to support the implementation of this framework and thus it remains as an online resource.

### *Key Finding Two – Application of Practices*

Whilst the list of resources is seemingly unlimited, understanding the effectiveness of frameworks, resources and tools is lacking. Further, the review identified several case studies discussing experiences of consumer and community engagement however there is a shortage of support and guidance to adopt and implement suggested practices. The analysis identified a lack of human resources to assist researchers or health professionals to recruit, manage, and engage with consumers in their projects. This human resource support and guidance was often referred to throughout videos and papers as a necessity and acknowledged that without human resources, organisations and projects will struggle to apply practices.

### *Key Finding Three – Most referred resources*

Monash Partners and Cancer Australia were the top two consumer and community involvement resource sources cited by participants. Resources from these organisations are readily available but are of varying quality. Review of the resources found Cancer Australia resources' application to health and research translation is sub-optimal albeit a sufficient starting point as a template. Monash Partners offers a range of videos and discussion points; however lacks support in the application of their discussions into practice. Their consumer connection service presents as a vehicle to collect details from interested consumers however there is no clear process for managing those consumers.



## Stakeholder Survey

The stakeholder study was carried out as an online survey disseminated to stakeholders and their networks inviting participants to share their experiences. The survey asked participants about their experiences both positive and negative. Further, participants were invited to take part in an interview to provide additional information on existing activities and experiences.

### Survey Dissemination

The survey was disseminated by Health Translation Queensland, consumer representatives, several clinical and research networks and Metro South Consumer and community engagement office who sent the survey to key contacts. The survey was distributed on 1 October 2021 and closed 25<sup>th</sup> February 2022.

### Survey Limitations

The survey questions were developed by Jessica Taylor through consultation with Health Translation Queensland and participants from the Metro South Research Council. While the survey was widely circulated, it was recognised that people with greater experience and connections with consumer and community engagement would respond thus some bias from respondents was expected. However the survey succeeded in capturing existing involvement, barriers, and opportunities; and identified key contacts across the partnership, supporting the stakeholder database. Further, despite attempts to disseminate the survey to underrepresented cohorts including culturally and linguistically diverse and Aboriginal and Torres Strait Islander communities, it is recognised that these communities are under-represented in the survey responses.

The total number of people who received an invitation to participate in the survey is not known and thus the response rate could not be calculated. The richness of response from those who did complete the survey is noted and their efforts assisted greatly in forming this report.

### Survey Results

A total of 45 people completed the survey. The professional profile of survey respondents is shown below. As people have more than one role across more than one organisation, survey participants were allowed to select multiple categories. Each was recorded as an “experience”. The online data collection disseminated two separate surveys (Appendix 1), categorised as Researchers, Health Professionals and Administrators as Cohort One; and Consumers as Cohort 2.

Category	Experience Count
Researchers	19
Health professionals	4
Consumers	21
Administrator	1
Grand Total	45

## Findings Overview

Consumer related responses from 45 participants indicated that:

- **Proportion of consumers engaged in research or healthcare:** 48% of consumer survey participants had participated in research or healthcare service design.
- **Barriers to participating in research:** all respondents raised concerns regarding the barriers to access research projects and reported confusion about where to apply or how to join to be involved.



- **Poorly managed involvement:** 96% of participants involved in research raised concerns regarding time and management from researchers or health professionals who chose to engage their services.
- **No reliable option to learn of opportunities:** learning of consumer opportunities is reliant on networking and researcher connections with currently engaged consumers.
- **Tokenism:** respondents reported concerns regarding tokenistic co-design and consumer and community involvement efforts across consumer and community engagement generally.

#### Health Professional / Researcher / Administrator Feedback Themes:

- **Good understanding of consumer involvement:** 100% of respondents positively articulated the value of consumers' involvement although participant bias is noted
- **Great attempts at utilisation of consumer and community engagement:** 92% of survey participants reported their efforts to involve consumers in their research projects
- **Less than half of the cohort utilised online resources:** 47% had utilised a framework, toolkit or guide to support their efforts to engage and manage consumers. Although the resources exist, application of such tools is lacking and respondents reports their confusion and overwhelm in attempting to apply resource recommendations in their daily practice.



# Engagement

## Background

Stakeholder engagement was key in developing relationships across the partnership for this project and Health Translation Queensland. The engagement interviews offered an opportunity to reiterate the updated branding and name change of the organisation, as well as offering an overview of key initiatives and activities being considered by the organisation.

