HEALTH CONSUMERS' COUNCIL

Independent Governance Review Consumer Carer Consultation

Notes from consumer, carer and family consultations hosted and facilitated by Health Consumers' Council on Wednesday 4th May 2022

Health Consumers' Council

Report collated by Pip Brennan

1. Executive Summary

This report summarises feedback from two sessions held with consumers, carers and family members held both online and in person on Wednesday 4th May 2022. One had a regional and the other a metropolitan focus. Both sessions were attended by Review Panel Members Kym Peake, Dr David Rosengren and Jo Gaines. Conversations were both plenary and in small groups, and the feedback collected by the recorded Zoom plenary session, the notes from room hosts, the Zoom chat and the evaluation form after the event have been synthesised and summarised here.

Section 1 - Executive Summary covers the key issues uncovered during the conversations on consumer involvement, patient experience and culture, emergency management and public health.

Section 2- Background provides a context for the consultation sessions and how they were undertaken.

Section 3- Summary of Feedback outlines peoples' responses to the questions put by the Review Panel. It also includes the reflections from the Panel from the Regional and Metropolitan sessions.

Section 4 - Next Steps summarises the undertakings of the Panel and HCC with this report and what happens with its contents.

Section 5, Appendix includes the Panel Member introductions including why they wanted to be involved in the Review, what they hoped to get out of the sessions and what they'd heard so far.

Consumer Involvement

- Many felt that consumer involvement had been sidelined during COVID-19 in 2020 and hadn't really regained momentum.
- There are pockets of good practice of consumer involvement across the system but it is not brought together. The absence of consumer voice at System Manager level is a concern – governance is definitely consumer business.
- A change in culture is needed: consumer involvement is not always valued – it is undertaken as something that "has to be done" rather than an essential activity that drives patient safety and a person-centred health system.
- Education, briefings and mentoring are required for all parties – health staff and consumers – to continue to embed effective consumer involvement. This needs to go beyond the acquisition of technical knowledge about ways to engage, and move into building people's experience – through "learning by doing" – so that people have the opportunity to learn how and why involving consumers adds value to activities
- Consultation that doesn't result in change is a concerning trend noted in health and mental health sectors.
- Addressing the power imbalance is key - what gets prioritised is usually not what's important to consumers
- Inclusion and diversity need time and commitment to build relationships

Patient Experience and Culture

- Patient experience and being able to navigate the system go hand in hand. Access to services is also key – there needs to be something to navigate to.
- There can be a stark difference in patient experience, highlighting inequities.
- Care Opinion has been a game-changer in seeing feedback turn into quality improvements but is inconsistently implemented across the system.

- HCC has done a detailed consultation on complaints and feedback, and more information on this can be accessed here https://www.hconc.org.au/what-we-do/policy-development/giving-feedback/.

Emergency Management

- Consumer Involvement was minimal in emergency management planning and having an expert consumer panel for future emergencies is a key opportunity.
- Communication and involvement with consumers would support more consumer-centred approaches, e.g. minimising the need to cancel elective surgery, a compassionate approach to visitor numbers, messaging that works for communities.
- Technology has been important in emergency response but consideration of those on the other side of the digital divide is important.

Preventative Health

- Both emergency management and public health initiatives require those well-established relationships with communities.
- Consumer involvement in prevention supports more effective campaigns and greater community uptake.
- Preventative health requires resources.
- Thinking more creatively is important – parenting classes and support can prevent more complex problems, peer supporters can assist people post a serious diagnosis or significant operation to stay well in the community.

Consumer involvement at all levels of the WA Health system needs to be implemented and connected to drive the implementation of key reforms articulated in the Enduring Strategies of Sustainable Health Review. This is the WA COVID-19 recovery blueprint and its implementation needs to be progressed.

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 2022 HCC was commissioned by the Independent Governance Review of the Health Services Act 2016 Review Panel to support them in seeking consumer, carer and family feedback about the Review. In essence, the Health Services Act has defined governance arrangements and operational instruments and the Review Panel want to know if these are delivering on patient experience and safety and quality.

We ran two consultation workshops:

• Wednesday 4th May 2022 online, targeted invitations (13 attendees)

• Wednesday 4th May 2022 online and in person, targeted and open invitation to people living in Perth (18 attendees – 4 in person, 14 online)

There were consistent themes across both the regional and metropolitan conversations, with some specifically regional issues also emerging. These are detailed Section 3 of the report – "What We Heard".

These sessions were hosted and facilitated by HCC staff and Pip Brennan, working as a consultant, who also wrote this report.

2.1 Methodology

Health Consumers' Council (HCC) had proactively reached out to the Independent Review Panel to highlight the importance of including the lived experience voice into the Review. An information session was convened about the Review by HCC and advertised through our networks prior to the May consultation sessions being confirmed. At this session a PowerPoint was developed which supported people to engage with this complex, strategic topic and think about how it related to them as a lived experience representative and as a patient or carer.

