

AMPLIFYING THE YOUTH VOICE:

**HEALTH CONSUMERS
QUEENSLAND YOUTH
ENGAGEMENT FRAMEWORK
2021**

ACKNOWLEDGEMENT OF TRADITIONAL OWNERS

The Board and staff of Health Consumers Queensland acknowledge the Australian Aboriginal and Torres Strait Islander peoples of this nation. We acknowledge the traditional custodians of the lands on which our organisation is located and where we conduct our business. We pay our respects to ancestors and Elders, past, present and emerging for they hold the memories, traditions, culture and hopes of Aboriginal and Torres Strait Islander Australia.

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CONTENTS

Glossary	2
References	3
Health Consumers Queensland Message	4
Youth Reference Group Message	5
Background	6
Why Focus On Young People?	8
Who Do We Mean By Young Health Consumers?	10
How Does This Engagement Framework Relate To Other Engagement Or Youth Strategies?	11
What Other Networks Exist For Young People To Get Involved?	12
Our Vision	13
What Does This Framework Do?	14
Principles For Engagement	15
When Engagement Makes A Difference	18
Measuring Our Success	20



GLOSSARY



Young Health Consumers

Young Health Consumers are health consumers who are in the age range from 16-25 years old, with some flexibility at either end of the scale. Health consumers are people who use, or are potential users, of health organisations including their family and carers. Consumers may participate as individuals, groups, organisations of consumers, consumer representatives or communities.

Health Consumer Representatives

A health consumer representative is a health consumer who has taken up a specific role to advocate on behalf of consumers, with the overall aim of improving healthcare for all. They may be nominated and supported by, and be accountable to, a consumer organisation.

Consumer Engagement

Processes through which consumers and carers actively partner with health organisations in their own healthcare and in health policy, planning, service delivery and evaluation at all levels of the health system.

Engagement Activities/Opportunities

Consumer and community engagement activities or opportunities may vary according to the level of influence consumers have over the process, and may include panels, presentations, positions on committees and working groups, co-design roles, consultations or focus groups.

Low-Value Care

Low-value care is care that provides little or no benefit, may cause patient harm, or yields marginal benefits at a disproportionately high cost.

Health Literacy

Health literacy has two separate parts:

1. Individual health literacy is the skills, knowledge, motivation and capacity of a person to access, understand, appraise and apply information to make effective decisions about health and health care and take appropriate action.
2. Health literacy environment is the infrastructure, policies, processes, materials, people and relationships that make up the health system and have an impact on the way that people access, understand, appraise and apply health-related information and services.

Health Services/Organisations

Health services refers to public and private health and community services delivering services that include health promotion, disease prevention, diagnostic, treatment, primary, acute, sub-acute and support services. It also includes the policies and activities of departments and Ministries, and related non-government organisations, consumer and community groups and professional associations as well as the university health sector.

Primary, Secondary and Tertiary Health Services

Primary care is community-based health care, for example GPs, Dentists and Practice Nurses. Secondary care mainly refers to specialists in private practice. Tertiary care refers to advanced specialist care such as hospitals, palliative care, and intensive care.

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HEALTH CONSUMERS QUEENSLAND MESSAGE

Young health consumers have a significant role to play in shaping health services and influencing system change. As the entire world grapples with the implications of the COVID-19 global pandemic, safe, affordable, timely and accessible services that are shaped and influenced by ALL consumers have never been more important.

Amplifying the Youth Voice: Health Consumers Queensland Youth Engagement Framework 2021 acknowledges the value of young people from all walks of life and their right to health services that meet their physical, social, emotional and cultural preferences. The framework provides health organisations with guidance on how to better engage with young health consumers. The work undertaken as part of the project to develop this framework has already led to increased engagement of young people in high-level forums such as the Clinical Senate. The voices of young people can be further amplified through a collaborative approach to strategic actions in the future. The framework lays the foundation for this collaboration to occur and is the first step in the creation of a youth engagement strategy.

The youth engagement strategy will include actions, developed in consultation, for implementation across Queensland.

As the next generation of consumers and carers emerge, it's our collective responsibility to nurture and support them and help build their ability to engage successfully with the system.