Health Translation Queensland partners were identified to interview to gain understanding of their consumer and community engagement experiences. The interviews took place through videoconference (zoom) and varied from thirty-minutes to an hour discussion.

Overall, 24 interviews were conducted with key people across the partnership and community consumers. To note, West Moreton Health was not interviewed due to time restraints and communication response due to staff leave. All participants were eager and delighted to hear of Health Translation Queensland's efforts to better understand the current activities in consumer and community engagement.

## Methodology

The engagement interviews were carried out as a videoconference meeting. The questionnaire and activity review were designed primarily as a description tool to seek baseline information on existing activities from participants regarding their involvement in consumer and community engagement in health service delivery, research, and translation.

## Response overview

- What does ideal consumer and community engagement look like to you?
  - Involvement at the very beginning and considered a peer at every step of the project – true co-design
  - Organised methods of involvement with clear outline and understanding of the consumer role and expectations at each milestone
  - Meaningfully connect with consumer groups who currently advocate in the space
  - Consumers and clinicians/researchers working as peers
  - Eliminating hierarchy and power issues at the meeting table
  - Acknowledging and supporting consumers throughout the engagement
  - Consumer advisory boards
  - Motivated and trained consumers with a permanent position
  - Credentialed and supported consumers to gain understanding and capacity in research
  - Capacity for researchers to engage consumers
  - Training for researchers to explain their project in layman terms
  - Effective resourcing
  - Continuous feedback to consumers engaged in the research
  - Mental health support for consumers where conversations may trigger trauma
- What have you found doesn't work?
  - Current disjointed approach to consumer and community engagement
  - Poor consideration of consumers mental health and wellbeing when engaging in a project that could often trigger a trauma response
  - Tokenism "it is really clear when someone has engaged a consumer to "tick a box!"
  - Funding, funding, funding
  - Peers unable to take different perceptions onboard



- Engaging consumers at the grant review stage only and considering that consumer engagement
- Claims of co-designed engagement when not the case
- Poor organisation i.e. no goal setting
- Lack of time to engage consumers
- Throughout covid-19 masks were a barrier to gauge body language
- Great consumer work going on – but only in small cohorts
- One-off sessions don't work
- Wide surveys will attract the same demographics
- Group consumer and community engagement – people aren't always comfortable to speak up in a group
- People new to consumer and community engagement i.e. lack of understanding from researchers /clinicians and consumers with no experience
- Difficult recruitment processes to follow
- Researchers/clinicians aren't trained in engagement, relationship management or stakeholder involvement
- Full-day or specific training sessions without follow up or mentoring
- Systems and financial processes unable to reimburse consumers
- Under resourced staff
- Poor diversity of consumer representation
- “Health Consumers Queensland offer a great service; however they don't have the expertise in research to effectively manage consumer and community engagement and their training sessions aren't suitable because of this” – researcher
- What education, tools and resources have you found useful?
  - Lunchbox sessions
  - Harrison Paper 2019
  - IAP2
  - “Consumer representatives across Advisory Boards and all levels of a project is a great resource” – clinician/researcher
- What resources, education or other support do you think would help to improve consumer and community engagement in research?
  - Consumer partnering training
  - Social media posts with quick, easily digestible facts
  - Co-design training and development
  - “How to support consumers”
  - “Establishing relationships with consumers”
  - “Advocating at the table for consumers”
  - Science communication training for researchers
  - Access to mentors
  - Funding to recruit
  - Collaborative Community of Practice
  - Co-authorship with consumers
- Where do you find consumers?
  - Current connections and network
  - Health Consumers Queensland



- Peak consumer bodies
- Online Facebook recruitment
- Clinics
- Patient Liaison Services
- The future of consumer and community engagement: how can Health Translation Queensland better support your role?
  - Consumer and community engagement integrity checks!
  - Part-time consumer and community engagement officer role
  - Centralised and coordinated consumer service
  - Assistance with consumer recruitment
  - Development of consumer network
  - Training and credentialing process for consumers
  - Decision tree pathways
  - Consumer portal to submit their interested and experience
  - Evaluation of resources
  - Effective marketing campaign to educate the wider cohorts on the benefits
  - Engagement Awards Program
  - Platform for researchers to post consumer role opportunities
  - Develop research focused resources including engagement plan, elevator pitch for projects etc
  - Define consumer and community engagement/involvement across the partnership
  - Education for researchers
  - Effective survey design to attract consumers
  - Opportunities for consumers to review grants before submitted to internal reviewers
  - Access to consumers for early career researchers
  - Remuneration!
  - Peer workers as consumers in the health and research systems
  - Consumer network meetings
  - Annual collaborative health/research conferences to identify top priorities and inform research questions/health needs early
  - Lead the development of shared understanding of terminology and develop benchmarks for consumer and community engagement/ involvement through a consumer and community involvement credentialing framework.