This talk was recorded and was included in a page on HCC's website on the Review. When the 4th of May consultation sessions were confirmed, we promoted the sessions in a number of ways:

Through our newsletters and social media platforms as well as targeted contact by HCC's Engagement Team to people who sit on relevant committees such as:

- Consumer Advisory Council members from metropolitan Perth hospitals
- District Health Advisory Council members from regional hospitals and health services,
- WA Primary Health Alliance Consumer members
- Representatives on state-wide committees and reform projects
- Current and former consumer members of Health Service Provider Boards
- Other consumer leaders we have worked with

We also targeted partner non-profit organisations:

- Mental Health Matters 2
- Carers WA
- Helping Minds
- Consumers of Mental Health WA

- People With disability WA
- Alcohol and Other Drug Consumer and Community Coalition

We sought people who:

- Were currently or recently a lived experience representative at different levels of the system from hospital to health service and also state-wide reforms.
- Were happy to take part in a group discussion either in person or online about their experience of being a lived experience representative and also someone who had utilised the health system.

We strongly encouraged people to watch the video debriefing the slide presentation about the review, and to think about their feedback in terms of how the WA health system is managed.

Three Review Panel members attended HCC's offices in person for both sessions, and both group and plenary conversations on the four key areas were conducted. There were scribes for the breakout sessions. The online sessions were held on Zoom to allow for the use of breakout rooms. A transcribing software was utilised for the plenary sessions and scribing for the breakout sessions. Quotes in this report come from notes taken by the room facilitators, Zoom recordings, text from the chat function, and from the evaluation survey.

3. What we heard

3.1 Consumer Involvement

Attendees in both consultation sessions had experience being a representative on a large variety of committees at all levels of the health system, from health service to board. Comments reflected in What We Heard were gathered from the plenary and breakout room discussions, the chat function and from the evaluation form sent to attendees. Responses have been themed and summarised in below.

Prompt questions explored:

- Is consumer input encouraged and supported?
    - To inform decisions of HSP boards and the work of HSP sub-committees?
    - In the design of new services and facilities?
- In the work of the Mental Health Commission?
- What could be improved?

The fact that there are Consumer Advisory and District Health Advisory Councils in place is a positive. But while some people had excellent experiences of inclusive involvement on the Committees they contribute to, others had less positive experiences to share.

The conversations covered these key areas:

- Impacts of COVID-19 and online engagement
    - how it changed before and after COVID-19
    - online engagement was a positive innovation but largely consumers have been shut out of COVID-19 preparations
    - When in 2022 online engagement activities needed to start again, this was not as easy as had been hoped.
- Importance of Consumer involvement at all levels –
    - the importance of involvement at all levels, from Board to Ward
    - named the absence of consumer involvement in the System Manager.
    - The variation in consumer involvement across the system is seen as both necessary and a lack of coordination and leadership
- Consumer involvement in the Mental Health Commission
    - Youth mental health is a key area and still it is difficult to know where to find help
    - While there have been many consultations consumers have had the chance to be involved in, change can be hard to detect when seeking help and services
    - Regional services need to be locally designed – and sometimes the variance is down to where the good community advocates are, rather than the real need
- What could be improved in consumer involvement
    - There needs to be an underpinning culture that values and supports engagement
    - Culture shifts can be supported by training, briefing and mentoring.
    - Addressing the power imbalance is key - what gets prioritised is usually not what's important to consumers
    - The impact of consumer involvement consultations and committees is often undermined by lack of implementation
    - Inclusion and diversity need time and commitment to build relationships

Impacts of COVID-19 and online engagement

- Most attendees in both the regional and metropolitan consultation noted that prior to 2020 consumer involvement was often functioning quite well but had slowed down from March 2020 when COVID-19 hit. One CAC Member discussed the benefits of Ward Walks and visiting patients for their feedback prior to Covid but these ceased during COVID-19.
- There was one shining example of a rural health service partnering with consumers to fine-tune their site-specific COVID-19 emergency management plan, but this was the exception, not the rule.
- The pivot to online engagement had been positive but highlighted the disparity with people unable to access IT in their own home. As confidential matters are discussed, it is not easy to participate effectively online in a public area like a library.
- When COVID-19 returned in 2022 there was a hope that online consumer involvement would be straightforward but that hasn't always been the case.
- Consumers who are experienced may be willing to persist when engagement opportunities are not readily offered, but others may not, and engagement activities will wane.

> There were staffing issues locally to a devastating degree. If we had a meeting cancelled it was because of staff shortages. We don't need an Ops Manager to convene a meeting. It was such a crucial time for staff to be on the ground, but we were crucial too.

> When they had to start online meetings again in 2022 it was like it starting from scratch. The last two years had been very important with all the goings on and keeping consumers involved. But it seemed consumer involvement was put on the back burner again.

> Throughout the COVID period, 2020 to present, I was working with all four health services and there was very little coordination apparent. They kept re-inventing the wheel. Everyone was waiting for the Department of Health to develop a strategy and formulate advice. There was little evidence of robust communication and an established plan.

Importance of Consumer Involvement at all levels

Consumer Involvement and Boards

- As those consumers on the HSP Boards have moved on they are not always being replaced by someone who also has a consumer lens. The Health Services Act specifies that there needs to be three clinicians on every Board, but it doesn't have the same specificity about consumer members.
- A line of reporting between the CACs, DHACs and the Board should be consistent across WA. There is a Board to Ward program where they have the opportunity for the board to hear directly from frontline staff and consumers – this is the kind of initiative that helps keep the system patient, carer and family focused.

The HSP Boards do their best, but they have a lot of responsibility, but no power. The power rests with the Director General. They are sympathetic to that coherent patient journey but there's so many other things on the agenda that makes it hard to really address that.

The feedback loop to the Board is important - when consumers making complaints about the same things, it's frustrating to see those same things keep coming up. There needs to be a mechanism for the Board to look at those things and act on them act on the consumer feedback.