Dr Erin Evans, Board Chair,
Health Consumers Queensland



Melissa Fox, CEO,
Health Consumers Queensland

YOUTH REFERENCE GROUP MESSAGE

To amplify the voice of young health consumers, Health Consumers Queensland established a Youth Reference Group in 2020 to ensure the engagement project was undertaken with young people at the helm. The Youth Reference Group came together regularly over the course of the project to help create and shape the vision, priorities, objectives and principles. Their involvement has been critical to the process and the project. The following message was developed in collaboration with them.

We are hopeful that this framework will help shift the mindsets of health professionals, health organisations, researchers and the larger health system, to engage with us in a genuine and meaningful way. As young people, we have unique health needs and it's important to respect and consider those needs when designing, developing, delivering and evaluating health services.

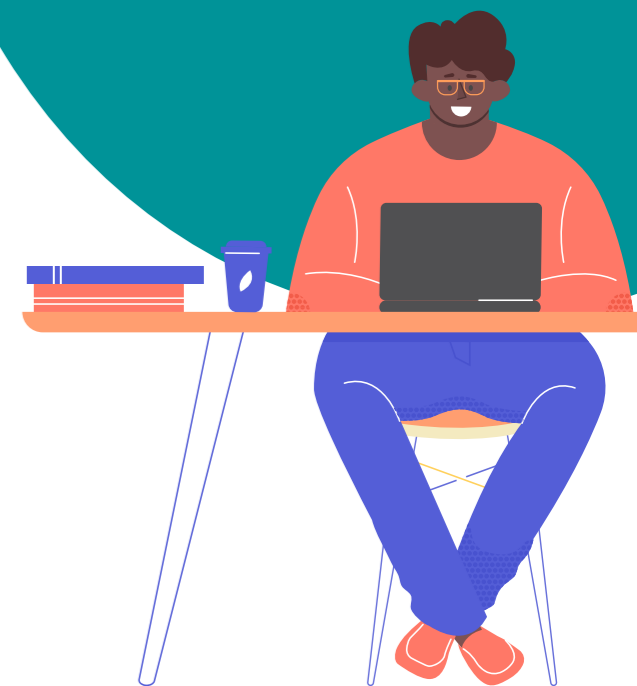
We ask you to take action:

- Challenge your perception of engaging with us and stay curious.
- Tap into multiple voices and perspectives.
- Encourage our involvement and be supportive.

The partnerships developing between young health consumers and health organisations should be underpinned by respect for young people's views. We look forward to engaging with you to amplify the voices of young people and shape our Queensland health services to meet the needs of all young people.

**“OUR GENERATION DESERVES
TO HAVE A SEAT AT THE TABLE.
ENGAGE WITH YOUNG PEOPLE
AND WE WILL HAVE A MORE
COMPREHENSIVE HEALTH
SYSTEM.”**

*Youth Reference Group,
HCQ, 2021*



BACKGROUND

Amplifying the Youth Voice Health Consumers Queensland Youth Engagement Framework 2021

aims to provide a strategic approach to amplify the voices of young health consumers in the development and delivery of health services across Queensland.

Thousands of young people access health services across Queensland, both those specific to young people as well as adult-oriented services. Despite this, young people are often not involved in decision-making processes for the design, development and implementation of health services they access. This framework aims to provide a set of principles to improve the engagement of young health consumers across Queensland health services.

This project has been possible due to the support of Queensland Health and the desire to understand more about young people's experiences and how services and young people can work together to build a better health system.

In September 2020, Health Consumers Queensland brought together a group of young health consumers – the Youth Reference Group - to guide and direct a project to improve youth engagement. The Youth Reference Group participants came from a range of backgrounds including young people from rural backgrounds, people with a disability, young LGBTQI+ people, young Aboriginal and Torres Strait Islander young people, young people from culturally and linguistically diverse communities, young people with chronic conditions and young carers.

Engagement with the group and their engagement with their communities of interest has informed this framework and its principles.

The group worked on the development of a vision, principles and objectives as well as the creation of an online youth network, the delivery of Kitchen Table Discussions and an accompanying survey, and a series of engagement and networking activities. Several key issues emerged including health literacy, inclusive and holistic care and affordability of services. Sexual health and mental health were also raised as topics requiring special attention.



