

Consultation summary report

Lived experience perspective on physical health care

Improving the physical health of people with a lived experience of mental illness and alcohol and other drug use

June 2021

Acknowledgement of Country

We acknowledge the Traditional Custodians on whose land we live, work and play and pay our respects to their Elders, culture, lore and values. We value our Aboriginal and Torres Strait Island cultures as national treasures and embrace them as a vital and rich part of our Australian identity.

Lived experience acknowledgement

We acknowledge the lived experience of those with mental illness or substance use and the role of carers, families, community and workers and the contribution you make to recovery. We thank you for the time and insights you have contributed to this project, which we have strived to reflect with integrity in this report. We honour the strength, resilience and compassion you demonstrate and hold your wellbeing at the centre of our work.

We also thank the peak bodies and service providers who helped our consultants to connect respectfully and appropriately with your clients. We acknowledge your own lived experience and the contribution you make to mental and physical wellbeing in our communities.

This consultation was commissioned by the Queensland Mental Health Commission

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1 Introduction

People with a lived experience of mental illness and problematic alcohol and other drug use can also experience poor physical health. Studies show they may have a poorer health status, lower quality of life and reduced life expectancy because of preventable illness and chronic disease.

In 2019, the Queensland Mental Health Commission (the Commission) published the *Improving physical health for people with a lived experience of mental illness or problematic alcohol and other drug use - Strategic Position paper* (Aspex Consulting, 2019).

This paper highlighted the outcomes of an extensive analysis of the current policy content and impact of the current system on the physical health of people with lived experience. The paper recommended a number of reform opportunities aimed to improve the physical health of people with a lived experience of mental illness and problematic alcohol and other drug (AOD) use.

The recommended reform opportunities were grouped into four categories:

1. Category 1: Individual
2. Category 2: Health service delivery
3. Category 3: System-wide
4. Category 4: Resources and enablers.

In 2021, the Commission engaged Engagement Plus to consult a minimum of 50 people with lived experience to learn their views and perspectives of these reform opportunities and identify preferred priorities for the Queensland Government to invest in.

2 About the engagement

2.1 Designing the engagement

The reform opportunities of *Improving physical health for people with a lived experience of mental illness or problematic alcohol and other drug use* were complex. To make it easier for participants to connect with reform opportunities, Engagement Plus created a board game based on them to make the consultation interactive and fun, while keeping in mind the seriousness of the outcomes.

Engagement was undertaken in focus groups and one-to-one interviews.

It was important to take care of people participating in the consultation activities, ensuring they were undertaken in a COVID safe way, included refreshments and, most importantly, caring for the participants' mental health and wellbeing. In many cases, counselling support was made available by the service providers who partnered with us to host the focus groups. All one-to-one interview participants opted to rely on their usual providers. Information on how to contact Lifeline was also provided.

The consultation focused on 20 reform opportunities in the two categories where the Queensland Government can make the most difference: Category 3 and Category 4. This format was prompted by preliminary discussion with Queensland Network of Alcohol and Drug Agencies (QNADA) who suggested concentrating on the reform opportunities where the outcomes could have the most influence and, therefore, participants in consultation could have the most influence. Discussion with the Commission determined that it was appropriate

to make Category 3 and Category 4 the focus of consultation in this context. Consultation included Category 1 and Category 2 reform opportunities when time permitted.

2.2 How participants were recruited

People with lived experience were invited to attend focus groups or interviews through service providers.

The following service providers hosted groups or helped to contact participants:

- Cairns and Hinterland Hospital and Health Service
- Mind Recovery College
- Central Queensland Hospital and Health Service
- Metro North Hospital and Health Service
- Queensland Injectors Health Network
- SANE
- Springboard.

Fifty-six (56) people participated in the project. Of these, 52 people completed feedback forms. Figure 1 shows the diverse representation of participants.