Consumer Involvement at the System Manager Level

- There is no transparency as to how the System Manager is getting consumer input, so while there are CACs at a service level there is no system-wide voice other than what the Health Consumers' Council and other peaks can bring.
- Given that governance is about direction, culture, policies - it is important to have skilled consumer representation in key strategic, system-wide decision-making committees right up to and including the Health Executive Committee.

I like the idea of a Senate at the top level - comprised of consumers, Carers and clinician representatives. Everything that goes to that top Board requires Senate approval.

Variation across the system

- Consumer feedback mechanisms across WA Country Health Service vary – but some of that variation is important - what might be needed from a consumer involvement point of view in one region might be different to another region.
- There were concerns expressed about lack of leadership across the whole system, and the importance of enabling cross-HSP engagement.
- It's difficult for consumer input from the regions to influence metro-based services, but it's important to factor this in. Regional people use metropolitan health services, and they need to be able to influence how they are designed to better meet rural consumer need.

> It seems to me that it is not recognized that the Health Services actually belong to the people. Our taxes pay for it . Therefore we the people of WA should have a say at all levels as to how the money is spent. We supposedly live in a democracy which I was taught means " by the people for the people".

> Since there are limitations with health services in the country, a lot of patients have to go to metro hospitals for specific services. A "popular" and ongoing issue that I hear about a lot is the lack of consideration with their scheduled appointments. Is it possible for metro health staff to check whether an 8am appointment is appropriate for someone who has to drive 3 hours? Is it appropriate to schedule different appointments in different hospitals within 30/60 minutes apart?

Consumer involvement in the work of the Mental Health Commission

- Youth Mental health issues are important, and people feel it isn't clear where to turn for help and services. There was a sense that this has all been discussed over and over again in the past and yet accessing the right services is still difficult.
- Psychiatric services into regions are complex due to staffing issues – it's challenging to get psychiatrists to even visit the regions. There are health and wellbeing concerns for mental health nurses in the regions, and much of the care is ad-hoc or one-off.
- Mental health issues can't be generalised - they are very much location specific. Available services can depend on how proactive local advocates are rather than actual community need. Regional models are sometimes based on a metropolitan approach – but these don't always translate well to a rural context.

What could be improved about consumer involvement

- There is an overarching cultural piece required to ensure that health staff value the consumer, carer and family voice.
- There is a large amount of information and resources available to health services about how to engage in an inclusive and engaging way, but these are not often consulted before engagement opportunities are created.
- Boards and Executives often need training to understand how to partner with consumers and the importance of training and mentoring consumers to enable us to contribute well. There was a suggestion to implement training for Boards and Executives in "Partnering with Consumers'. A video could be produced where Boards and CEO's who are Partnering well with consumers express the benefits that Partnering has brought e.g., quality improvement.
- Consumer leadership also needs to be nurtured – members of the public have many skills to offer along with their lived experience but induction and training for representatives can be non-existent or patchy.
- There should also be consistency of supports available to lived experience committee members. There's a discrepancy between the consumer, who's there for several hours a month, working alongside a group of people who are there all the time and who are living and breathing and immersed in the subject. Consumer members need both training and ongoing briefings.

> Consumers are the experts of their own experience and this needs to be seen on the same level as the expertise of a clinician, or we're just going to keep going around in circles

Valuing engagement

- While people felt that consumer engagement processes often worked well, there was at times a "tick-a-box" feel to the involvement activities. This varied significantly depending where in the state or in Perth people were.
- There was an important conversation about involving consumers not just being encouraged but also **valued.**
- Reimbursement is an important signal of that value. Valuing engagement was also signalled by the attendance of senior staff at meetings, and the inclusion across many different committees.
- Valuing engagement also looks like being involved from the beginning and all the way along. Others felt that there was an inbuilt bias against consumers on committees.
- There was a call for every hospital's emergency department to have a community advisory group.

> The Board Chair cares, and the consumer engagement staff care, but at an executive level there seems to be a feeling that it's something that we must do rather something which adds value.

> HSPs need to be encouraged to value CACs as experts.

Power - whose agenda?

- Consumer roles can evolve in some cases where they become like a job where one person sits on many different panels and committees. They may have a big impact internally on system and service priorities, but it can be difficult to progress the things that matter to consumers.
- There was also concern that many safety and quality committees in health services have no consumer representation. This is a core consumer issue – nobody is more impacted when things go wrong than consumers and their families.
- Measuring impact is also an important issue to tackle – there was a discussion about using an outcome measuring framework and this does need to be tackled to support consumer involvement being valued and supported.

My experience is that most of the HSPs will seek consumer input on their own ideas and initiatives as it is well known now that they need to. The difficulty is in 'getting up' consumer-led or consumer-initiated ideas. There is not always a clear avenue for this, and there is considerable variance across HSPs in getting consumer-led ideas off the ground. So many consumers will be asked to approve programs that are already designed, but not asked what they want to see designed to begin with.

Implementation of recommendations, reports, models of care etc.

- There was a common theme across both metropolitan and regional sessions noting that recommendations have been raised in many reports many but some of which have not yet been implemented. A feedback loop on how implementation is tracking is important, otherwise the value of engagement activities (even those done well) is diminished.

