Inclusive and equitable partnering with consumers

A staff guide for respectful consumer and community engagement with our diverse communities.

Purpose of this document

Partnering with consumers representing diverse community perspectives is an effective way to design healthcare improvements and reduce health inequities. Frequently in healthcare, there is reliance on a small number of consumers to represent the views of many. This may unintentionally increase health inequities because the voices of people who experience barriers to healthcare access may be underrepresented. To address this, Metro North has included a performance indicator in the *Collaborating in Health Strategy 2022-24* for all directorates to demonstrate at least 5 quality improvement activities annually demonstrating partnerships with consumers who are underrepresented in engagement activities.

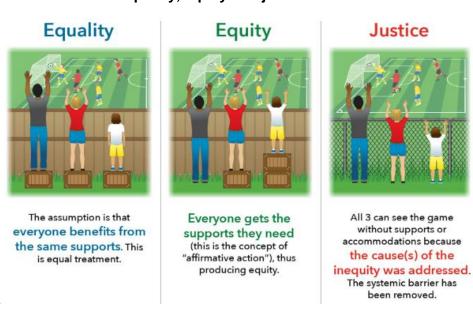
This document outlines strategies and tips for overcoming barriers to equitable consumer participation in healthcare. The concepts of health equity, intersectionality and equitable engagement are described below. It is important to understand these concepts when designing engagement activities.

Health equity and intersectionality

Health equity ensures all consumers (including carers and families) and communities have an opportunity to attain their full health potential and no-one is disadvantaged from achieving this potential by creating an agile and responsive health system that recognises that different people with different levels of advantage require different approaches and resources to achieve equitable health outcomes. This concept is illustrated in Diagram 1. We can only achieve health equity with equitable consumer and community participation.

Metro North's vision is to create a healthcare system that is responsible for addressing health inequities. To do this we must successfully bring together the consumers, health providers and health services as we strive to make health equity our everyday business¹.

Diagram 1 - Differences between equality, equity and justice



Metro North Health Equity Strategy 2022-25



When planning engagement activities with consumers and communities, it is important to acknowledge and understand the concept of intersectionality. The Institute for Healthcare Improvement White Paper on Achieving Health Equity: A Guide for Health Care Organizations (2016) explains intersectionality:

Populations are often separated into distinct groups: heterosexual or LGBTQ; black or white; women or minorities. Making these distinctions is important for understanding differences between various populations. However, these distinctions present a significant problem, as individuals simultaneously possess many characteristics. Thinking about an individual through only one of those lenses does not capture a complete understanding. This idea is called "intersectionality" — a framework for understanding how "multiple social identities such as race, gender, sexual orientation, socioeconomic status, and disability intersect at the micro level of individual experience to reflect interlocking systems of privilege and oppression."

Appendix 2 has examples from the literature of health inequities experienced by people who identify with one or more population groups. Inequities can be compounded when people identify with multiple groups.

Equitable engagement

Equity in consumer and community engagement exists when the resources and opportunities for participation are distributed in a manner that responds to historic and ongoing disadvantages faced by marginalised groups.

Equitable engagement provides **mutually beneficial** opportunities for people to contribute and is mindful of power and privilege within engagement processes, institutions and broader systems².

Consider the following when planning to engage individuals from diverse communities:

- Is this a "table" that everyone can access?
- Can everyone at the "table" participate meaningfully in the discussion?
- Do participants feel at ease at the "table"?
- How will participants be assured they are being listened to and heard?
- Will participants want to re-engage in the future?

Tips for inclusive and equitable engagement

Consumer engagement is about valuing the knowledge and lived experience of a diverse range of people to better understand the problem from different perspectives and work through solutions collaboratively.

Working with community advocates/representatives, for example, community leaders, Elders or community support workers is important, in addition to working with individual consumers.

Be aware there is as much "in group" diversity amongst communities as there are differences across groups and cultures.

When engaging consumers with diverse backgrounds be respectful and offer flexibility about how individuals would like to be identified in terms of their gender, race, sexual orientation, socio economic status or disability. This includes offering the option to "prefer not to say". Some people may prefer to share information about themselves after trust is established. Be cognisant of consumer preferences when describing their identity on meeting agendas and workshop programs.