17

17 YRG MEMBERS

11

11 YRG MEETINGS

1.5K

MORE THAN 1500 INTERACTIONS ON THE ONLINE PLATFORM

6

SIX KITCHEN TABLE DISCUSSIONS, AND A YOUTH POLL TO HEAR FROM 66 YOUNG HEALTH CONSUMERS ABOUT THEIR EXPERIENCE OF COVID-19, THE BARRIERS TO ENGAGEMENT AND PRIORITIES FOR HEALTH SERVICES.

66

WHY FOCUS ON YOUNG PEOPLE?

Firstly, the stats...there are an estimated 661,901 young people (13% of the total Queensland population) aged between 15 and 24 years old in Queensland. Of these young people, approximately 463,912 (~70%), live in the Greater Brisbane area, Townsville and the Gold Coast. About 35,884 (~5%) of them are young Aboriginal and Torres Strait Islander people¹.

Mental health problems and disorders account for almost 50% of the burden of disease among young people². LGBTIQ+ young people are five times more likely to attempt suicide than their similar aged peers and LGBT young people are nearly twice as likely to engage in self-injury than their similar aged peers³. Both male and female secondary students who reported a mental health condition were more likely to report higher use of tobacco, alcohol and illicit substances than those that had not been diagnosed with a mental health condition⁴.

Approximately 31.3% of Queenslanders aged 18-24 years are considered overweight or obese⁵ with young people aged between 14-18 years getting 45% of their total daily energy intake from unhealthy foods.

Though these statistics are compelling, they are not the whole story. Only about one-third of young people consider their lifestyle to be very healthy⁶. Health loss in adolescence and early adulthood is characterised by the consequences of risk taking, and mental illness⁷.

Prioritising the engagement of young people in health settings, despite their on average lower utilisation of health services, may lead young people and health practitioners to make better decisions that may even lead to decreased hospitalisation rates and emergency admissions. Improved engagement and health literacy in turn contributes to improvements in decision-making⁸ and subsequent reductions in the prevalence of low-value care, that is, unnecessary tests and procedures.

The engagement of young people has benefits that resound across the entire health system. We want to make sure that young people are informed and educated consumers, and that healthcare is designed and delivered in a holistic way that meets the needs of all young people.

“Young people who feel connected, have opportunities to participate in meaningful activities, are included in decision making and feel safe and secure in supportive environments report better health and mental health. As a result, they are more likely to be engaged in schooling, family life, positive peer relationships, civic activities, employment and contribute to the shaping and building of better communities.”¹⁰

“INVOLVING YOUNG PEOPLE IN THE DEVELOPMENT OF POLICY, PROGRAMS AND SERVICES IS THE RIGHT THING TO DO, AND RESULTS IN BETTER OUTCOMES FOR YOUNG PEOPLE AND THE COMMUNITY.”⁹