We talk about the same thing year after year after year. And sometimes we never hear back from consultations

It's been called a Plandemic. We have SO many plans and reports. The system is currently set up to create

The health system needs to embed within its structural framework and governance systems, meaningful mechanisms to engage with consumers. We need to put the humanity back into health care and cease with excessive and 'busy making' reports that often don't change things.

Inclusivity and diversity

- The same (non-diverse) consumers are involved in different committees – while continuity can be very positive and it takes time to be across all the issues, there was concern that this was not inclusive.
- One initiative that works well to support inclusivity is the multicultural DHAC in Katanning.
- Others noted that having documents in Easy Read supported inclusivity and this is easy to do now in Word.

There needs to be energy and resources put into recruiting and supporting people.

Sometimes get the usual people attending and how do you seek out some of those voices that might not come along?

Building relationships with multicultural communities is so important. The Multicultural DHAC representatives took time to learn about the DHAC and get used to speaking up and providing their feedback at meetings; and some even participate in external meetings

3.2 Patient Experience and Culture

Patient experience reflections differed between regional and metropolitan consultations. In particular, workforce challenges impacted what services were available in the regions, and providing feedback or making a complaint about a service in the regions provides a very different challenge.

This session reflected on

- What contributes to a positive experience for patients/consumers?
- Do HSPs capture information about patient experience? How could this be improved?
- Are there effective system for consumer complaints and open disclosure in WA's health system?
- Are patients supported to be partners in their own care? How could this be improved?
- Are lived experience roles established and valued in HSPs (eg peer workforce and consumer navigation services)?
- Should these roles be used differently? How could they be better supported?

Key themes that emerged were:

- Reflections on the Patient Experience:
    - Being able to navigate the system is inextricably linked with patient experience.
    - There can be a very big gap between a positive and negative patient experience, e.g. for someone with a disability, a young person.
    - Access and co-ordination of services – having something to navigate to is also key, and particularly in regions this is a barrier to a positive patient experience
    - Peer navigators and better inclusion of carers were key strategies attendees discussed as supporting a better patient experience.
- Feedback and Complaints
    - Limitations of surveys were discussed
    - The lack of visible follow-through from complaint to system change was highlighted
    - Barriers to providing complaints, especially for regional people were discussed.
    - HCC has done a detailed consultation on complaints and feedback, and more information on this can be accessed here https://www.hconc.org.au/what-we-do/policy-development/giving-feedback/.
- Care Opinion dominated the discussion on capturing the patient experience as a positive innovation, however it is not uniformly utilised across WA.

Reflections on the patient experience

- Understanding the health system and a good patient experience were seen as inextricably linked. Initiatives such as Choosing Wisely Australia's "5 Questions to ask your Doctor" are important health literacy supports, and there is the opportunity to build health literacy into school curriculum.
- There have been some good initiatives such as "Hello My Name Is" and the "Teach Back" education program for clinicians to understand how to communicate with their patients better – these need to be embedded into health professionals' training curriculum.
- How consumers are welcomed into a facility makes a huge difference and systems and process are needed to make sure key information is given upon admission, printed perhaps but verbal too.
- The difference between a positive and not so positive patient experience can be very stark. The journey for consumers with intellectual disability for example can be very different and less positive than the journey for non-disabled people.
- Mature minors - young people between 14 and 17 can be considered mature enough to have ownership of their own health care, but they're often left feeling quite helpless and powerless. They are not aware of the Mature Minor policy and process. More work on the rights of young people and making sure that health consumers understand their rights in general is important.
- Policy and staff training is needed to increase interpreter use – children of patients being used as interpreters is not acceptable.

> The patient journey from beginning to end, needs to be consistent. You want to feel like everyone has your back. Good handovers, being listened to. Patients can often be vulnerable and frightened once they get into the system. The difference between a good journey and a bad journey is marked.

> Consumers need to be supported as partners in their own care. Only people who have the courage to speak up get what they need. Community awareness of health rights is needed.

> Bed block is a major issue - I waited as an inpatient for a week for an MRI. The bed management system not efficient and needs reform.

> We have very good visual resources about consumer rights but more can definitely be done besides sticking a poster on walls and expecting that to empower people.

Access to and Coordination of Services

- People in the regions highlighted that there are fewer service options, especially in smaller in towns. Also, as they often need to access Perth services the lack of co-ordination between the HSPs in Perth and between Perth and WACHS was a barrier to a joined-up patient journey.
- Regional participants noted that health is set up as a metro-centric model necessitating travel to Perth for services that can't be accessed closer to home. Travelling to Perth can create isolation for those away from loved ones - the Patient Assisted Transition Service is insufficient to support people's travel costs.
- A key discussion was the importance of tackling the many challenges in getting agencies to work together – and this goes well beyond health and mental health services it could include a range of other government and non-government social care agencies and services on the ground in the area. A key question was – how can we use existing resources in a more collaborative way? The WELL Collaborative from the Healthy Weight Action Plan Implementation was cited as a positive example of emerging collaborative governance. https://www.thewellcollaborative.org.au/
- The importance of a place-based approach to providing the right health and social care services was acknowledged. However, there was concerns that there can be inconsistencies with programs offered and that available services may reflect areas where there are more effective advocates rather than actual social need.
- All attendees noted that the interface between health and other systems, e.g., getting access to NDIS and the Aged Care system doesn't work well with the health system, and that even GPs and hospitals don't interface that well. It is key to consider the interfaces between different systems, not just the lack of connection within the health system.