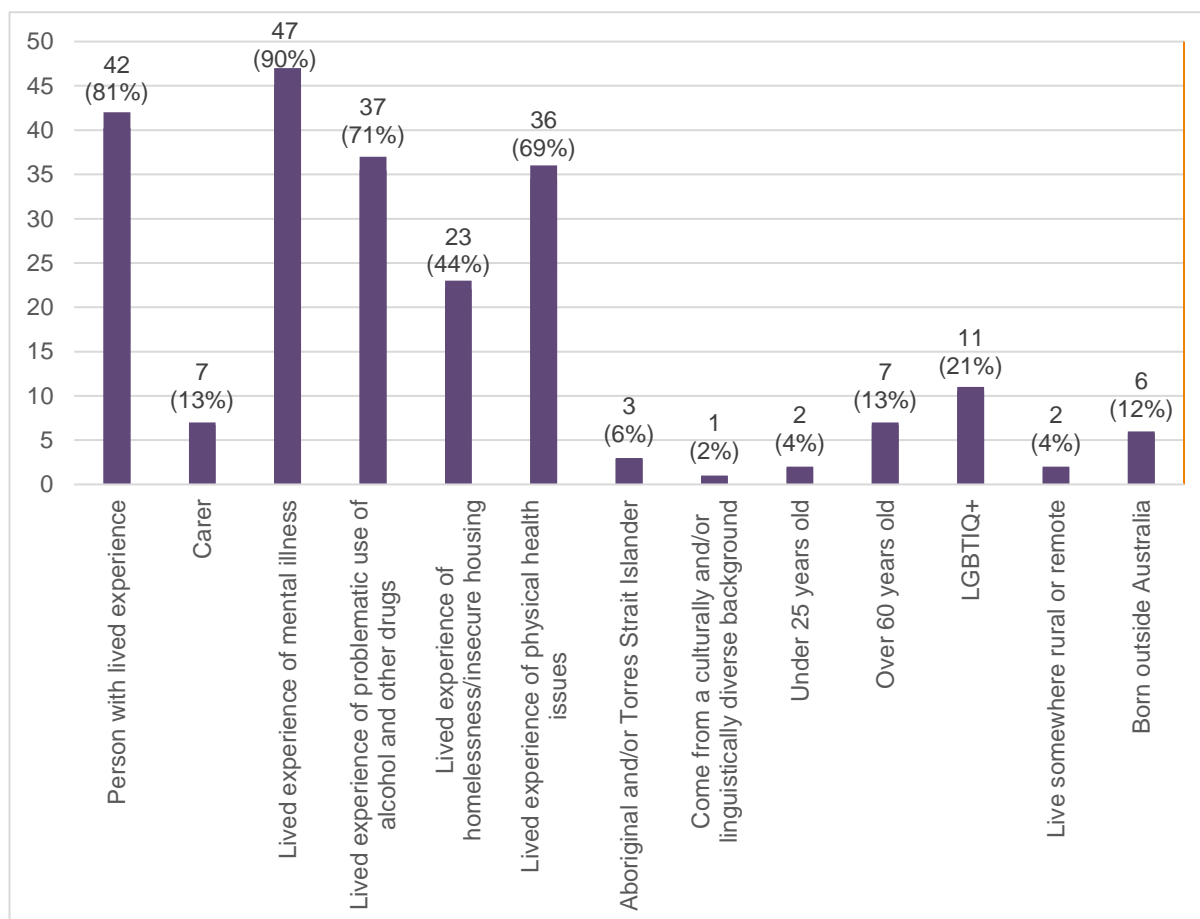


Figure 1: Representation of cohorts, self-identified by participants

2.3 How participants engaged

Participants were engaged via focus groups, one-on-one interviews and an online survey for people who preferred to engage that way.

The focus groups were centred on the board game, as shown in Figure 2, with each person taking a turn to roll the dice, pick a card and lead a discussion on the recommendation written on the card. A priority rating was given to each recommendation, ranking from 1 to 3, lowest to highest priority (although in some cases participants opted for a 0, 4 or 5 ranking). In some cases, opportunities were not ranked, for example due to time constraints; in these cases, comments were assessed and a ranking assigned by the facilitator. Rankings were collated and averaged across focus groups and interviews.

Groups were facilitated by a consultant who guided discussions, where necessary, to ensure everyone had a chance to speak. The facilitator took notes of the discussions, asked questions to clarify understanding, interpreted the reform opportunities when asked to do so and recorded the conversations to be sure nothing was missed. Participants consented to the recordings which were deleted after the discussions were written up.

An interactive digital tool was used for the virtual focus group. For the interviews we either worked through the list of reform opportunities or used the digital tool as shown in Figure 33.