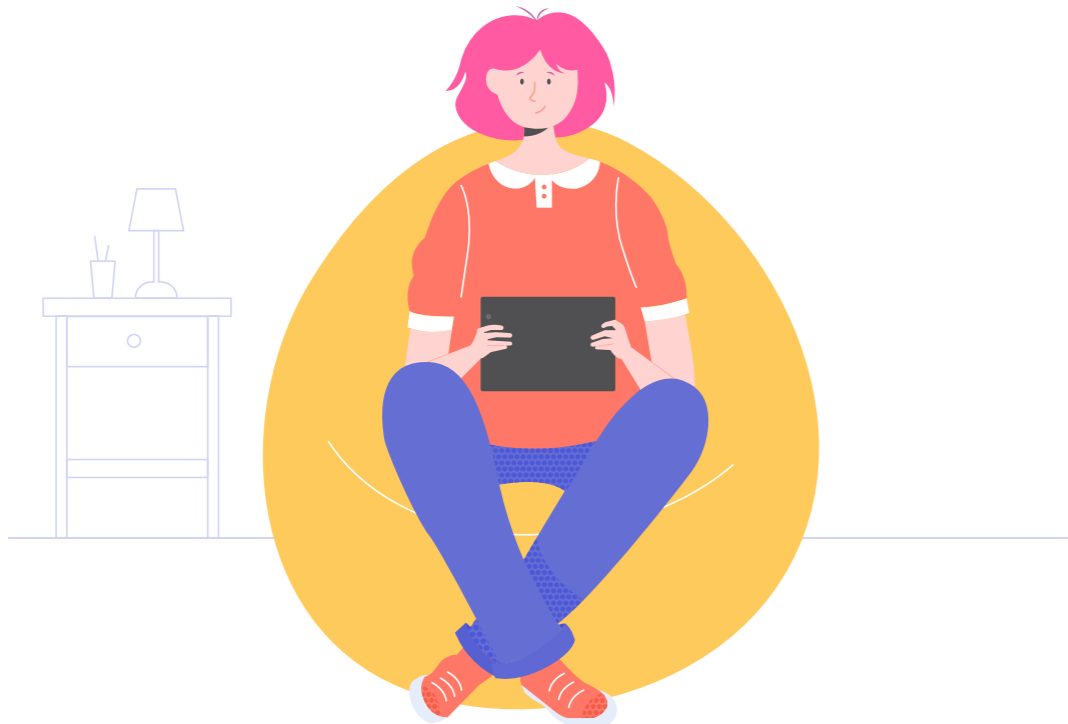
*Youth Engagement Charter,
Queensland Government 2019⁹*



WHO DO WE MEAN BY YOUNG HEALTH CONSUMERS?

There are many definitions that apply to 'young people', dependent on the service, program or activity. The term 'young people' can variously apply to those aged between 13 and 25 years old, 13 to 18 years old, 16 to 25 years old or 16 to 30 years old, depending on the context and the setting. From a service delivery perspective, 'young people' usually does not refer to children (0-12 years) but is specific to teenagers and young adults. Overall, the term 'young people' was preferred by the Youth Reference Group to the term 'youth' though both were considered satisfactory.

For this framework, the terms 'young person/people' and 'young health consumer/s' are used to refer to young people aged between 16 to 25 years. However, this age range is flexible at either end of the scale. For example, a 15-year-old young health consumer may undertake engagement activity in relation to a service aimed at adolescents with the consent of their parent or guardian. Though this framework focuses on young people and does not include children aged 0-15 years, we acknowledge the importance of engaging with children, now and into the future. Engagement of children and young people led by Children's Health Queensland provides an opportunity for further consideration of best practice in relation to children and their families in Queensland.



HOW DOES THIS ENGAGEMENT FRAMEWORK RELATE TO OTHER ENGAGEMENT OR YOUTH STRATEGIES?

A range of other documents exist to support the engagement of young people in the health sector.

1. Youth Engagement Charter – a whole-of-government commitment to engaging with young people.
2. Queensland Youth Strategy: Building young Queenslanders for a global future 2019 - sets the vision for young people to actively contribute to Queensland's economic, civic and cultural life, with a whole-of-government action plan.
3. Queensland Health Statewide plan for children and young people's health services to 2026 - Five service directions for public sector children's health services in Queensland.
4. Strong Bodies, Calm Minds and Resilient Spirits Queensland Aboriginal and Torres Strait Islander Youth Health Strategy 2020-2023 – a strategy developed with young people and led by the Queensland Aboriginal and Islander Health Council.



WHAT OTHER NETWORKS EXIST FOR YOUNG PEOPLE TO GET INVOLVED?

Existing engagement mechanisms and youth networks include, but are not limited to the following:

- Queensland Aboriginal and Islander Health Council (QAIHC) Youth Health Network - The Youth Health Network provides an opportunity for young people to come together, yarn about health and develop solutions for their health and wellbeing.
- Queensland Youth Engagement Panel – the Youth Engagement Panel informs the Queensland government on the best ways to engage with young people.
- Queensland Family and Children’s Commission (QFCC) Youth Advisory Council – the QFCC Youth Advisory Council (YAC) champions the voices of children and young people to provide youth perspectives and leadership to the Queensland Family and Child Commission.
- Youth Health Forum - the Youth Health Forum is a network of over eighty young leaders from across Australia who work together to determine and champion youth perspectives on the current health system, supported by Consumers Health Forum (CHF).

