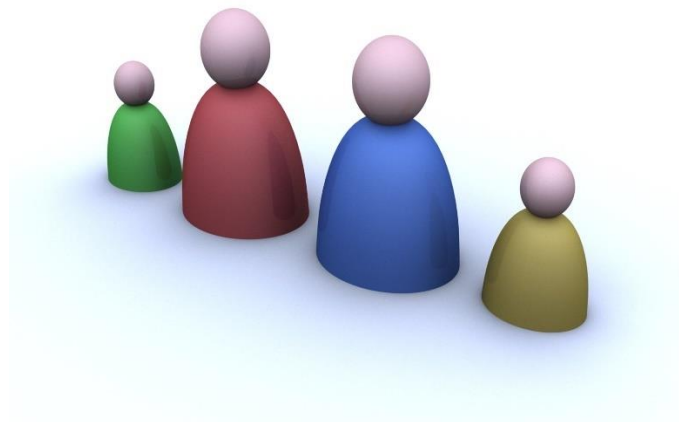




HEALTH CONSUMERS' COUNCIL

Datix Consumer feedback and complaints

Notes from consumer consultations hosted and facilitated by Health
Consumers' Council



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Contents

1. Executive summary	3
1.1 Key issues	3
1.2 Common barriers to giving feedback or making a complaint	3
1.3 What do people want?	4
2. Background	5
2.1 Methodology	5
3. People’s experiences	7
3.1 The start of the process	7
3.2 How people had given feedback or made a complaint	9
3.3 When giving feedback – responses from health services	10
3.4 In meetings about feedback or complaints	11
3.5 Other system level issues	12
4. People’s suggestions for improvement	13
4.1 System level improvements	13
4.2 Increase awareness of the process and increase opportunities for feedback	14
4.3 A more personalised and caring response	14
4.4 Training for staff	15
4.5 Increase support available to consumers to give feedback/make a complaint – including independent support	15

1. Executive summary

This report summarises the feedback from the three consumer workshops and the interviews carried out with regional Aboriginal consumers.

Section 1 provides a brief summary of the key issues and common barriers. Section 2 provides the background to the consultation process. Section 3 outlines a summary of people's experiences of the feedback and complaints process. Section 4 summarises suggestions for improvement.

1.1 Key issues

- There are many barriers to giving feedback or making a complaint – most of which WA Health can influence
 - Importantly, people from all groups described how difficult it was to find out how to give feedback or make a complaint.
- Feedback mechanisms don't match the complexity of the system
- Many people experience the responses received to feedback or complaints as impersonal and unhelpful
- Many Aboriginal people described experiences of racism in the health system which impacted on the likelihood and way they give feedback or make a complaint. There is much more to do to embed feedback mechanisms that are experienced as culturally safe by Aboriginal people.
- Providing feedback is often an emotional experience – a trauma-informed response could help create an environment where staff are more able to receive feedback and consumers are more supported to provide it.

"Your feedback process begins on admission..."
Consumer, 12/02/20

"All I wanted... was to feel like someone cared."
Consumer, 12/02/20

1.2 Common barriers to giving feedback or making a complaint

A prominent reason for not giving feedback is simply that people were not asked. There was a strong theme in the workshops about providing consumers with opportunities to give feedback "in the moment". Suggestions included putting information next to hospital beds and making this known to people and having a visible presence – in the shape of a person – in a prominent place in a health service.

The common reasons we heard for people not giving feedback were:

- Lack of time and energy on the part of the consumer – dealing with one's health (or that of their family) is already time consuming.
- Unsure of the process for giving feedback/making a complaint
- Have previously had a negative experience of giving feedback
- No confidence that investing the time and energy in giving feedback will result in positive change
- Fear of being treated less well as a result of making a complaint – this was particularly prominent from people living in regional areas
- Literacy and language issues

"The consumer liaison person works for that hospital. They could just have had lunch with the person [I was complaining about]" Consumer, 12/02/20

"I won't put in a complaint again... because [the last experience] was so hurtful"
Consumer, 12/02/20

1.3 What do people want?

A system where it is easy to give feedback.