Here are some practical ways to enable inclusive, equitable partnerships:

² Simon Fraser University Morris J. Wosk Centre for Dialogue. (2001). *Beyond Inclusion, Equity in Public Engagement A Guide for Practitioners*. Downloaded at <u>Beyond Inclusion - Equity in Public Engagement.pdf (sfu.ca)</u> on 18 April 2023 (pp 7).

- Establish trust by building relationships in advance for example, participate in community events that are community led and sustain relationships with community leaders and representatives.
- Avoid a "tick box" approach to diversity. Instead consider the broad range of lived experiences of that each individual consumer may contribute.
- Offer multiple options for people to participate in activities and make it worth their time.
- Hold meetings at a venue that is welcoming, culturally safe and easy to access.
- Allow time and preparation before meetings offer consumers the opportunity to meet with a subject matter expert prior to formal meetings to increase their opportunity to contribute.
- If an individual is asked to "represent" their community or peers, the engagement process needs to
 allow extra time prior to meetings or workshops so consumers can consult their peers about the issues
 being discussed. This means preparing agendas a few weeks prior to the meeting and providing
 relevant information in a format consumers can understand. Consumers need time to consult their peers
 so they can "represent" a range of lived experience perspectives.
- Allow time for consumers to debrief after workshops and meetings particularly if they have shared their personal experiences.
- Offer individuals support to participate. Refer to Metro North Partnering with consumers procedure.

Overcoming barriers to equitable engagement

Table 1 outlines 6 of the common barriers to engagement. Use Table 1 to design activities that enable equitable partnerships. **Appendix 1** has Metro North examples.

There are many resources to guide the design of engagement activitites including:

- 1. Metro North Inclusive Engagement Toolkit
- 2. Aboriginal and Torres Strait Islander Knowledge Lens co-design engagement tool

Table 1 – Barriers to inclusive engagement and how to design equitable engagement³

Barriers	Issues	How to enable equitable participation
Process of engagement	 Consultation fatigue. Lack of consultation. Past negative experiences of engagement and no visibility of feedback being used. Discomfort with formal processes. Problems with techniques of engagement (e.g. meetings, small groups, large groups). 	 Identify previous consultation processes and results of these. Begin by acknowledging past feedback and checking if it is still relevant. Use a range of engagement techniques. Undertake joint engagement with other agencies to reduce the risks of community frustration and cynicism caused by over consultation. Find out what is important to consumers who you are trying to engage and focus the

³ Adapted from a resource produced by Metro South Health. The original source of barriers and strategies is from: Department of Communities. (2005) Engaging Queenslanders: Introduction to working with Aboriginal and Torres Strait Islander Communities, Queensland Government

Department of Communities. (2005) Engaging Queenslanders: Introduction to working with Culturally and Linguistically Diverse (CALD) Communities, Queensland Government

Department of Communities. (2005) Engaging Queenslanders: A guide to engaging people with a disability, Queensland Government

	engagement.	as important.
		 Partner with consumers to design actions that address the issues or problems with past engagement that have been identified.
and information	 Use of jargon and acronyms in committee meetings that are understood by people who work in the organisation but that are unfamiliar to consumers. Lack of follow up communication after community consultation leaving participants asking – "what happened with my feedback?" Cross cultural communication issues. Interpersonal communication and government jargon. Not offering interpreters for people who speak a language other than English. Not offering provision of written feedback in person's 	 Arrange pre-meetings with consumers to prepare and enable them to participate in discussions that require knowledge of the organisation context or technical aspects of care. Promote the adoption of a shared language in meetings involving consumers. Offer training opportunities to consumers specific to the context of their involvement. Document participants' feedback and check back with participants as to whether it accurately reflects their perspectives. Involve participants in all stages of change planning, implementation and evaluation i.e. use a co-design process to enable meaningful engagement and ongoing communication. Use interpreters for people who speak a language other than English/or sign language and/or budget for translation of feedback.
	preferred language.	
and systemic	 Lack of confidence and trust in government agencies and officials. Lack of knowledge about appropriate behaviour with government officials. Feelings of powerlessness and issues of fear and authority. Complicated systems and processes. Lack of clarity between different program components. Expectations that people can access technology and have the skills to use it. Cultural barriers. 	 Be aware of unconscious bias in language and potential for stigma. Always offer people flexibility about how they would like to be identified, particularly in written communication. Offer numerous engagement opportunities which enable people to participate in ways that suit their confidence and ability and avoid over-reliance on technology-based strategies. Make office or meeting environments welcoming to the people being engaged. Ensure transparent decision-making processes which involve consumers from diverse backgrounds: nothing about us without us. Promote services and programs in culturally sensitive ways. Celebrate diversity through events.