Interviews were based on the *Improving physical health for people with a lived experience of mental illness or problematic alcohol and other drug use - Strategic Position paper* or used the interactive digital tool.

The survey considered the reform opportunities extracted from *Improving physical health for people with a lived experience of mental illness or problematic alcohol and other drug use - Strategic Position paper*.

Participants were paid in accordance with the Commission's [Paid Participation Policy](#). Payment was \$150 per person for focus groups over two hours, and \$75 per person for interviews under two hours.

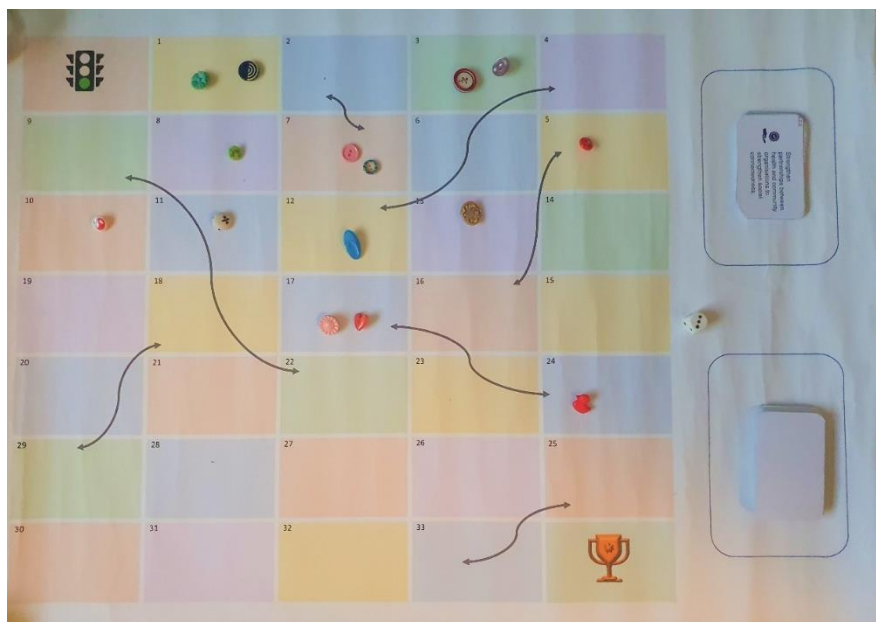


Figure 2: The board game used in focus groups

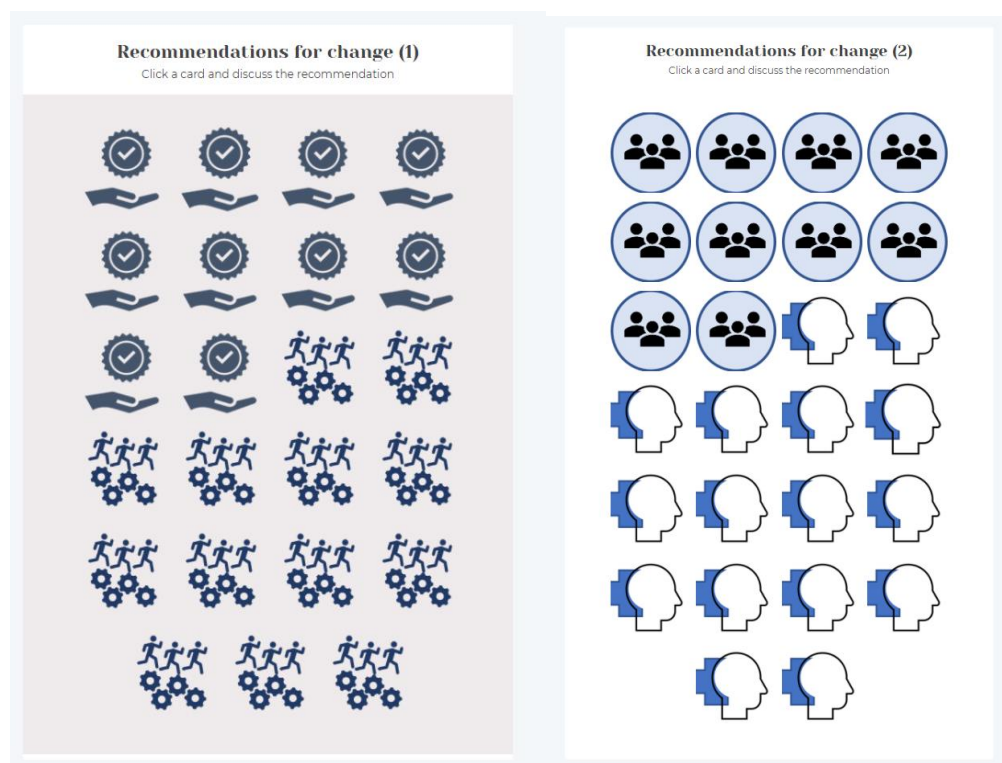


Figure 3: The digital cards used in virtual engagement

2.4 Where participants engaged

Focus groups were held in Cairns, Rockhampton, Brisbane, and online using a video conference platform. Most focus groups were hosted by service providers, allowing participants to come together with other participants they already knew, in a venue they were comfortable with, and with hosts that they trusted.

Three people were interviewed by telephone and video conference. This approach was used either for their convenience or because they lived in remote areas.

3 What participants said

Participants had diverse views on many reform opportunities both within the same group and between groups and interviewees. In the focus groups, participants listened respectfully to alternative views, sometimes moving their position based on new information and understanding, and sometimes they maintained their initial view.

Analysis of all feedback was used to identify:

- top priority reform opportunities overall
- top priority reform opportunities in Category 3: System-wide and Category 4: Resources and Enablers, and
- lowest priority reform opportunities overall.

One task of this consultation was to identify other reform opportunities that were not outlined in the Strategic Position Paper. Participants shared a lot of ideas that were similar to the existing reform opportunities. One additional recommendation was to divert people who were

charged with possession or use of drugs away from a judicial response and into a health response.

Participant comment

You need somebody who helps you effectively navigate care pathways like a Disney princess's sidekick: it's not their story, they don't do it for you, but they're with you every step of the way.

3.1 Priority reform opportunities