> There was potential idea of pooling resources by postcode - it all broke down because each level of government wanted to be the lead and could not come to an agreement on who and how - although lots of ideas were raised on the good that could come from a place-based way to spend the allocated resources.

Peer navigators

- There was agreement that Peer Navigators would be a positive initiative, especially having someone to talk to face to face. This was especially important when there had been a serious diagnosis. However, there were concerns that it might come down to a choice between a Nurse and a Peer Navigator and that this makes it difficult to prioritise developing a Peer workforce.
- There was also the discussion of the positive implementation of Mental Health Peer support workers in a regional area which has helped with intervention and support before clinicians are available in our area. While the implementation of peer support workers is new it had been a positive start.
- Peer Navigators could be particularly beneficial for Aboriginal people, those from other cultures and people with disabilities.

A positive experience is possible, but you need to know how to navigate the system effectively. Most people don't spend much time in the health system. It's just that one event, e.g., a birth, a broken leg, appendicitis –and suddenly they've got to find their way around the system.

The Manage My Care App is a movement in the right direction, but there's nothing better than being able to speak to someone. You need that face-to-face support.

Inclusion of Carers

- The importance of including family and carers so they can be part of the team was stressed in both consultations. Carers can build a bridge between what the consumer needs and what the staff understand about those needs. Also, it was acknowledged how busy nurses are and carers can be an important asset to supporting a good patient experience.

It's important that we also include disability services & aged care support workers here as sometimes they know the person the best.

It is a mindset – we need to see carers as part of the team!

Feedback and Complaints

Surveys

- Attendees reflected that patient surveys don't necessarily capture a diverse voice. There was also a discussion on the importance of having Consumer surveys which don't just rate experiences, but which also invite comments on what worked, what needs changing, what went wrong. Ratings do not give information that enables change - ratings only indicate if people are happy or not but give no information about the reasons why.

The Experience Survey has been set up to capture different voices. But the format of the survey, will exclude people. People don't have the confidence that anything is going to happen, so they don't want to fill it in. The questions are too siloed, and they don't really work for what really matters to consumers. Surveys can be very long – simplify and they will get a better result.

Complaints leading to change?

- There was also a recognition that there are mechanisms for providing feedback, but it wasn't clear how this then results in change. Also, people aren't always aware of what is available, e.g., that there are Consumer Liaison Officers, Aboriginal Liaison Officers etc they can talk to.
- There was also a discussion on the variance of how complaints are handled – while there is one policy across the state, the way it is implemented is dependent on staff on the ground.

Barriers to escalating concerns, especially in the regions

- Some consumers shared that in the smaller towns with smaller populations it can be difficult to escalate concerns and that you might lose your anonymity if you make if you make a complaint. Other regional consumers noted that with lack of access to other services, people will put up with that service because it's the only one available to them. Complaining may jeopardise the services that are available.
- Others talked about how the struggle to access services had to be prioritised over the time it takes to give feedback.
- In 2019 HCC undertook a detailed consultation on complaints and feedback, and this can be accessed here: https://www.hconc.org.au/wp-content/uploads/2022/05/200504-DATIX-Consumer-feedback-consultation-sessions-summary-ALL-Copy.pdf

From our DHAC point of view we analyse just a small section of what's happened in the month, we question the hospital and ask what has been done to stop this from happening to others. They don't necessarily like it but there's a massive amount of accountability.

Word of mouth is a popular way for CALD patients to share their experiences. I have heard about people who had wonderful experiences with a health professional who was patient, reassuring, encouraged and prompted questions. I have also heard about experiences where their health professional seemed curt and they had unanswered and more questions after their appointment. A consumer recommended the health service to use this document https://widgit-health.com/downloads/A-and-E-passport.htm.

Care Opinion

- This is working well in that it provides accountability and visibility as to how the patient experience can inform the cycle of safety and quality improvements. DHAC members in one area of WACHS have a role in looking at the stories each month and reflecting on what change has been created from the stories.
- It was also noted that the responses are thoughtful and tactful and are seen not just by the consumer but publicly.
- There was a discussion that it is not always well advertised or known about by health consumers.

> There were no Care Opinion posters in SJOG Midland but there were at Northam.

> We are massive advocates for the Care Opinion platform – I love being able to channel people to use that. That's been one of the greatest evolutions in patient feedback

3.3 Emergency Management

For reasons of time, attendees had the option to select which of the two topics – emergency management or prevention in the community – that they wanted to discuss. There was agreement that there was an overlap between emergency management and prevention in terms of the importance of relationships to the success of communications and programs.

Prompt questions on emergency management were

- what has worked in how WA Health responded to managing COVID-19?
- how were consumers involved in the emergency management activities?
- what could be improved for any future emergencies?

The key themes that emerged from the discussion are as follows

- There was a discussion on how WA had been well-protected during COVID-19, in a command and control/ top-down approach to emergency management.
- Consumer involvement
    - the discussion highlighted one shining example of involving consumers in pandemic planning.
    - there was a discussion on how little consumer involvement there had been in the pandemic in general.
- What could be improved
    - Consumer involvement could be planned and supported well in advance by a consumer committee being established
    - Elective surgery planning and how important it is to reduce the likelihood of cancelling surgeries
    - Visitor rules and how they were inconsistently applied
    - Pandemic messaging and how these need to be designed with consumers
    - Use of technology in a pandemic needs to be thought through and impacts of those not connected to technology

What worked

- There was a general acknowledgement that the pandemic had been handled well in Western Australia in terms of reducing fatalities and achieving high immunisation rates.
- It was also noted that the pandemic has brought positives with the use of technology for virtual meetings which in particular allowed for connection with those living rurally and those with mobility issues.
- The speed of change which occurred for telehealth to be brought in was an amazing achievement - telehealth is a real positive outcome of the pandemic.