- Information about giving feedback or making a complaint that is
 - more visible
 - clearer
 - proactively given – seek feedback throughout the process of care
- Ways to collect feedback that include
 - Culturally safe options for Aboriginal people
 - More face to face options
 - More options that don't require written feedback
 - More opportunity to give feedback in the moment
- A more personalised and caring response
- A streamlined consistent process that
 - Is simpler
 - Is consistent between health service sites
 - Is focused on the needs of the consumer not on the needs of the system
 - Includes a clearer and more effective process for complaints that are complex or that relate to multiple parts of the system
- More support to provide feedback
 - More independent support focused on the interests of the consumers
 - Focus on removing barriers to giving feedback
- Accountability
 - More external review of complaints and feedback process
 - Assurance that feedback leads to positive action and change.

2. Background

The Health Consumers' Council (WA) Inc. was established in 1994 with the purpose of giving a voice to health consumers in Western Australia and improving health outcomes by encouraging and supporting consumer engagement and involvement in health services.

In late 2019 HCC was commissioned by the Department of Health to support them in seeking consumer feedback about the process of making a complaint and giving feedback.

We ran three consultation workshops:

- Wednesday 12 February 2020, face to face, open invitation, Perth (15 attendees)
- Thursday 13 February 2020, by video conference, open invitation to people outside Perth (18 attendees)
- Wednesday 19 February 2020, face to face, targeted invitations for Aboriginal community members, Perth (17 attendees)

HCC staff also spoke with four Aboriginal community members who live in regional or remote areas and that feedback is also included in this report.

There were many themes in the feedback that were consistent across all of the consultation sessions and interviews. Some of the groups highlighted particular issues and these have been noted below.

Since we ran these sessions, Patient Opinion has changed its name to Care Opinion. We refer to Patient Opinion throughout because this is what was discussed at the time.

2.1 Methodology

Health Consumers' Council (HCC) was approached by the Patient Safety Surveillance Unit (PSSU) at the Department of Health to undertake two workshops of at least 10 consumers in each – one in Perth and one via video conference (VC). PSSU also asked HCC to provide advice on obtaining feedback from vulnerable groups. HCC's advice was to extend the consultation to include targeted sessions for Aboriginal consumers – both in the metro area and regionally – and also to seek targeted feedback from consumers with mental health conditions. HCC recommended working with Consumers of Mental Health WA (CoMHWa) for this session, which PSSU did.

HCC organised three workshops as outlined above and carried out interviews with four Aboriginal consumers who live outside Perth.

The workshops were promoted in a number of ways:

- Through targeted contact by HCC's Advocacy team to clients who may have had a relevant experience
- Via email to the Chairs of consumer and community groups including Community Advisory Councils (CACs), the District Health Advisory Councils (DHACs) and other consumer groups in the health system including primary care
- Via HCC's newsletters to our stakeholders and health consumer representatives.

We sought people who:

- Had provided feedback to public health services in WA – this could be by making a complaint, providing positive feedback, or sharing their story on Patient Opinion
- Had had an experience with public health services where they considered giving feedback or making a complaint, but didn't – to understand why people decided not to give feedback or make a complaint

- Were happy to take part in a group discussion about the experience and process of providing feedback/making a complaint.

We confirmed with people registering for the session that we would not be discussing the detail of the issue related to any complaint or feedback, but the process of making the complaint or providing feedback.

In the week before each session, an HCC staff member rang or made contact with all attendees to confirm their attendance and to confirm everyone's understanding of the purpose of the session.

The session by VC was held using Scopia. Three consumers who registered for this session also volunteered to coordinate groups of other attendees from their areas – this was a valuable way of reaching other consumers who were not already connected with HCC.

HCC also created a survey for anyone who was interested in attending a session but was unable to attend at the time they were being held. There were eight responses to this. Comments from this survey were considered alongside the notes from the consultation sessions and interviews.

Quotes come from people's notes as well as from verbatim notes by the facilitator on the day.

3. People's experiences

As might be expected, most people who participated in these sessions and interviews had less than ideal experiences of giving feedback or making a complaint. All were keen to share their feedback so that the process can be improved.

In each session, there were at least one or two people who had had a positive experience that resulted in positive change.