OUR VISION

OUR YOUTH REFERENCE GROUP VISION IS FOR YOUNG HEALTH CONSUMERS FROM ALL BACKGROUNDS TO BE ENGAGED AT EVERY LEVEL OF THE HEALTH SYSTEM, WELCOMED AND SUPPORTED BY HEALTH ORGANISATIONS, AND RECOGNISED AS VALUABLE ADVOCATES AND CONSUMERS.



WHAT DOES THIS FRAMEWORK DO?

This framework is a starting point for improving and increasing engagement of young health consumers in the Queensland health system and beyond, with the aim of better health services for young people and a health ecosystem that values the voice and involvement of young people.

The framework's objectives are to:

- Raise awareness across the health system in Queensland of the importance of working with young people with guidance on different ways to implement meaningful engagement opportunities for young people from all walks of life.
- Encourage health organisations and services to listen to, support and recognise young people and utilise their healthcare experience in the design, development, and delivery of health services.
- Enable young people's voice to be included at all stages of health organisations service design, delivery, and evaluation through the creation of sustainable opportunities for representation such as governance roles, consumer advisory groups, community networks and so on.
- Implement and support programs that optimise young peoples' health literacy, so they are informed and educated about health services, how the health system works, and their healthcare rights.
- Ensure that health organisations have a point of reference for engagement with young people, with service planning and design that considers the needs of all young health consumers.
- Ensure engagement with young people is age appropriate, respectful of values, beliefs and expectations and is culturally safe to participate.

PRINCIPLES FOR ENGAGEMENT

Consumer and community engagement must be underpinned by clear principles. Health Consumers Queensland Consumer and Community Engagement Framework lists four key principles — Partnership, Respect and Dignity, Inclusive, Improvement. The principles reflect our expectation of the way engagement is done and the values we expect engagement to uphold.

Following consultation with young people, a number of key values were also put forward that should underpin any engagement with young people and be considered in line with the existing key principles. Young people want health care that is designed and delivered holistically to meet the needs of all young health consumers; supported by engagement that is age-appropriate, respectful of values, beliefs, and expectations, and is culturally safe.

1 PARTNERSHIP

2 RESPECT AND DIGNITY

3 INCLUSIVE

4 IMPROVEMENT

Engagement Principles

Partnership

Working relationships between engagement partners are built on transparent and accountable processes. The purpose of consumer and community engagement is to shape service delivery to better meet consumer and community needs.

Engagement takes place at all levels of the service: planning, design, delivery, evaluation and monitoring.

Respect and Dignity

Engagement partners value each other's perspectives, knowledge and beliefs and develop relationships based on clear and open communication and shared goals. Partnerships focus on solutions and support the participation of consumers and community.

Inclusive

Engagement processes are accessible, flexible and designed to promote partnerships with populations that reflect the diversity of their communities and identified health needs. The health service engages through outreach and is respectful of existing community resources and expertise.

Improvement

All engagement activities are evaluated by health staff and consumers and findings implemented for continuous improvement. Ongoing training and development opportunities are provided to support the capability building of all engagement partners.

Principles in Action

Guidelines, policies, and procedures are in place to guide transparent, accountable, and creative processes that support staff to create meaningful and equal partnerships within their health organisation and communities.

Consumers and community are engaged at the planning phase of projects to maximise their opportunity to contribute to and shape the outcome.

Consumers and staff are provided with clear information about the engagement activities they participate in, including the scope and responsibilities of their roles (e.g., in Terms of Reference) and the outcomes and progress of their partnerships.

Creative engagement methods are explored to ensure that activities are appropriate for all parts of the community, e.g., people with low literacy, children and young people.

Both health staff and consumer feedback on activities is sought.

Remuneration and reimbursement processes are in place to ensure consumers are not out of pocket and are remunerated for their time.

Health organisations partner with external agencies (e.g., multicultural, youth agencies) and where appropriate external staff lead culturally appropriate processes.

Engagement activities are held external to the health organisation in local communities and are scheduled at a variety of times and days to respect the needs of consumers with work and family responsibilities.