Due to the complexity of the reform opportunities, the consultation focused on 20 reform opportunities in the two categories where the Queensland Government can make the most difference: Category 3 and Category 4 and, therefore, participants in consultation could have the most influence.

Category 3 and 4 reform opportunities for change are presented here in order of priority as rated by participants.

3.2.1 Prioritise areas with the highest burden of disease and socio-economic disadvantage for co-designed, inter-sectoral strategies focused on health promotion and integrated service models.

Participants had a variety of perspectives on this recommendation, but positively considered co-designed and intersectoral strategies that focus on integrated service models.

Participants noted that if this reform opportunity was implemented, it would be helpful to have flexible boundaries on prioritised areas. That way, people in adjacent areas would not be left out of relevant health promotion and integrated service models.

Participants said they knew that there was high demand on services. While some participants agreed with this recommendation, others felt it would leave behind those who were not prioritised. Some people noted, *'Mental illness and problematic AOD use occur across the board, not just to poor people'*. At the same time, other comments suggested that *'Money equals power and access to treatment and health interventions'*. Participants questioned the data on the association between poverty, problematic AOD use and mental illness.

Some participants did not like the term 'burden of disease', *'We already know we're a burden on society. No need to rub it in, thanks!'*

4.2.2 Invest in capability building to strengthen the skills and competencies of the workforce.

Participants had mixed views about this reform opportunity. One perspective was that investment should be made in service delivery and to spend the money on people with a lived experience, not on the workforce. There was a concern that workforce development could be a *'...tick-the-box exercise to get training numbers up'* instead of to improve service delivery.

The other perspective was that it is important to support ongoing training and development to build capabilities, skills and competencies so that the workforce can use different approaches and tools. For example, ongoing training and professional development would enable health professionals to use and deliver new therapies, such as dialectical behavioural

therapy and alternative modalities such as reiki or art therapy. There was also a view that workforce investment could be spent on education for people with a lived experience and employing them in a range of roles (i.e. not only as peer workers).