Feedback about people's experiences are summarised in these areas:

- The start of the process
 - Barriers to giving feedback
 - How people found out how to give feedback/make a complaint
- How people have given feedback or made a complaint
- When giving feedback – responses from health services
- In meetings about feedback or complaints
- Other system level issues

3.1 The start of the process

3.1.1 Barriers to giving feedback

People cited a number of reasons for not giving feedback or making a complaint:

- issues relating to knowledge or awareness of the process
 - not being asked for feedback – this was a very common response from consultation participants
 - not knowing how to
 - many people commented they had no idea it was possible to give feedback or make a complaint. Some people commented that there were feedback forms in the packs beside the hospital bed, but others commented that they had not been informed about these.
 - some people asked staff who did not know the process
 - many people commented there was no opportunity to give “in the moment” feedback – rather than having to give feedback after being discharged, for example.
 - People commented that being able to give feedback “in the moment” could prevent something escalating to becoming a much bigger issue. **This was commented on particularly by consumers at the open invitation session in Perth.**
- issues relating to the process itself
 - having to give feedback in writing was cited as a barrier for several reasons
 - low literacy or reading difficulties such as dyslexia
 - low self-confidence in one's ability to write about the issue clearly
 - English not being someone's first language
 - cultural barriers

“I have dyslexia and anxiety kicks in [about having to write a letter]”
Participant, 13/02/20

these circumstances meant that some people didn't, while others escalated their concerns to a politician.

- For others it was because their healthcare experience was so negative that they had no confidence any complaint would be taken seriously. **This was a point that was particularly highlighted by Aboriginal consumers.**
- Not being confident that their feedback is “worthy” of a complaint
- Not wanting to complain about one part of their experience (which was bad) when other parts of their experience have been good.
- issues relating to the consequences of the process
 - Many people said they had limited or no confidence that their feedback would result in positive change. For many, this was because of a previous experience they'd had giving feedback which had not resulted in positive change.
 - Many people commented that they were afraid of their care being negatively impacted if they made a complaint
 - **For people living regionally, many commented that living in a small town made them particularly cautious about giving feedback due to the likelihood of them meeting health service staff in their daily lives**
 - **Aboriginal consumers commented that fear of getting caught up in the legal process was also a barrier to some people providing feedback or making a complaint**

“there is fear about the complaints process – people don't want to get caught up in the legal system and processes” Participant, 19/02/20

3.1.2 How people found out how to give feedback/make a complaint

For those people who knew or had learned about how to give feedback/make a complaint:

- Some people found out from friends or family
- Some found out from other health consumers including members of Community Advisory Councils (CACs) or District Health Advisory Councils (DHACs)
- Some people invested time researching via various health services websites to try to find out how to complain or provide feedback.
- Some people have submitted complaints on behalf of other community members.
- Some people heard about how to give feedback from staff. In one case, a staff member noticed that they were upset and spoke to them about the process of giving feedback.

3.2 How people had given feedback or made a complaint

- People had experienced giving feedback in a number of ways:
 - Verbally
 - In writing
 - Directly to health service staff
 - To consumer/patient liaison staff
 - To Aboriginal Liaison Officers
 - Via Patient Opinion
 - In response to a follow up telephone call after discharge – **this was mentioned in particular by Aboriginal consumers both in the metro and regional areas.**

3.2.1 About Patient Opinion

- Most of the comments about this platform from these groups were positive but there were also some negative comments

<i>Positive</i>	<i>Negative</i>
<ul style="list-style-type: none"> • Timely • Anonymous – although the comment was made that in a small town anonymity may not be preserved • Transparent • Easy to do • Gets a quick response 	<ul style="list-style-type: none"> • Needs access to stable internet • Relies on writing – most people were not aware that you can telephone the Patient Opinion team • Is just another thing to do • Given the nature of the platform it is not possible to get a personalised response to the particular issue (i.e. often encouraged to “get in touch with the consumer liaison team...”)