## Identified themes

### *Fundamental Principles*

Participants noted a lack of fundamental principles to engage consumers including poorly organised communication with consumers, lack of ongoing communication with consumers following their organised engagement, poor acknowledgement of consumers at meetings and the perceived hierarchy amongst project groups, poor support for consumers throughout the project and lack of understanding regarding the benefits of when and how to engage consumers.





### *Meaningful Consumer and community engagement*

Interview participants discussed the importance of engaging consumers at the beginning of a project and ideally at the research or service issue questioning phase. This does require researchers and clinicians to have an already established relationship and participants noted their difficulties in sourcing appropriate consumer representatives. Further, developing structure and an organised approach with effective recruitment, resources to manage stakeholder engagement and consumer and community involvement throughout the entire process was identified as critical.

### *Education and Training*

Interviewees suggested a peer support program would assist in their consumers and community involvement efforts. They noted the extensive list of resources online however struggle to apply the resources in their practice. Several participants requested additional training however the majority discussed their disappointment in currently offered training and ineffectiveness to apply their learnings into practice. In addition, participants noted their lack of availability to attend training sessions and preferred short and digestible information delivered through their current engagement platforms, for example, Instagram TV “IGTV”.

### *Duplication*

Duplication across the partnership was highlighted with several partner representatives and research individuals currently working on frameworks and resource lists for their internal networks. Further, each partner shared their struggles to source, manage and support consumer and community engagement, despite the growing need.

### *Tokenistic Engagement*

Tokenistic consumer and community engagement was a common concern amongst interviewees. Tokenistic engagement is considered engaging a consumer to “tick a box for a grant application which is often last minute” and is obvious when it occurs in a research application or service project plan. Although participants acknowledged current constraints to engage consumers, there was greater understanding of the benefits to engage consumers early and effectively.

### *Remuneration*

Remuneration for consumer and community engagement and researcher time was supported by all interview participants. Again, noted was a developing requirement to engage consumers at research question stage. However, as the research cohorts are limited in resources and budget before receiving the grant, the financial barrier to support their efforts often resulted in tokenistic engagement. Participants suggested a central funding pool to utilise across the partnership.

### *Opportunity*

Interviewees welcomed leadership across the partnership and identified the significant gap in effective consumer and community engagement. Participants noted Health Translation Queensland’s unique position to relieve pressure, build capacity and support the partnership through centralised and coordinated services addressing the aforementioned themes.



## Partners

### Metro South Workshop Outcome & Recommendations

The Metro South Health Research Partners Forum invited facilitators, Jessica Taylor Consumer and community engagement Consultant and Katrina Cutler, Health Translation Queensland to design and facilitate a consumer and community engagement workshop which took place on 23<sup>rd</sup> November 2020 at the Translational Research Institute, Queensland. The workshop aimed at identifying consumer engagement barriers and opportunities amongst the cohort.

It was acknowledged that those attending the workshop were amongst cohort of professionals who are supportive of consumer and community engagement in health design, research, and translation. The attendees discussed a greater need to educate and showcase examples of successful consumer and community engagement to their colleagues. This recommendation aims at increasing knowledge and understanding of effective consumer engaging through peer networks and current platforms.

The workshop was informed by the experiences of Metro South Research Council members and partner representatives who attended on the day. The cohort discussed four themes including:

- Who and how to involve consumers?
  - Why do we do it?
  - What are the benefits?
  - How and when do we?
- What works?
  - What has worked well for you in the past?
  - What resources have been useful?
- What doesn't work?
  - What hasn't worked well in the past?
  - What are the challenges?
- What helps?
  - What might help to address challenges?
  - What would help you to confidentially undertake consumer and community engagement

### Identified Themes

Key messages from workshop discussions:

#### *Tokenistic Consumer and community engagement*

**Workshop attendees shared their experiences with identified tokenistic consumer and community engagement** where consumers are involved to “tick a box” for a grant application and to meet selection criteria. There was agreement that whilst this is sub-optimal, several barriers lead to this outcome which need to be addressed to combat tokenistic engagement.