	Concerns participation will not make a difference to the outcome.	Develop multilingual printed and online material.
4. Institutional trust	 Fear of authority. Lack of relationship building. Different perceptions about the role of government. Mistrust of government. Perceptions of tokenism and disillusionment based on past experiences. 	 Involve members of diverse communities and/or paid community workers in designing engagement processes. Develop institutional relationships and networks with communities through joint activities and regular communication. Recognise that engagement can be part of a long term relationship building process, which supports stronger links between the health service and diverse communities.
5. Knowledge and capacity issues	 Different levels of knowledge and understanding of community issues. Differing understanding of communication and engagement processes. 	 Minimise power imbalances by listening and developing an understanding of the cultural profile of a community. Respect and value lived experiences and community knowledge and its influence on improving health outcomes.
6. Accessibility	 Location not accessible for people with disabilities, or people who rely on public transport. Work, carer or family commitments prevent participation. Access to and capability to use information technology if required. Health issues. Cannot afford or not able to organise childcare. 	 Undertake an accessibility audit for the activity including the venue and method of engagement. Ask, "what support do you need to participate?" Vary times and locations of the activity. Use multiple engagement techniques e.g. online survey with the option for a telephone call to discuss feedback with someone.

Appendix 1: Metro North examples of engagement with diverse communities

Mental health co-design project

Power differentials can be pronounced in a mental health context for people with a lived experience of mental health issues. Therefore, workshops commenced with activities to address power differentials which saw staff, consumers and carers working together to define what partnership means for the purposes of the co-design initiative and express their thoughts on barriers, enablers and ideas. Staff were asked to put their staff badges and lanyards away.

Community and Oral Health co-design initiative

The team at Community and Oral Health have partnered with the LGBTIAQ+ community. This project started from an observation that services needed to be more welcoming and supportive of LGBTIAQ+ consumers. A co-design approach was implemented, and a working group established. Leadership from the LGBTIAQ + community was essential in capturing perspectives of the LGBTIAQ+ community and their

networks through the working group. Collaboration with the LGBTIAQ+ community resulted in a better understanding about the social determinants of health, breaking down stigma, eliminating discrimination and identifying concerns around confidentiality which can greatly impact on people's healthcare journey. These aspects are very important to person-centred healthcare.

Infrastructure project

The Safe Space was a partnership initiative involving staff, consumers and community partners. A Safe Space committee with leaders from across Mental Health, Emergency Department and Infrastructure Services at TPCH, Mental Health, Alcohol and Other Drugs Branch (MHAODB), as well as four consumer and carer representatives, were involved in the design, furnishing and fit-out of the space, and the development of the service.

To ensure that people with a lived experience of mental health crisis were supported and have capacity to participate in a committee structure, TPCH Mental Health committed to a consumer and carer 'buddying' approach on the steering committee. They recruited four people with a lived experience: two experienced consumer and carer advisors to be "mentors" to consumer "mentees" who were new to this type of activity and had had recent or ongoing lived experience. Processes were introduced to ensure relationships and trust were built within this group with mechanisms for pre-meeting briefings and debriefings and out-of-session consultation.

Ngarrama

Our community partners had ongoing involvement by inclusion in steering group meetings, face-to-face meetings and participation in collaborative working parties to capture their needs and feedback.

Consumers were invited to participate in patient feedback questionnaires and conversations on what they wanted to continue and grow with the Ngarrama service. Yarning circles were also introduced for a less formal more culturally appropriate opportunity to hear their needs and to support connectivity to the service, staff and local Elders.