3.3 When giving feedback – responses from health services

- There is a lack of information and knowledge about the process
 - Many people commented that even after giving feedback or making a complaint they were not clear on what the process was supposed to be and what should happen from that point on.
- Many people commented on the power imbalance in the process – people felt that consumers had little power to influence change.
- Many people commented on the lack of acknowledgement, response or feedback
 - Some people commented that their feedback or complaint was not acknowledged
 - Many people commented that they never received any feedback at all about any changes made
 - Others commented that they observed that change had happened, but were not informed about it
 - One person commented that they sometimes received a verbal response despite having been required to submit the feedback in writing.
 - People described often feeling ignored, dismissed and unheard.
 - People commented that it seems staff believe they are not allowed to say sorry – sometimes this is all that people want and it could prevent a complaint from escalating further.
- When giving feedback via staff, people were unsure if their feedback was being formally recorded.
- When giving feedback via staff, some people had a positive experience. They felt heard and it led to positive action. Others had a positive meeting, but it did not result in change.

- A number of people spoke about how giving feedback can be quite an emotional experience.
 - Often the experience that has prompted the feedback has been quite emotional and difficult for the person.
 - Giving feedback about that process is also often an emotional experience.

“Services need to know that sometimes the feedback looks like an angry person. They need to stop being so precious about what they will and won’t tolerate. It’s too subjective and they are missing the opportunity. Angry people don’t tend to be angry for no reason. Learn how to work with people before they get angry. Communication. Don’t ignore the signs. Remember the power isn’t with the sick Aboriginal person.” Regional Aboriginal participant

- Many people described receiving an impersonal response, with a few people having had a positive experience

- Many people commented that the response they received was impersonal
- Some commented that responses lacked compassion or kindness
- A few people commented about positive experiences they had had with Consumer Liaison or Patient Liaison or staff. **Some Aboriginal consumers in Perth had a positive experience with Aboriginal Liaison Officers at a number of metro hospitals.**

- Some people commented that the initial response from staff was defensive and that staff did not appear to be open to receiving feedback.

- Some people recognised that staff are often very busy, this was particularly commented on by **consumers in the regional VC session.**
- Some people saw positive change as a result of their feedback, but this was rare. **In one case, an Aboriginal consumer in a regional area saw their feedback result in a systemwide change. They believe this was due, in some part, to the consumer having raised the issue of racism and paternalism in their complaint, which they believe led to action being taken.**

“[It’s not necessary to give feedback to a nurse or doctor...] we know they’re busy – but perhaps to a consumer liaison person that supports clinicians.” Regional VC participant

3.4 In meetings about feedback or complaints

Across all the sessions, only a few consumers had experience of having meetings about any feedback. People’s experiences were mixed:

- Some people had a positive experience – they felt heard and understood, were able to meet with people at a senior level in the organisation, and saw positive change as a result. This included an experience described by a regional Aboriginal consumer.
- Others felt the experience was less positive. They described the power imbalance in meetings, particularly where there may be multiple staff from the health service and only one consumer.

“The power is held in the service and can be intimidating.” Aboriginal consumer

3.5 Other system level issues

- **Aboriginal consumers – both in Perth and regionally – described how Aboriginal consumers regularly experience racism in health services.**
- **They described how aspects of the system were systemically racist and culturally inappropriate.**
- **Many Aboriginal consumers expressed a lack of trust in the system, based on negative experiences they have had.**

“People are disempowered by white systems. They give feedback but nothing ever changes for them or their family... Constant racism and judgement makes people complacent. It brings us down.” *Regional Aboriginal participant*

4. People's suggestions for improvement

Suggestions for improvement fell into these categories:

- System level improvements
- Increasing awareness of the process and increase opportunities for feedback
- A more personalised and caring response
- Training for staff
- Increasing support available to consumers to give feedback/make a complaint – including independent support

4.1 System level improvements

- Acknowledge there is still a need to address racism at an individual and systemic level across WA health
 - One approach would be to collect data relating to where people have experienced racism in the health system as part of the consumer feedback process. There is no information in the reports over the last 8 years relating to experiences of racism in the Your Safety in Our Hands in Hospital reports. While there is reference to “discrimination” it is not clear if these relate to racism or discrimination on other grounds.
- Increase the number of Aboriginal staff in diverse roles and at all levels
- Create a more culturally safe service in general
- Implement a trauma-informed approach
 - This would contribute to a more psychologically safe environment for staff, which would in turn lead to a better experience for consumers.
- Change KPIs regarding feedback to focus on how many complaints lead to action or positive change
- Provide funding for Aboriginal advocacy in the health system – currently there is no service available
- The issue of accountability and external oversight was raised by a couple of the groups. There was interest in ensuring that there was an external process to ensure that complaints and other feedback are recorded and being acted on appropriately. This was particularly highlighted by **Aboriginal and regional consumers**.
- One opportunity is to involve consumer groups such as Community Advisory Councils, District Health Advisory Councils or Aboriginal Cultural Advisory Group members more in the process. For example, we heard about one metro hospital where Community Advisory Council members are involved in reviewing the hospital's responses to complaints. This approach could be extended across all sites.