#### *Knowledge & Understanding*

It was acknowledged that workshop attendees were amongst cohort of professionals who are supportive of consumer and community engagement in health care design, research, and translation. The attendees discussed a greater need to educate and showcase examples of successful consumer and community engagement to their colleagues. This recommendation aims at increasing knowledge and understanding of effective consumer and community engagement through peer networks and current platforms.



### *Duplication*

**Participants reported duplication of efforts** to manage and engage consumers across the partners and within each organisation. It is important to note the impact of organisational and systematic influencers here, however workshop attendees called for a networked approach to support consumer and community engagement.

### *Recruitment & Ongoing Management*

**Challenges in engaging skilled consumers is a barrier to engagement:** Researchers and clinicians discussed their struggles to engage with consumers where no long-term relationship was established. Further, identifying and sourcing skilled consumers with experience in the health system was also a barrier. There was consensus among workshop participants for the involvement of consumers and suggest mentoring and training to build consumer capacity and networking would be useful.

**Recruiting and supporting ongoing consumer and community engagement is human resource heavy:** Workshop participants reported that despite their best intentions, recruitment of consumers and ongoing management of their engagement is unmanageable. Often this increase in workload with minimal support is a deterrent to engaging consumers and results in poor engagement practices and inability to meet grant criteria.

### *Remuneration*

**Financial support to enable participation:** All participants supported the adoption of financial support for consumers and researchers, prior to grant approval to engage consumer. There was discussion regarding the rigidity of the systems when remunerating a consumer.



## Gap Analysis

### Current landscape and actionable activities to improve consumer and community engagement

Despite the growing interest and activity in consumer involvement in health and research, consumer and community engagement is currently poorly organised across the networks, and only a minority of researchers and health professionals effectively engage with consumers. The duplication of efforts and resources was highlighted across all project activities.

The recent updates from funding bodies regarding the inclusion of consumer and community engagement weighting significantly on grant outcomes is top of mind for partners. However clinical and research groups lack pathways to source and engage consumers in the co-design of their projects. Likewise, there is a growing network of interested consumers seeking education and opportunities to share their lived experiences with health services and researchers.

The following table outlines the current gaps, minimal requirements, and recommended actions:

Current landscape	Future of consumer and community engagement – critical requirements	Recommended action
Poorly organised engagement	Structured engagement	Centralised consumer service and HTQ develop process and structure to build a register of credentialed consumers.
Remuneration a barrier to engage consumers	Centralised funding request source to support consumer and community engagement	Establish a central remuneration funding pool for utilisation across partnership.
Lack of effective education and training for consumers	Co-designed training with credentialed consumers	As part of a centralised consumer service, co-design training with experienced consumers and consultants. Following training, consumers could be granted a level of scope identified in a credentialing framework.
Lack of effective education and training for researchers and clinicians	Short (max 5min) content published across currently referred to platforms such as social media	Co-design short videos on the following topics: peer case studies, consumer and community engagement recruitment, sourcing consumers, connecting with peak bodies, understanding current disease cohort questions through consumer and community engagement, how to communicate research in layman terms, what effective



		consumer and community engagement looks like.
Lack of meaningful engagement, true co-design and understanding of key issues across the partnership	Annual collaborated efforts to jointly identify key research and health delivery issues or needs.	Conferences or workshops inviting peak consumer groups and partners to identify priority areas for research and health service review or design.

## Recommendations

There is growing interest in the engagement of consumers in health and research. This brings opportunities for Health Translation Queensland to work as a key partner and invest in driving consumer and community engagement services in Queensland. To reduce duplication, Health Translation Queensland partner representatives call for a collaborative effort to design a program of work around the following recommendations. The collaboration would be underpinned by partner representation and consumer advice across the partnership at all stages including the adoption and ongoing evaluation of the recommendations.

### Leadership

Health Translation Queensland could lead consumer and community engagement in defining language, standards of good practice, management, and support across the partnership.

Consider the following areas for leadership:

- Clarify language to define Consumer and community engagement and Consumer Involvement and other commonly used terms through marketing material
- Offer guidance on how to involve consumers and community in all stages of a research project; from identifying priorities to understanding and implementing the project itself.

