Health Matters

Health Consumers' Council (WA) Inc. Magazine
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Engagement

HEALTH CONSUMERS' COUNCIL

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Contents

HEALTH CONSUMERS' COUNCIL

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Cover image: Stock

Welcome to the Engagement edition of Health Matters, where we're looking at the many and varied ways health service providers and consumers can engage to create authentic, productive partnerships in healthcare. As we saw across the country during the height of the COVID-19 pandemic, we can never underestimate the importance of consumer input when it comes to our country's health. We need consumer voices to ensure the services being provided meet the needs of our communities, but also to ensure that public health messaging is understood and acted on by our communities.

Becoming a consumer rep

Wanting to help drive change or create better experiences for others going through a similar treatment is an enduring motivation for people to speak up. It's for this reason that I think it's important to acknowledge that many people come to the role of consumer representative after having a negative medical experience.

As we've talked about before, sharing personal stories can have a huge impact for those in health services and for other consumers, and it is certainly a brave way to advocate for change. In our Introduction to Consumer Representation training we talk about how to be effective as a consumer rep, and this involves important discussions around boundaries, how to best speak about our own experiences, and the importance of consumers representatives putting their own health needs first.

This edition includes lots of resources for anyone interested in becoming a consumer, carer or community representative, and we hope that you'll consider joining us on our mission to ensure the consumer voice is heard.

HCC restructure

As Health Consumers' Council continues to grow and evolve, we've made a few changes to the structure of our team so that we can continue to take on new challenges and opportunities. In the wake of COVID-19 we have seen many changes in how we operate, with increasingly complex requirements across all areas from engagement and advocacy to our daily operating needs.

We are excited to have Clare Mullen, previously our Engagement Manager, take on the role of Deputy Director. Clare will be working closely with me, the leadership team and the management committee on our strategic goals, while continuing to manage the Engagement team.

We extend a warm welcome to new team members who have joined us as part of this restructure – Gary Tindale in the role of Business and Systems Manager, Sarah Glenister in the role of Healthy Life Engagement Coordinator, and Nancy Peters in a job-share role of Administration Assistant. We welcome long-term team member Jenni Dlugi to the new role of Intake and Advocacy Officer.

We would also like to wish a fond farewell to Sheree Mears and thank her for bringing so much value to the organisation in her role as Operations Manager.

We're excited to see what the future holds for HCC and we look forward to continuing to develop our capabilities across the board.

PIP BRENNAN

EXECUTIVE DIRECTOR

HEALTH CONSUMERS' COUNCIL

How to become a consumer rep

*We use the term consumer representative to encompass consumer, carer, community and family representatives.

The consumer voice is vital to ensuring a safer, kinder health system. And consumer representatives are one important way of ensuring the consumer voice is heard.

Many consumer representatives start their journey wanting to share their personal experiences, providing valuable feedback to health services. But the role of a consumer representative is much more than bringing your own story to the table, it's also about speaking up for those who may not otherwise have their voices heard.

Consumer representatives provide feedback and constructive input on behalf of others – including other people with the same health condition, who have used the same health service, or who belong to the same cultural or geographical community.

Many consumer representatives are also involved with community groups or support groups, or have a connection with their community that allows them to speak to a wide range of perspectives and experiences.

It is vital to have the consumer voice involved when health care services are being planned, reviewed and delivered. We agree with the statement that "expertise lies at both ends of the stethoscope" and consumers have the capacity to influence ongoing positive change in the health system. But we know it isn't an easy task, and that's why we are here to support health consumer representatives in WA.

Where to start

Health Consumers' Council hosts training workshops that can help you use your experience as a patient or carer to create a better health system. Get started with our Introduction to Consumer Representation workshop, which covers the roles and purpose of a consumer representative, the benefits of consumer representation, barriers to participation for consumer representatives and how to overcome them, and how to maintain effectiveness as a consumer representative.

The Introduction to Consumer Representation workshop is held twice per year. Find out more at www.hconc.org.au/consumer-representative-introductory-skills/

Once you've had some experience as an active consumer representative, you can join our Advanced Consumer Representation workshop. This workshop aims to keep your skills and information up-to-date and increase understanding of the current international, national and local safety and quality focus in health care and how to integrate these concepts into effective representation.

The next Advanced Consumer Representation workshop will be held on 22 October – find out more at www.hconc.org.au/consumer-rep-advanced-skills/

You are also welcome to attend our quarterly consumer representative networking sessions – keep an eye for details at www.hconc.org.au/what-we-do/workshops/

How to get involved

The first step is to look for opportunities to become a consumer representative, and apply for positions with an advisory group or committee.