Participants also said that the workforce should be competent in trauma-informed care and in the basics of physical healthcare, for example, taking blood or managing the side-effects of medication. Another area of required competence identified by participants was in providing remote health services and customer care, *'People providing phone services need to be trained to do that. It is very different from face-to-face.'*

There was recognition that workforce roles can change and that staff will be promoted or transferred. In these cases, it is important for workforce to do training and upskilling, including refresher training to make sure they were competent in new roles. This was considered to be particularly important if the staff member had limited experience working in a mental health ward or in AOD services.

Participant comment

Confident and competent staff are proud to work for an organisation that values healthcare.

Communication skills were seen as a major gap, particularly when working with people with a lived experience who may be very unwell and not be able to communicate well. One participant commented on the need for health professionals to, *'...understand that just because a patient isn't talking to you, doesn't mean they have nothing to say'*. The therapeutic relationship and rapport were seen by some participants as more important than the type of therapy. One reason for this was because while continuity of care is so important, it was considered to be very difficult to achieve, *'Having a plan in place is important; it's hard to develop that without continuity of care'*.

There was also recognition that the workforce required better understanding and training in newer and more frequently diagnosed conditions, such as PTSD and clinical depression in children. Participants noted that mental health and AOD training should be mandatory modules for all nursing staff both pre-service and in-service.

The majority of participants also suggested the, *'...workforce should have training in compassion, in being less judgemental'*. At the same time, participants recognised, *'...the high toll on the workforce, that coldness can be a defence against burnout'*. They also said that skills development to build workforce resilience is needed. Staff would then be able to, *'...recognise and respond appropriately and efficiently without feeling personally slighted'*, for example when a person with a lived experience is experiencing a paranoid episode.

One participant commented, *'The practitioner needs to be like a waiter in a busy restaurant where the customer is always right and gets great service without noticing how stressed and rushed the staff are'*. Many participants were concerned that over-worked and under-supported staff could burn out and *become unwell* too.

3.3.3 Strengthen partnerships between health and community organisations to strengthen social connectedness.

This reform opportunity was seen as very positive because social connectedness is important to reduce stigma and isolation. Participants' experience was that community organisations were not well connected with health providers. They said that developing and strengthening partnerships would support effective referral pathways so that community-oriented treatment options could be accessed through community organisations.

Professionalism, conducting and resourcing of community groups were raised as concerns. People with lived experience need to know what to expect from community organisations, for example if they are a service provider or a social or self-help group. Participants acknowledged that there should be enough community organisations for everyone to have access but not so many that they were organisations doing the same things and using up limited public funds.

4.4.1 Invest in performance monitoring, targeted research and evaluation to strengthen the evidence base.

Discussions on this reform opportunity focused on a need to strengthen and expand the evidence base to include a range of alternatives. As such, this opportunity was generally supported, with participants prioritising gathering evidence for therapies that people with lived experience know work for them, but they can't get through current referrals or claim through Medicare. Examples included alternative medicines and therapies as well as traditional cultural modalities such as strengthening or facilitating connection to Country. To have these therapies included in the evidence base would also create awareness for health professionals to provide information and referrals to these alternatives.

Participant comment

Yes, but it must be informed by individuals with lived experience and include holistic alternatives.

There was a strong view that developing performance-monitoring regimes, designing research, and undertaking evaluation must be informed by people with a lived experience and that research subjects must represent diverse cohorts of people.

4.3.2 Invest in critical information technology enablers that enable information sharing between health practitioners.

This recommendation presents as a 'wicked problem' for people with lived experience; it generated a lot of discussion, more than any other reform opportunity for change. Many participants would not consent to their information being shared. There was recognition that investing in this kind of technology enabler would benefit people with lived experience but it would have to be designed to protect privacy and choice.

Participants noted potential benefits of investment in this critical information technology included consistency of care. Participants also noted that it would be more efficient for health professionals and people with a lived experience to have information collected from a person once and then be made accessible among multiple health professionals. They

Participant comment

*Centralised data could have a tyrannical hold over a person; when you've been unwell for a long time it adds up to a lot of data, many comments, and opinions. They add up to, "You're just f*cked up".*

suggested this would also reduce the risk of, '*...being retraumatised by telling our story over and over again*'. However, participants were also concerned that sharing of information could impact on, '*...control over our own story*'. They were also concerned that health professionals having access to historical mental health and AOD records would expose the person to discrimination.