### Centralised Consumer Service

To reduce duplication of resources across the partnership, delivering a central coordinated consumer service where consumers are educated, recruited, managed, and upskilled is recommended.

A network of consumers could be managed within Health Translation Queensland and provided to partners. It is recommended to resource this service with dedicated personnel, estimated starting requirement at 0.2FTE. The role could manage relationships, resourcing and ongoing support for consumers and researchers. Further, this role could support engagement and co-design with consumers and researchers at project design stage and act as a central knowledge hub for consumer and community engagement in research and health service activities occurring across the partnership (to identify opportunities for further collaboration).

Consider the following as part of the service:

- Access for early career researchers
- Manage pool of consumers and upskill / build their capacity
- Remuneration pathways
- Connect consumer organisations with researchers
- Centralised consumer and community engagement credentialing framework and develop supported education and training material (consider credentialing scope of clinical practice framework via QHEPS)



- Centralised credentialed consumer mentors
- Consumer registry
- Relationship development with peak consumer bodies

### Partnership Development

Involve partners, consumers, researchers and clinicians to develop and understand research priority areas, key research and clinical questions i.e. the Top 10 priorities for future research agreed by patients, carers, and health professionals. Further, this report recommends Health Translation Queensland build stronger relationships into health service delivery. Note that this priority setting process is an opportunity to identify priorities and gain commitment from participants.

### Central Funding Pool

To allow effective and diverse consumer and community engagement, Health Translation Queensland could develop and manage a central funding pool, potentially with support from partners. Partner representatives could apply to the central pool to fund initiatives to support consumer involvement. It is suggested that this initiative is developed in collaboration with an annual research prioritisation process.

### Network

To drive strategy, generate new lines of collaboration, discuss current problems, and promote the awareness of best practice, the establishment of a network, consumer and community engagement community of practice or similar is recommended. Membership of the group could be open to all partners. The group could deliver coordinated quarterly networking events and peer mentoring opportunities. This initiative would support building capacity, providing resources and case studies to promote across the network.

### Education & Capacity Building

Facilitate the sharing of information, existing resources, and expertise to the network or community of practice.

- Repurpose and share information without duplicating resources
- Develop short “ted-talk” style videos (speakers could be drawn from the CCI network or pool of interviewees from this report) on topics regarding consumer and community involvement including:
  - Case studies
  - Engagement tips
  - Effective consumer and community engagement
  - Co-design training and development
  - How to support consumers
  - Establishing relationships with consumers
  - Advocating at the table for consumers”
  - Science communication training for researchers
  - Consumer partnering training
  - Co-authorship with consumers
  - Access to mentors
  - Management of existing resources and tools
  - Measuring the impact of consumer and community engagement



## Conclusion

Consumer and community involvement in healthcare and research is a burgeoning area. There is wide support and recognition of the need to formalise consumer involvement and engagement across the partnership. This support is heightened with the push from grant funding bodies and recent grant eligibility changes. It is clear that attempts at engagement at each level of the health system and research cycle has targeted activities to engage consumers and community, however without effective education, support and collaboration, significant barriers will continue to impact translation to the consumer and community.

As evident throughout this report, Health Translation Queensland's partners are not immune to the barriers and challenges to achieve effective consumer and community engagement. Therefore, this report recommends a number of activities Health Translation Queensland could undertake to build capacity and opportunities for their partners, and establish new standards to improve the consumer and community engagement landscape.





# Appendices

## Stakeholder Survey

### *Clinicians/Researcher survey questions*

1. Where are you located? Enter your suburb:
2. Health Translation Queensland acknowledges the diversity across the research and health sector and whilst we have considered the terminology used, we may not have used the right description that aligns with you throughout this survey. We acknowledge that identity is a complex and ongoing conversation. For the purpose of this survey, we ask that you select or expand on what identity best aligns with you (select all that apply):
3. What academic disciplines do you work in?
4. Describe the role of a health consumer in research?
5. Describe what factors have motivated you to become interested in involving consumers in research?
6. Have you involved consumers in your research projects? If so, tell us your experience (number of projects, outcomes, learnings, and opportunities you experienced)
7. Where do you source consumers to engage with research?
8. Have you used a toolkit or framework to engage consumers? If so, which one? Did you find this useful? Yes, why? /no, why not?
9. Where do you see the barriers and/or challenges for consumers when engaging in research?
10. Can you suggest three solutions to help overcome the challenges?
11. If offered, would you utilise a grant to fund the consumer and community engagement for your research?
12. If you were given three wishes to improve consumer and community engagement in research, what would they be?