Evaluation of engagement activities is built into all project plans and undertaken to assess the quality of the partnerships and encourage continuous improvement.

Engagement partners have opportunities for professional development e.g., attending conferences, forums, and external training.

All staff and consumers are provided with training on consumer and community engagement, how to partner effectively, and effective communication and facilitation.

What it means for Young People

Engagement opportunities between health organisations and young people are built on transparent and collaborative processes.

Information is shared and health organisations ensure young people are included and supported to contribute to shared goals and decision-making. Young people have access to opportunities to engage with health organisations at all levels and stages of health service design, delivery, evaluation, and monitoring.

Engagement with young people is underpinned with respect and understanding.

Young people's perspectives, knowledge and beliefs are valued, and their participation is supported. They are accepted as who they are and feel free from judgement.

Young people feel safe and supported to engage in a meaningful way.

Young people are provided with support to participate.

Young people's participation is valued.

Engagement is accessible, flexible, and adaptable to meet the needs of young people.

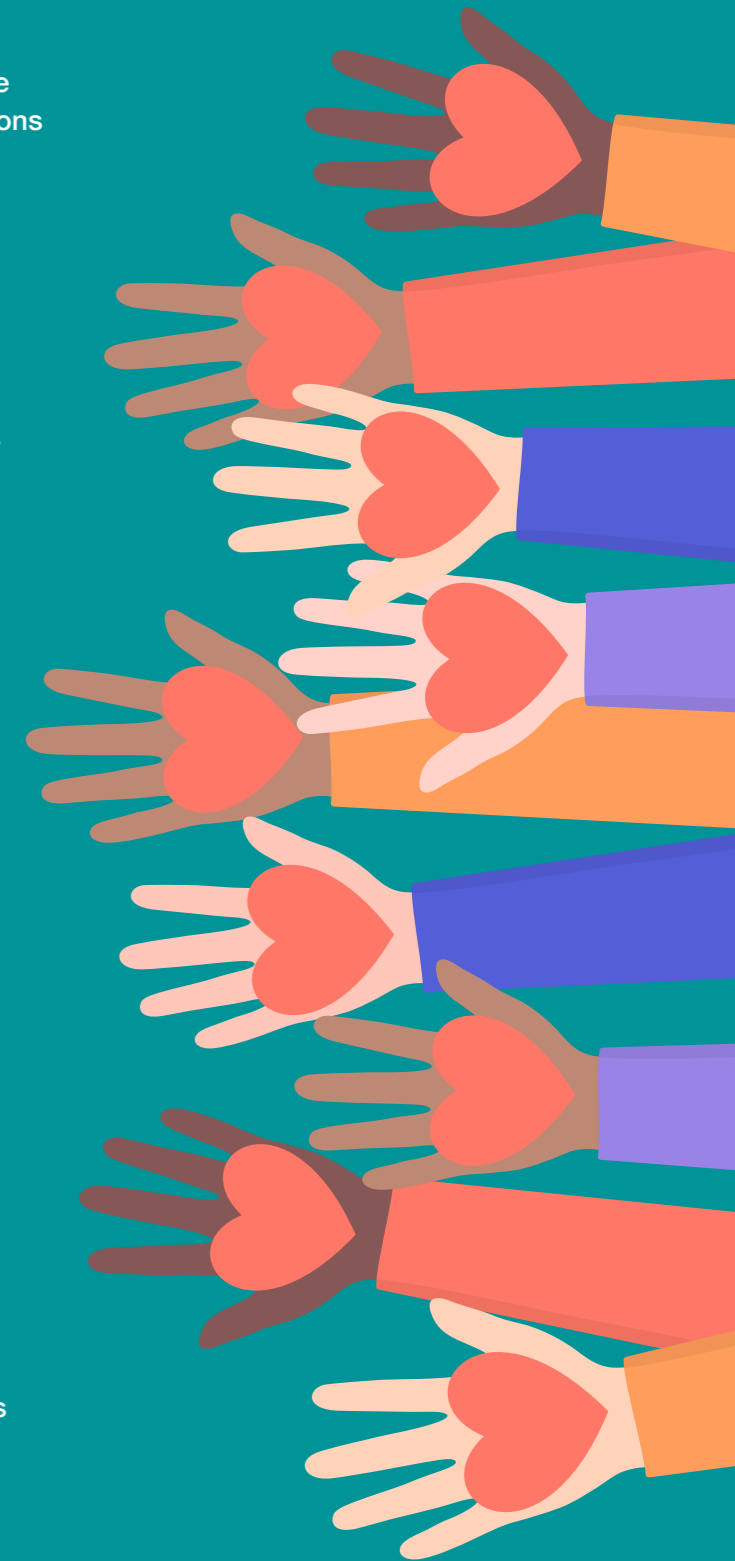
Engagement reflects the diversity of young people and their identified health needs.