Participants suggested that protecting privacy, supporting choice and reducing the risk of discriminatory practice could be enabled through systems and procedures where the person with a lived experience could control how their information is accessed, for example, opt-in

software to services could share data, but the person with a lived experience could say *'Here, I share my file; you can see it, you can add to it'*. Participants also recommended that providers, *'...should do the notes with the person, not a report afterwards'* and that there should be, *'...profoundly robust ways to challenge and correct information about yourself'*.

3.1.5 Develop prevention strategies for oral health for implementation across clinical mental health and specialist AOD treatment services and public-funded oral health services.

Oral health was identified as a significant issue by all participants. Dentists are, *'...scary and expensive'*, a challenging combination for most people, regardless of mental wellbeing. Publicly funded oral health was very important because, as one participant said, *'Poor oral health equals poor physical health equals poor mental health'*.

Participants acknowledged that prevention is better and cheaper than cure; however, intervention rather than prevention was seen as being more useful to repair damage before symptoms worsen and teeth are lost. It was considered critical that strategies for oral health care include information and options for managing the impact of certain medications, for example how to get a dental splint to reduce impacts of medication-induced grinding of teeth.

Participants also commented on the issue of a person's ability to self-care during acute episodes, *'Personal physical self-care doesn't happen when you're having an episode. We know it's important, but it's going nowhere until someone is well enough to get out of bed, let alone brush their teeth, let alone go to a dentist'*. Prevention strategies need to address capacity for self-care and provide relevant information and support options to empower a person to improve their self-care routine when well enough to do so. Strategies should also consider the role of the carer and support person when a person is unable to care for themselves and experiencing an acute episode of ill health or substance use.

Participant comment

Need subsidised dental care once the damage is done to build you back up, heal physically as well as mental health and AOD recovery.

Participants commented on the issue that, in recovery, the public health care system may fund extractions but not dentures, resulting in poor nutrition, low self-esteem, impacts on social connectedness, reduced help-seeking and potential relapse.

3.2 Other reform opportunities priorities

Table 1 shows the highest priority reform opportunities overall, as ranked by participants. They are all from Category 1 and Category 2. It should be noted that fewer participants provided comments and rankings for Category 1 and Category 2 reform opportunities because more time was spent on Category 3 and Category 4 reform opportunities with Category 1 and Category 2 reform opportunities discussed where time permitted.

Table 1: Highest-rated reform opportunities across all categories

Reform opportunity (recommendation for change)	Average priority rating	Sample of participant comments
2.2.6 Co-design models of care with people with lived experience to ensure services are culturally safe, relevant and accessible to	3.20	<i>100% yes, because otherwise they won't know what people need.</i>

Reform opportunity (recommendation for change)	Average priority rating	Sample of participant comments
populations including Aboriginal and Torres Strait Islander people, culturally and linguistically diverse people and LGBTIQ people.		
1.1.5 Invest in opportunities for individuals with lived experience to connect into local activities and support services.	3.00	<i>Social inclusion, connectivity, acceptance, purpose in life and a reason for living are all necessary things in life.</i>
1.1.6 Promote the importance of the psychological and physical wellbeing of carers and families.	3.00	<i>This is very, very important. (It) isn't allowed for enough. Often, it's the only thing for a person in early stages of getting better. (They) might not have many people and the ones they have are struggling to do their own thing.</i>
1.2.1 Jointly develop and promote clear clinical care pathways.	3.00	<i>There should be a portal where professional and lived experience people can log in and find each other Online navigation could be with chat support.</i>
1.2.3 Target investment in care coordinators/nurse navigators and case management support.	3.00	<i>Divert people with a mental health need from GP appointments to a care navigator, so GPs don't have to know everything. But where are these care navigators?</i>

3.3 Lowest priority reform opportunities overall

Table 2 shows the reform opportunities that received the lowest ratings across all categories. Again, note that more time was spent on Category 3 and Category 4 reform opportunities than Categories 1 and 2. The upper rating cut off for these ratings was 1.89 points. Above that, the gap between ratings is then 0.11, the second largest gap in the ratings after the gap of 0.20.