Consumer involvement in the emergency management activities

- As noted elsewhere in the report, in one WACHS area the involvement of a consumer in the site-specific COVID-19 plan was exemplary. It was also an isolated and atypical example.
- There was an important reflection about what it has really been like to try and try and manage COVID, when you've got to drive 70 kilometres to get a test. You can't be admitted to hospital without a COVID test, but you can't access that test.

What could be improved for any future emergencies

Involving consumers

- There was consensus that consumer involvement in pandemic planning is important. There was a suggestion for the Department to set up an expert panel of consumers to be ready for the next emergency.
- As well as supporting consumer-centred pandemic planning it could support more uniformly implementable pandemic planning processes. Some felt that a national system of rules would have really helped, and that we could have learned lessons from other states.

> Should we use consumers on emergency planning? Absolutely. A consumer should be able to be involved in that process. Making sure that we're thought about first.

Elective surgery

- Elective surgery being cancelled has had a huge impact. Perhaps in 2020 it was necessary but by 2022 and for future we need to have emergency management plans which have surge capacity, e.g., through use of private hospitals for backlog and setting up sites for COVID-19 care and COVID-19 safe sites.

Visitor rules

- Visitor exemptions have seemed illogical at times. Explanation to consumers, consistency and logic would improve the situation. Exemptions for maternity and end of life care were inconsistently (and sometimes cruelly) refused.
- Visitor rules have been especially hard for families with low health literacy and with English as a second language.

Pandemic Messaging

- Consumers need to be consulted on messaging. There needs to be clearer messaging with less jargon, explaining WHY things have to be (e.g., ceasing elective surgery).
- One source of truth for the messaging would also be helpful. Websites are often not updated at the same rate and have broken links etc.

Use of technology in a Pandemic

- There has been a lot of reliance on technology through the pandemic which has its advantages but also disadvantages and future planning is needed to support those on the other side of the digital divide.
- Some of the Covid apps and websites have been too complicated – booking the vaccine via Roll Up for WA was so hard it was a deterrent; the Service WA app was also very complicated to download.
- Attendees expressed the view that Government agencies need to coordinate emergency responses better as often they appeared un-coordinated.

> Not every town has a community centre. The household RATS have been available regionally but there was no way for us to get hold of them…

> You have to repeat everything to the hospital doctor as well as the Telehealth doctor and there's no connectivity between the two. If there is no connectivity between the two doctors how can Telehealth be effective?

> Emergency Management procedures were 20 years too late – we are looking into a review in 2022 – the first outbreak of Corona viruses was 2002

3.4 Prevention in the community

Prompt questions were:

- What do you think of any WA Health activities that focus on preventing ill-health or injury in the community?
- How could the WA Health system better involve consumers in decisions about its prevention activities?

As highlighted in the previous session, it was noted that relationships underpin both emergency management and public health initiatives in that in that you need to have those well-established relationships with communities to make these things work effectively.

The conversations across both sessions uncovered these themes:

- Importance of consumer involvement in prevention – especially when developing public health materials and campaigns. Communications designed by consumers for consumers, and nurturing relationships ensure prevention messages "land".
- Importance of relationships – people seek their advice from people they trust
- Preventative health requires resources
- Approaches to prevention in the community was also discussed and key themes emerged
    - The first five years – the importance of support in the early years was highlighted, with the comment that parenting programs are a preventative health intervention
    - Schools could potentially be utilised more effectively to deliver preventative health messages in the community
    - Community and peer supports – the role of peers in keeping people well after hospitalisation was discussed
    - Role of GPs and non-government organistions (NGOs) – noting that people do not generally approach a hospital for preventative health advice and support. The NGOs and GPs who have relationships with people over time can be a better avenue for preventative health.

Consumer involvement in prevention

- Prevention opportunities are not working as well as they could because they're not co-designed with consumers, e.g., smoking cessation and drug awareness public health messaging for young people. They need to be more "bottoms-up" – rather than "top-down" – public health campaigns to really work. It was suggested that the Department could write into Public Health plans that they need to involve consumers in campaigns and initiatives.
- Public health messages need to include lived experience words; what helped me, why it was good to seek help early, here's where you can find help. It's so important to be conscious of reducing stigma, not blaming people, meeting them where they are.

> I'd love to know what consumers got involved particularly in mental health and alcohol and drugs given the high prevalence of smoking that said, yes, we would like these services smoke free. There are two residential, alcohol and drug rehabilitation centres, one in Brunswick, one in Nannup. Brunswick has a lot has a lot more people accessing it because you can still smoke there.

Importance of relationships

- Regional communities have central (Perth-based) offices wanting us to promote their health prevention activities. When we promote these prevention activities, it's important especially in small country towns, and with the multicultural community, to build relationships if you want to engage with people. Going to local champions, like the community leaders, without even building a relationship with them first, and expecting them to help promote these activities to their community without getting that trust and being transparent doesn't work.
- There was a discussion about Victoria where there is a separate standalone agency – VicHealth – that focuses on prevention. They've appointed a cohort of youth champions through an expression of interest process who are then trained and supported to hold conversations with peers about health promotion.