Respected Elders were invited to participate to hear their knowledge, experience, and aspirations on the Ngarrama service and ways to improve to support a strong start to life for both families and children. Elders were supported to attend informal yarning circles, open days, meetings individually and in larger community forums alongside Ngarrama staff.

Appendix 2: Focus areas for quality improvement identified in the literature

Populations with special needs and groups at higher risk of poor health

The below information has informed the Metro North Local Area Needs Assessment 2022. Please consider the impact of intersectionality when reading the information below.

Some population groups require increased support, resources, and access to health care services to optimise their health and wellbeing. The following population groups have been identified as groups with specific health needs. Their specific health needs are summarised below and sourced from reports and data papers.

Aboriginal and/or Torres Strait Islander peoples⁴

Aboriginal and/or Torres Strait Islander peoples have a high burden of illness and specific health needs. Good health is more than the absence of disease or illness; it is a holistic concept that includes physical, social, emotional, cultural and spiritual wellbeing, for both the individual and the community. Culturally safe and appropriate health services are critical for the overall wellbeing of Aboriginal and/or Torres Strait Islander peoples.

Specific health and service needs of Aboriginal and/or Torres Strait Islander peoples are in the areas of:

- pregnancy care, specifically lack of access to and/or attendance at antenatal care appointments
- low infant birthweight
- · kidney health services and dialysis
- respiratory conditions
- cardiovascular diseases
 - o ischaemic heart disease
 - heart failure
 - o peripheral vascular disease
 - o cerebrovascular disease (including stroke) which affects blood vessels in the brain
 - o high blood pressure
 - o rheumatic heart disease
 - o acute rheumatic fever
- cancer with most common cases of lung, breast, bowel, prostate, health and neck, uterus and liver
- diabetes
- injuries
- substance use disorder
- mental health conditions including anxiety and depression
- disability.

People from culturally and linguistically diverse, refugee, and asylum seeking backgrounds

Culturally and linguistically diverse (CALD) communities may:

- have low levels of health system literacy
- have difficulty in accessing and navigating health services
- have poor service response due to language, literacy, identification of culture, ethnicity or place of birth
- not be provided with, have access to, or use interpreter and translation services
- not be provided with a correct language interpreter or gender or a person may not feel comfortable sharing personal health information with the interpreter if they belong to the same community

⁴ Sourced from government reports, particularly those produced by the Australian Bureau of Statistics (ABS), the Australian Institute of Health and Welfare (AIHW), the Australian Health Ministers' Advisory Council (AHMAC) and the Steering Committee for the Review of Government Service Provision (SCRGSP).

- the ethnicity of the interpreter may impact the sharing of information for some people from refugee and asylum seeking backgrounds
- perceive aged care as something negative and stigmatised, and subsequently be less likely to engage in help-seeking behaviours and regard looking after their elders as a family responsibility
- have spiritual, physical and/or cultural needs, preferences, beliefs, behaviours, and traditions needing consideration
- have cultural beliefs that prevent access to or engagement with areas such as mental health, sexual health, aged care and palliative care
- not have awareness of screening and sexual health prevention due to lack of information and stigma
- have a preference for gender-specific health care for men and women's health issues
- be less likely to seek help for their health, particularly men from a CALD background
- have limited understanding and access to disability support and services
- Other factors to be considered include:
 - Migration and visa status
 - Experience of past trauma and exile/ separation from home and family
 - Experience of discrimination and racism
 - Socio economic/ social determinants of health.

The top four areas showing the highest areas of use in Metro North Health (2021-2022) for admissions for people born in non-English speaking countries were:

- Emergency Department
- Obstetrics
- Renal/nephrology
- Oncology.

The top contributors to Potentially Preventable Hospitalisations (PPH) were diabetes complications, urinary tract infections and cellulitis, together accounting for 46% of PPH. People from a range of CALD backgrounds have higher rates of diabetes and diabetes related hospitalisations.

The Pacific Islander community are less likely to engage in preventative health, have low literacy and social determinants of poor health, and are presenting at hospital at a higher acuity for chronic disease such as diabetes.