Table 2: Lowest-rated reform opportunities across all categories

Recommendation for change (reform opportunity)	Average priority rating	Sample of participant comments
2.1.2 Develop a joint statement between the Royal Australian College of General Practitioners, Australian College of Rural and Remote Medicine, Royal Australasian College of Physicians and the Royal Australian and New Zealand College of Psychiatrists to clarify	1.40	<i>Sounds like an HR response. Does it develop medical practitioners' capacity? Do they not know it's their job? Joint statements don't make change.</i>

Recommendation for change (reform opportunity)	Average priority rating	Sample of participant comments
the role and responsibility of medical practitioners working across primary, secondary and tertiary care settings. Allied health professional bodies should also develop position statements regarding accountability of their respective providers.		
2.1.3 Develop a joint communications strategy to reinforce roles and responsibility expectations.	1.60	<p><i>Joint... by whom? Communicating to whom?</i></p> <p><i>Better ways of communication and effective handovers can be essential in helping a person get better.</i></p>
4.4.3 Establish shared 'performance measures' that assess performance of the system as a whole.	1.71	<p><i>Yes but why don't we already do that!</i></p> <p><i>Not everyone needs to access the whole system.</i></p> <p><i>How and who would assess these measures? Who would have access to this criteria?</i></p>
2.1.4 Review the extent private health insurance provisions create barriers to the provision of integrated physical and mental health service provision.	1.75	<p><i>Private health cover is a luxury.</i></p> <p><i>You can't get it if you've hurt yourself in the past.</i></p> <p><i>We shouldn't need private health insurance for a high standard of care.</i></p>
3.1.2 Continue current comprehensive implementation of biomarker screening across clinical mental health and specialist AOD treatment services.	1.77	<p><i>It's not trauma-informed. Mental health care must be holistic.</i></p> <p><i>Using (it) to determine which medications may work best is a useful thing if it works.</i></p>
3.1.4 Implement systematic and comprehensive prevention strategies, with a priority focus on smoking cessation, across clinical mental health and specialist AOD treatment services.	1.80	<p><i>People know what their priority issues are, and if it's not smoking, that's their choice.</i></p> <p><i>You can't just ask people to stop without doing something to support them.</i></p>
4.4.2 Invest in data capture systems and data monitoring to drive uptake of evidence-based approaches.	1.88	<p><i>There should already be a place to do this in the systems.</i></p> <p><i>They need to ask the right questions ... data needs to be interpreted without prejudice or politics getting in the way.</i></p>

Recommendation for change (reform opportunity)	Average priority rating	Sample of participant comments
4.1.1 Independent review of the capacity of funding models to support patient-centred models of care. This includes funding mechanisms for primary care, pharmacy, and dental care, among other service streams.	1.89	<i>A good idea, but incredibly costly.</i> <i>Patient-centred should be business as usual.</i>

4 Participants' feedback on engagement

There were 56 participants across all forms of consultation. Of these, 52 completed feedback forms.

This feedback indicates that the consultation was a worthwhile and enjoyable experience for most participants who also felt safe and supported and able to share their views.

Figure 4 shows levels of agreement with statements about the engagement activity participated in. Note that all instances where 'strongly disagree' was selected were from a single participant who made positive remarks about the experience both in person and on the same form, so perhaps they 'straight lined' their response on the strongly disagree rather than strongly agree column by accident.