A variety of engagement mechanisms are used to collaborate with young people to hear different perspectives.

Young people's participation is valued for its positive impact on health services, improving patient experiences of care and better health outcomes.

Young people can build their capacity to participate in engagement.

Ongoing training and development opportunities are provided to support the capability building of all young health consumers and engagement partners.



WHEN ENGAGEMENT MAKES A DIFFERENCE

Queensland Clinical Senate Adolescent to Young Adult Care: Doing Better Forum

The Queensland Clinical Senate (QCS) Adolescent to Young Adult Care: Doing Better Forum was held on the 4th December 2020 with a focus on the transition from paediatric to adult healthcare services. Health Consumers Queensland supported the Queensland Clinical Senate and Queensland Health to partner with young consumers. QCS encourage and recommend young adults should be included in the planning, design, implementation and evaluation of all recommendations.

The healthcare needs of adolescents and young adults are different to those of adults. The delivery of the right care and support during the transition from paediatric to adult healthcare services is critical improving the experience and health outcomes of young people, family/carers.

We invited Youth Reference Group members to speak at the forum to show a diversity of experience of transition and to demonstrate the “arc” of transition. Youth Reference Group members also participated in the breakout workshops to share their experiences with QCS members.

“THE QUEENSLAND CLINICAL SENATE WERE INCREDIBLY PRIVILEGED TO HEAR FROM 3 CONSUMERS AND CARERS WHO SHARED THE MOST POWERFUL STORIES THAT BROUGHT HOME WHY OUR MEETING ON ‘ADOLESCENT TO YOUNG ADULT CARE: DOING BETTER’ WAS SO IMPORTANT. THANK YOU KEREN, KELLARA AND ELLIE FOR YOUR HONESTY AND COURAGE IN SHARING YOUR STORIES.”

Queensland Clinical Senate, 2020.

Youth Reference Group members shared their feedback about participating in the forum:

“

I feel like some groups, when there is a lot of people around the table who have more experience than you, sometimes you feel like they listen to you, but they don't REALLY listen to you. But with the Senate it was a great example of feeling like you matter and your opinion matters. It was a great experience for me.



“

For me it was a real culture shift. A lot of the audience were senior clinicians and policy makers and can be sometimes a faceless interaction, and tokenistic. But I found it to be really good that they were genuinely interested in the person behind the patient and the patient experience.

“

I found it very comforting even though there was this clinical knowledge imbalance with these senior clinicians from across the State, but they were willing and open and genuinely wanted to know what we had to say from our perspectives. They weren't looking down on us, they were at the same level in the way that we work hand in hand together.



The young health consumers all agreed that knowing that they were not the only young person in the room, generally helped with peer support. They said, “knowing that when we broke up into groups, even though I was only with clinicians it was confronting but there were a few of us so that helped, I was not the only one out of my depth”.

Many of the young people who participated in the forum are continuing to share their experiences and perspectives in ongoing consumer representative roles.

MEASURING OUR SUCCESS

How will we know if we are making change?

The following indicators are offered as a preliminary set of indicators to measure change across the entire health system. Health Consumers Queensland will aim to further develop indicators for success in collaboration with other youth health networks and key health organisations and services.



1 More young people are confident about their ability to engage within the health system.

More young people take up consumer representative positions in Queensland. **2**

3 Health staff are more confident to engage with young people.

Increased awareness of the proposed Youth Network by health consumers and health service employees. **4**

5 Increased number of young health consumers in leadership and decision-making roles helping to shape the health system in Queensland.



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