“There is no external accountability in the system – it's all internal” Perth Aboriginal consumer

4.2 Increase awareness of the process and increase opportunities for feedback

- There needs to be increased visibility and awareness of how to provide feedback/make a complaint.
 - Two of the groups suggested having someone who is very visible on site – by wearing a sash for example – who is available to take people’s feedback there and then.
 - Ensure members of consumer advisory committees and District Health Advisory Councils know about the process – they are likely to be approached for information by community members
 - Promote Care Opinion (previously Patient Opinion) much more widely
 - Ensure consumers know about the option to telephone with their feedback
 - Provide information about the process in a range of ways including in local languages
 - Information should include the range of ways to give feedback and what happens after you give feedback – what to expect.
- Embed asking for feedback at every stage in the process – don’t wait until discharge
 - One suggestion was to look to hospitality and their “sequence of service”. Ask immediately during service “how is it?”. And after service “how was it?”
 - Include the opportunity at clinical handover
 - Include methods that enable people with low literacy or young children to give feedback such as methods that capture 😊 or 😞
 - Ensure people know about the ways they can provide feedback “in the moment”, for example, through a feedback form by their hospital bed
- Increase opportunities for “in the moment” feedback.
 - For example, at some sites, Community Advisory Council members visit wards and invite consumers to give feedback about their experience. This peer to peer collection method is likely to result in more candid feedback and could reduce concerns about possible retribution.
- Use technology to gather feedback in a timely way
 - For example, kiosks on site where people can leave quick feedback by clicking on an icon.
- Ensure the process is aligned and consistent across all WA Health sites.
 - For example, using the same terminology for consumer/patient liaison staff across all sites.

“Need to make sure the posters and brochures and feedback forms are done in language, not every blackfulla is from Perth and speaks English” Regional Aboriginal consumer

“We need more information on the complaints and feedback processes. And not animated videos, proper videos and resources” Regional Aboriginal consumer

4.3 A more personalised and caring response

A common suggestion for improvement was to make the responses to feedback more human, more compassionate, more person-centred – more caring. This applied across all methods of response including verbal and in writing.

People should be discouraged from using “stock standard” responses. See below for the issue re apologies and medico-legal issues.

4.4 Training for staff

- Training and awareness raising for all staff
 - On the complaints/feedback process – so that they are able to describe the process to consumers, or at least know where to direct people for more information.
 - On responding to feedback
 - For example, adopting a customer service approach of “listen, acknowledge, apologise, act”
 - Staff need to be able to tolerate an emotional or angry response and be able to help to deregulate or de-escalate the situation – while acknowledging the heightened emotions and not becoming defensive.
 - Ensure staff understand how to appropriately acknowledge and apologise when an error has been made – ensure they understand the medico-legal issues so that those do not become a barrier to a human, personalised, and caring response.
 - Increase Aboriginal cultural awareness training for all staff – to consist of face to face training and not only online training

“I had to ask [staff how to give feedback], and they couldn’t tell me how to give [even] positive feedback”
Participant, 12/02/20

“Sometimes all people want is an apology and to be heard.”
Consumer, 12/02/20

4.5 Increase support available to consumers to give feedback/make a complaint – including independent support

- Increase access to an independent person who can support and advocate for a consumer in the complaints process
 - Participants believed this should be a paid role. Some suggested this could be a peer worker.
 - People felt strongly there should be someone they can turn to who has their interests at heart and not those of the health service.
- Increase the ability to be able to provide feedback face to face.
 - Aboriginal consumers suggested there should be more Aboriginal Liaison staff
- Increase availability of consumer/patient and Aboriginal liaison staff – including access to staff in the evenings and at weekends.