Preventative Health requires resourcing

- Holistic approaches to difficulties such as weight could assist in this and other complex problems. A One stop shop was suggested where holistic help is available and different clinicians can share consumer info so person not continually telling their story e.g., psychology, dietician, social worker, exercise physiologist, yoga, support group co-ordination, talks on a variety of topics by a variety of clinicians.
- Trauma and preventative health are intimately connected and this needs to be addressed in order to have successful preventative health interventions.

> They develop all these great things. A program where they were diverting money from crisis service to prevention, but it doesn't continue. The system always focuses on tertiary care, not prevention.

Approaches to prevention

3.5 Reflections from Panel Members – Part One – Regional Consultation

Kym Peake

- Whilst there's part of the infrastructure and architecture in place to support consumer input, it's partial. There needs to be a much stronger and more consistent approach to how the both the input to design of services and connections between hospitals and other services is taken forward.
- There needs to be an approach to capture the patient experience to look at the system as a whole. There's a real need to be more consistent at a hospital level – and there's a gap at the whole system level about ensuring the same patient experience wherever you go.
- There's an important theme around making sure that there is support for navigating the system so not just input to the design of the system and feedback loops, but also then support for consumers and carers about how to ensure that that they know what will come next and they know what is available to them.
- It reassures me about the importance of health system leaders making the time to listen to consumer and carer perspectives to ensure that we remain connected to the importance of the outcome for our consumers, carers and members of the community.

David Rosenberg

- As a clinician and a healthcare leader, I find health really hard. And I'm reassured that you find it really hard as well, so I'm not the only one.
- I certainly heard a sense of frustration in some stories and some experiences, but I did also hear plenty of people talk with some sense of pride around some of the things that they are achieving and some of the connections that they are fostering and some of the outcomes that they are, even if they've got to needle away and continue to be persistent.
- It is very clear that the experience that you have across the system varies enormously, according to where you live the services that you interact with. And in particular, the size of the community that you're in. A key question for us is "what can we do from a governance framework point of view to try and reduce that variability?".
- Closing the loop is also strong reflection.

Jo Gaines

- We recognize the difference for the experience of people living in regional areas who are those in metropolitan areas and I think that's what today was so important.
- The delivery of health care in communities really does underpin the health of communities. And if you don't have good health care, it really does impact on people's decisions about whether they can stay and live in the communities they love.
- The experiences and the solutions are different and that's why the consumer has become so important.
- I was born in a regional hospital and moved around WA all the time. I've been a patient at Derby hospital and other hospitals in my travels as a child. So, it is a really lived experience for me, it's something I'm very passionate about.

- It's important that we continue to make sure the connections between the service, the consumers and the communities are strong. We've got a keen eye on the healthcare experience and those connections between services, the importance of connectivity.

3.6 Reflections from Panel Members Part Two – Metropolitan Consultation

Kym Peake

- Positives - there have been improvements over the past five years, some of the examples around the tone of letters to patients, younger doctors been more open in their communication, but there's a long way to go and a long way to go.
- Recognizing that carers and families are an important bridge between the patient and the clinical team and should be seen as part of the care team.
- It's important that there's greater diversity in the consumer voice in the more structured mechanisms that relate to boards of hospitals, but also in the mechanisms that give consumer voice into all sorts of different processes.
- Some of the practical measures that would make a difference could be
    - requiring consumer reps on boards in the same way that clinical representation is required under the Act,
    - simplifying experience surveys so that they are more accessible to a broader range of people in hospital settings.
    - Having standing mechanism for engaging consumers in public health units so that it's not a need to recreate the wheel when there's an emergency but that there are pre-existing relationships.
    - There needs to be more consistent reporting lines between the consumer advisory councils and board
    - There is a real gap in terms of the consumer voice in decision making at the system as a whole, specifically the Department of Health
    - Those mechanisms both at a hospital level and at a whole system level should enable consumer-led service redesign - not just commenting on new service models that are presented as a kind of fait accompli, but genuine co-design
    - There would be value in thinking about some different types of roles, probably independent of hospitals, but in reaching into them that provide that patient navigation support in a more systematic and routine way.
    - There is real value in providing more support to consumer reps in the system about what's reasonable to expect of them and support and development of them, but also developing Board's understanding of the role of consumer reps
    - Educating clinicians about having consumers and carers and families as partners, and what that really means in practice, taking account of the feedback about their experience to really think about them as a whole person in the way to care is delivered.

Jo Gaines

- How do we ensure that the voice of the people that are probably least able to speak up gets heard through the system?

- We need to treat people in the system and persons in the system with their whole needs and the holistic view of people and their families as they make their way through the health system and make their way in and out of the health system.
- We need to think about how we make that experience as seamless as possible

David Rosenberg

- We must find better ways to take note of consumer, carer and family feedback and build that into our strategies, our policies, our procedures, the way we govern health care.
- The level of energy and enthusiasm and passion that people have brought to the conversations will be fed back to Western Australian Health Department to say there is so much opportunity to leverage this.
- We need to better support the system to learn how to take advantage of consumer feedback and consumer contribution.
- There's enormous diversity in the community and enormous diversity in the experiences that people bring from their interactions with health care. No two of them will ever be the same, but each one of those is a lesson for us.