People from refugee and asylum seeking backgrounds:

- are more likely to be affected by mental and emotional health and wellbeing, short and long-term
- · vitamin and nutritional deficiencies are health issues in some refugee background communities
- trust and perceptions of feeling safe and welcome in health services
- much less likely to make a complaint due to perception that it will impact care
- less likely to understand health is a human right.

People with a disability

A disability can encompass intellectual, cognitive, neurological, sensory, physical or psychosocial impairments. People with disabilities are diverse with unique needs and experiences which should be recognised and addressed ⁵. People with disabilities (inclusive of intellectual and physical disability) ⁶ may:

- have high rates of comorbidities
- have low levels of health literacy
- need health navigators/ disability liaison officers in health services
- need special care and services for transition to adulthood

Oueensland Health COVID-19 Policy and Action Plan for Queenslanders with Disability 2021 National Roadmap for Improving the health of people with intellectual disability July 2021

- need support with healthy lifestyle
- need increased access to dental services.

People with disabilities experience:

- more than twice the rate of avoidable deaths
- twice the rate of emergency department and hospital admissions
- substantially higher rates of physical and mental health conditions
- significantly lower rates of preventative healthcare.

Older persons

Older persons accessing care may have cognitive impairment and / or frailty which can add to the complexity of care required during their treatment Specific health and service needs of older persons include:

- care needs to be coordinated across providers and across settings including transition of care between providers and age groups
- difficulty in health system navigation due to low levels of literacy
- appropriate and respectful care for older people with cognitive impairment, palliative and end of life care.

People who are homeless or at risk of homelessness⁷

The highest service needs are in the areas of medical, mental health and drug and alcohol services. Other health and service needs include:

- lack of access to a regular GP
- no fixed address impacting care
- health problems as consequence of homelessness, including depression, poor nutrition, poor dental health, substance abuse and mental health problems.

A survey of individual 1578 adults experience homelessness in Brisbane 2019-2022 found the following8:

- 90% of individuals have used at least one public emergency department
- 69% have current or past experience of trauma
- 62% have anxiety diagnosis
- 63% have diagnosis of depression
- 28% have asthma
- 24% have a brain injury or head trauma
- 22% have experienced dehydration
- 18% have Hepatitis C

Persons' experiencing domestic and family violence 9

Specific population at risk women, children and young people, people living in lower socioeconomic areas, people living in remote areas, Aboriginal and/or Torres Strait Islander peoples. Specific health and service needs include:

- high needs in depressive disorders, anxiety disorders
- hospitalised admissions due to injuries, physical assault and sexual assault.

⁷ AIHW Health of people experiencing homelessness 2020

⁸ Brisbane Zero Data Collaboration. (2019-2022). Unlocking systems to end homelessness Brisbane Zero. (Over 3 years 1578 individuals experiencing homelessness in Brisbane were surveyed about their physical and mental health conditions.) brisbanezero@micahprojects.org.au.

⁹ AIHW Health impacts of family, domestic and sexual violence

Lesbian, gay, bisexual, transgender, intersex, and questioning (LGBTIQ+)

Specific health and service needs include:

- difficulty in navigating the health system
- access to health professionals that possess adequate knowledge and sensitivity to assist LGBTIQ+ consumers
- high rates of substance use and alcohol consumption among people who identify.

Children and youth 10

Around 1 in 4 children in Australia aged 5–14 are overweight or obese.

Children population group of focus with higher health needs are Aboriginal and/or Torres Strait Islander children, children from CALD communities or children born overseas, children living in different geographical areas (remoteness), children living in areas which different socioeconomic characteristics and children with disability. Children also have high needs for dental care.

Mother and babies

Specific health and service needs include:

- mothers in rural and remote areas with reduced access to health services
- teenage mothers, older mothers, and mothers who have multiple births and their babies
- mother born in other countries may influence the health and wellbeing of both the mother and the baby
- high needs for primary and hospital care during pregnancy and birth.

End of life care

Specific health and service needs include:

- access to palliative care locally and in the home setting
- cultural, spiritual, psychological, emotional and bereavement needs of family and carers. Families and support of a patient at end of life are identified as requiring additional support during this period. Access to social work is required for all patients and their families and support networks.

¹⁰ AIHW Australia's children in brief 2019