### *Consumer Survey Questions*

1. Where are you located? Enter your suburb:
2. Health Translation Queensland acknowledges the diversity across the research and health sector and whilst we have considered the terminology used, we may not have used the right description that aligns with you throughout this survey. We acknowledge that identity is a complex and ongoing conversation. For the purpose of this survey, we ask that you select or expand on what identity best aligns with you (select all that apply):
3. In your own words, describe the role of a health consumer in research:
4. Have you been involved as a consumer in research projects? If so, tell us your experience (number of projects, outcomes, learnings, or opportunities):
5. What advice would you give to your previous research team/research project if you could?  
\*Your response is confidential.
6. As a consumer, what's important to you when engaging in a research project?
7. Where do you see the barriers and/or challenges for consumers when engaging in a research project?
8. Can you suggest three solutions to help overcome the challenges or improvements to assist consumer involvement in research?
9. Given the chance, what skills would you like to learn to support you to engage in research as a consumer?
10. How do you learn about consumer and community engagement opportunities?



11. If you were granted three wishes to improve consumer and community engagement in research, what would they be?

*Example of Published Survey*



**Health Translation  
Queensland**

*Accelerating discovery into practice*

## Clinician & Researcher Engagement Survey

Health Translation Queensland is a partnership organisation that brings together 11 of Queensland's major medical research institutes and health care providers. We help to solve some of Queensland's most pressing health challenges by supporting well evidenced research to be more quickly and efficiently translated into clinical practice.

Engaging consumers in research can be a rewarding but difficult task to navigate. Health Translation Queensland is seeking to understand how to better support researchers and clinicians engage consumers as part of their research projects. We invite you to complete this short survey by sharing your experience as a clinician or researcher.

The survey is 14 questions in total and we suggest allocating 10-15 minutes of your time to complete the questions.

All responses are confidential and will help to inform future opportunities for health consumers.

If you require assistance in completing this form please contact us.

**Email \***

Valid email

This form is collecting emails. [Change settings](#)

Before we jump into the survey questions, we ask that you complete three very short demographic questions about yourself.

Description (optional)

**1. Where are you located? Enter your suburb: \***

Short answer text

**2. Health Translation Queensland acknowledges the diversity across the research and health sector and whilst we have considered the terminology used, we may not have used the right description that aligns with you throughout this project. We acknowledge that identity is a complex and ongoing conversation. For the purpose of this survey, we ask that you select or expand on what identity best fits you below: \***



# Health Translation Queensland

Accelerating discovery into practice

## Consumer Engagement Survey

Health Translation Queensland is a partnership organisation that brings together 11 of Queensland's major medical research institutes and health care providers. We help to solve some of Queensland's most pressing health challenges by supporting well evidenced research to be more quickly and efficiently translated into clinical practice.

Health Translation Queensland is seeking to understand how to best support consumer engagement in research. We invite you to complete this short survey by sharing your experience as a health consumer.

The survey is 12 questions in total and we suggest allocating 5-10 minutes of your time to complete the questions.

All responses are confidential and will help to inform future opportunities for health consumers.

If you require assistance in completing this form please contact us.

### Email \*

Valid email

This form is collecting emails. [Change settings](#)

Before we get into the survey questions, we ask that you complete three very short demographic questions about yourself.

Description (optional)

Where are you located? Enter your suburb: \*

Short answer text

Health Translation Queensland acknowledges the diversity across the research and health sector and whilst we have considered the terminology used, we may not have used the right description that aligns with you throughout this survey. We acknowledge that identity is a complex and ongoing conversation. For the purpose of this survey, we ask that you select or expand on what identity best aligns with you (select all that apply): \*

I am currently involved in research as a patient or member of the public (health consumer)



## Engagement Interview Sample Questions

- What does ideal consumer and community engagement look like to you?
- What have you found doesn't work?
- What education, tools and resources have you found useful?
- What resources, education or other support do you think would help to improve consumer and community engagement in research?
- Where do you find consumers?
- The future of consumer and community engagement: how can Health Translation Queensland better support your role?