4 Next Steps

- There will be a report written up from the consultations which will be provided to the Review Team and attendees of the two sessions. It will also go up on HCC's website.
- The Review Team have met in person and talked through all the consultations they've had in the last couple of months.
- From all the material reviewed the Review Team will draw out the key themes and start to think about what recommendations they want to make to the Health Minister
- Surveys and submissions received (deadline of 20th May) will further refine this thinking.
- The Review Team will provide a report to the Minister in August
- The report will provide a feedback loop on what the Team have heard and what they think should change in the system.
- There will then be a government response to the Report

5. Appendix - Panel Member Introductions

At the beginning of each session, Panel members were asked:

- why they wanted to be involved in this project
- what they'd like to get out of this session
- what they've heard so far

Dr David Rosengren, Executive Director Royal Brisbane and Women's Hospital

Practising Emergency Physician as well as Acting Chief Operating Officer for the Queensland Department of Health.

Why he wanted to be involved in the project

I have the privilege of both being able to contribute to the strategy and the governance of the system, and then to be able to work in the system as a clinician and see the impacts and see the opportunities that a good quality healthcare system can provide, but also get to see where it doesn't work and where complexity around service delivery affects patient experience and patient outcome. And the ability for consumers to navigate through a complex system. We all suffer from the same complexity in healthcare - we're all challenged by demand and complexity the same way and being part of this review process is an opportunity for me to be able to hopefully bring some of the learnings from the other side of the country where we have remarkably similar challenges. It is a very similar governance structure, maybe a few more years of experience in this system.

What he would like to get out of the session

I'm hoping to bring some of the strengths of my experience from Queensland, it also gives me the opportunity to take some learned experiences back with me to the system which are by contribute to so it's a little bit of a shared value proposition for me.

Kym Peake, Partner, EY Port Jackson

Why she wanted to be involved in the project

Previous role was Director General of the Department of Health and Human Services. We also had responsibility for a range of social services and community development community building responsibilities, and I'm passionate about the way that we bring the perspective on how systems work for people to the thinking about the management and the design of those systems. Governance might sound like a bit of a dry topic, but at the end of the day, systems are all about relationships. They're about the interactions between people and institutions. And governance is what gives permission for those relationships and interactions to work well. We want to get the governance to be as effective and enabling and empowering as possible.

What she would like to get out of the session

Our real ambition from this session is to hear from you what works well in the WA health system in terms of consumers and carers. Being able to influence decisions being Partners in Care and being able to provide feedback about experiences and outcomes that matter most to you, and where you see the opportunities for improvement so that we can take account of that in making sure that we are thinking about all the perspectives in all the relationships, all the interactions that impact on how the system works.

What you've heard so far (KP)

What we have heard in the last couple of months:

- there's been a real benefit of the new governance arrangements that have now been in place for the last five or so years in building the opportunity for closer relationships between hospitals and the hospital administrators and their local community.
- But there is a real opportunity to elevate the voice of consumers and carers in the policy decisions and the priority setting for the whole of the WA Health system.
- There's an opportunity to really capture the outcomes and experience feedback from consumers in a much more consistent and structured way. In particular, to improve equity of experience and to improve the experience of moving between health services.
- There has been the new governance arrangements pre COVID-19 and the experience during COVID. What do we want to hold on to that has worked well during COVID? What do we need to reset as we come beyond COVID? What would we want to put more effort to into going forward?

What's your take on the Sustainable Health Review as a blueprint for COVID-19 recovery? (KP)
All the themes in the Sustainable Health Review are still relevant about how to improve the connections between health and other social services, particularly disability and aged care, but also between primary care and hospital care. And that SHR focus on putting patient outcomes at the centre of everything we do is still really, important. But that COVID-19 has disrupted progress in in implementation of the SHR so it's important to reinject the energy around its implementation.

Mental Health and Consumer Experience Discussions (DG)
Consumers, clinicians and health administrators all noted that discussion we've got a system of governance that provides responsibilities and accountabilities to people for certain jobs and certain roles and everybody's tackling the responsibilities with a level of responsibility and enthusiasm and commitment that typically underpins what we see in health care. But one of the challenges is the connectivity between the bits.

Governance and the patient experience
When you're a member of the community needing to access health care, the governance structure or the alignment of the system is completely irrelevant to you. You want to be able to access the health system and have a seamless journey or transition through that system to get the best care and then the return to health and the ability to continue to return to your wellbeing in the community. And that's where our gaps are. That's where people get lost or confused or disorientated around the ability to bring together and connect those individual components.

The governance structure gives permission to people to form the relationships to provide better connectivity. And so, as a clinician and as a as a healthcare system executive. That's the messages that I've been interpreting and hearing as we've gone through this exercise.

COVID-19 has been a disrupter, but it has taught us and given us permission to do a whole range of things differently. And I would encourage, in the conversation today is to look at some of the things that you might have experienced or change which have been better because of being forced into doing different things differently with COVID.

We need to now have the courage to move past using COVID-19 as an excuse for not making progress and driving things forward. We've had a lot of time to prepare and plan. I know that across Western Australia. Currently there are challenges; the numbers have been growing and hospitalization and the impact on the community is certainly significant. But as a system, we need to have the courage to be able to continue to make sure we're doing the things that are expected of us and driving improvements, irrespective of that. And so COVID-19 is complex and has been really challenging, but I'd like to see us be taking that as an opportunity to drive improvements to embed some of the changes that have worked and to have the courage to look at doing things differently.