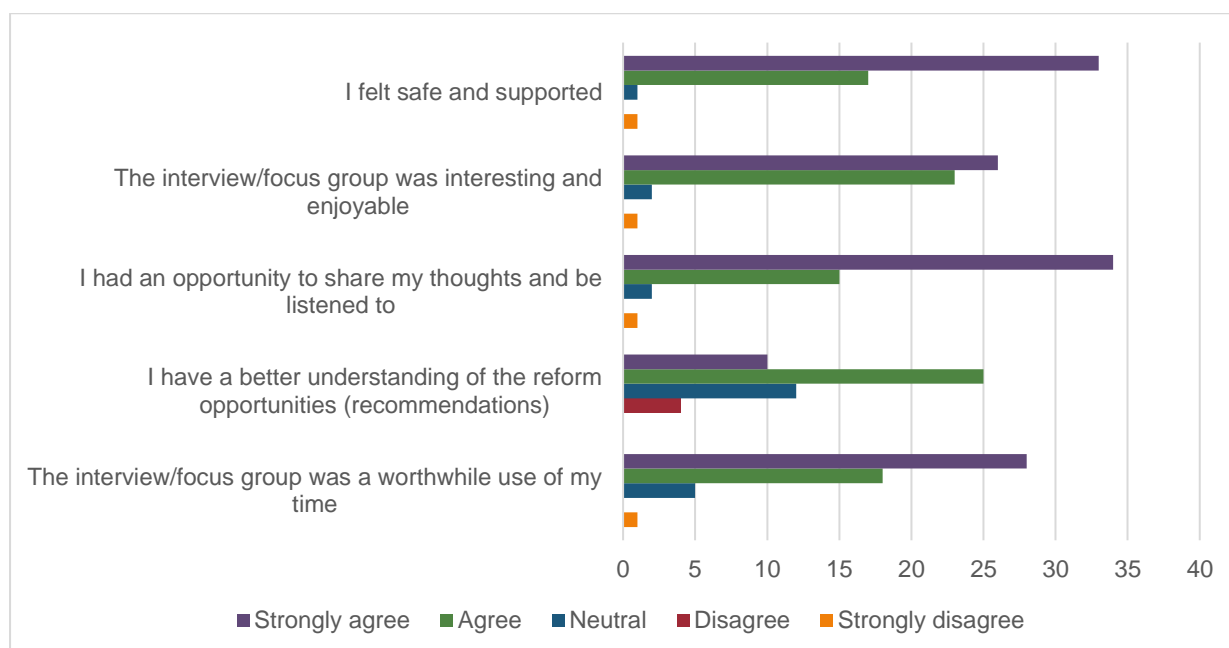


Figure 4: Participant ratings of focus groups and interviews

Almost all participants said that the wording of the reform opportunities made it difficult to understand them: not just big words but too many of them, long sentences, and apparent repetitiveness of opportunities expressed in slightly different ways ('Are they asking again to trick us? It's like a DAS assessment!'). Participants also noted a lack of attribution as to who would be doing what ('Clarify professional roles: Whose roles? Who should clarify them? By what means? With what audience?').

Participant comment

If a word is bigger than vegemite, it's not in my vocabulary! I'm fine with three syllables, but can you please translate this into English?!

Comments on the engagement were almost all positive and hopeful of recommended changes making a difference to the physical health of people with lived experience:

- Great format for easy discussion, wide range of viewpoints - diverse.
- It was a really well organised and co-ordinated experience. Fun way to approach.
- There should be more of them. It was great.
- To me, all the questions were the same. And no one answer fits.
- My only issue is the constant speaking over the top of other participants when they have the floor. Maybe something to reiterate (this) at the beginning of the sessions.
- Would suggest a survey for services that need funding for specific causes, strategies, needs.
- Great workshop. Amazing to have my voice and opinions heard and respected. Thank you.
- A big yes to feeling safe and supported in this. A big thank you.
- Really enjoyed workshop, felt heard. Nice to have an opportunity to give feedback and also see a little into potential care path strategies coming up.
- I really appreciated being given the time to put context around my experiences and opinions.
- Great concept; however the language on the cards needs to be simplified.
- Enjoyed listening to my peers and their experiences.
- Worthwhile if ideas are put into place. Further funding to ensure all requirements are met and ideas in place.

A participant in the first focus group suggested that there should be more cards—fun cards—not just the reform opportunities. We took this on board and made an extra set and included these in the remaining activities. We also included fun cards in the digital version.



Figure 5 'Fun' cards were added to the board game based on participant feedback

5 Conclusion

This consultation gathered the views and perspectives of people with lived experience on reform opportunities outlined in the Commission's *Improving physical health for people with a lived experience of mental illness or problematic alcohol and other drug use - Strategic*

position paper (Aspex Consulting, 2019). Engagement focused on 20 reform opportunities in the two categories where the Queensland Government can make the most difference: Category 3 and Category 4 and, therefore, participants in consultation could have the most influence.

With that perspective, the following suggestions are made:

- Prioritise investment in the reform opportunities discussed in Section 3.1 and be guided by that discussion when implementing them.
- Where possible, influence and support the implementation of the highly rated reform opportunities from Category 1 and Category 2 as outlined in Section 3.2.