We share many opportunities for consumer participation, so make sure you sign up for our monthly e-news at www.hconc.org.au/resources/enews/ or for our weekly consumer representative opportunity emails at eepurl.com/cREYkn

You can also join our Facebook group Source – Connect, Learn, Share, which is for consumer, carer, community and family representatives at www.facebook.com/groups/hccsource/

Stay connected on specific topics of interest:

» **Partners in Change – healthy life for longer**

We have an email list for people interested in living a healthy life, with an initial focus on the WA Healthy Weight Action Plan – sign up for that at eepurl.com/dHephD. We also have a private Facebook group for this topic at www.facebook.com/groups/248123835784261/

- **Maternity services**

We host a private Facebook group for people interested in maternity services at www.facebook.com/groups/WAMaternity/

- **Aboriginal Health**

We host a Facebook group at www.facebook.com/groups/2551000611789401

- **People with disability**

We participate in a Facebook group at www.facebook.com/groups/1238258316345979/

- **Health for people from culturally and diverse communities**

Join our mailing list at www.hconc.org.au/cald-community-panel/

- **COVID-19**

Join our statewide network of consumers and carers who are interested in being involved in COVID-19 responses at www.surveymonkey.com/r/COVID19COI

- **Health Engagement Network**

Join an emerging community of practice for health service staff and consumer representatives to promote best practice and build capability at www.hconc.org.au/issues/engagement-community-of-practice/

Other consumer groups

Depending on your area of interest, you may wish to get in touch with some of these organisations:

- **The Consumer and Community Involvement Program:** connects consumers with opportunities in medical and health research – cciprogram.org/
- **Consumers of Mental Health WA:** consumer representative opportunities and training in the area of mental health – www.comhwa.org.au/
- **Carers WA:** carer representative program – www.carerswa.asn.au/our-services/carer-representation/

What is a consumer representative?

A Consumer representative participates as a member of a health related board, committee, advisory group or council by voicing consumer perspectives and contributing to decisions-making processes on behalf of consumers. Consumer, community, carer or family consumer representatives provide a voice not just for themselves, but on behalf of others with similar experiences. Please note that consumer representatives in WA do not speak on behalf of Health Consumers' Council.

Why be a consumer representative?

Health services must be accountable to the communities they serve. Representing the real needs of consumers is important and constructive, because it enables real, positive changes to be made and the rights of consumers to be defended and upheld.

What should you expect as a consumer representative?

You should be:

- heard, listened to respectfully and understood by other members
- able to ask for clarification and more information
- receive all relevant information, meeting agendas, and time to read, understand and consult with consumers and consumer groups before any meeting
- entitled to respectfully disagree with the rest of the committee and have this opposition recorded
- able to talk to others about information from the committee, its deliberations and processes, within the constraints of confidentiality

What are your responsibilities as a consumer representative?

Consumer representatives are advised not to disclose confidential information discussed during committee meetings.

Consumer representatives have a responsibility to share non-confidential information with other health consumers to inform and facilitate discussions with consumer groups and communities, to ensure the health system is patient-centred.

We're inviting you because it is about you

Living as healthy a life as possible is a goal for many people, and Health Consumers' Council has recognised this by employing a Healthy Life Engagement Coordinator, thanks to funding from the Department of Health.

The initial focus for our new team member, Sarah Glenister, is the Healthy Weight Action Plan (HWAP) and ensuring the perspectives of consumers and community members are included in the development and implementation of policies and activities of this plan.

But what is needed?

The best way to create change is to hear directly from those who are impacted and who have real-life experiences with overweight and obesity, to make sure a wide range of opinions and experiences are considered in planning and projects.

Involvement on the HWAP can happen in many ways.

- Over the last year and a half, we have received feedback through surveys and online forums. We'll be building on that soon so if you are interested in answering a few questions or telling your story please contact us on info@hconc.org.au
- We will be visiting places that people gather like shopping centres, family centres and community events to speak to people and hear their experiences, so if you have an event coming up or are part of a group that would like to have a say please email info@hconc.org.au
- To ensure a diverse range of voices are heard, we will sometimes seek feedback from specific communities. At the moment, we would like to hear more from Aboriginal people, children and families, people from culturally and linguistically diverse backgrounds, people living in rural and remote WA, people over 45, people with disability, and men.
- The agencies we work with sometimes ask us to help them seek consumer input on projects people to test out ideas related to the HWAP. Diabetes WA are running a trial of meal replacement products in general practice and we worked with them to hear consumer voices around this topic to inform the design of the trial. You can read more about this below.
- Occasionally we hold meetings that include clinical staff and a range of policy people from agencies with an interest in the HWAP. At these meetings we ask for representation from consumers or community members. If you are interested in being involved in this more formal way, you can email info@hconc.org.au

> *"There was a common belief that obesity management should be about improved health and well-being, rather than focusing solely on weight loss."*

Current projects

There are already several projects underway that you may be interested in:

DIABETES WA

Diabetes WA have been running (virtually) a Total Meal Replacement program and trialling it in the Rockingham/Kwinana area.

- Referral is through the local GP
- It is an 8-week total meal replacement program followed by a maintenance phase
- Participants receive allied health support from a dietitian and exercise physiologist via telehealth, plus online support through virtual support groups, an app, weekly emails, and information sessions on Zoom
- Consumers have been involved through a HCC focus group for people to share their weight loss journeys and experiences using meal replacement products.

Through the consumer consultation we heard how people living with obesity have experienced judgement and stigma around weight issues.

There was a common belief that obesity management should be about improved health and well-being, rather than focusing solely on weight loss. With this in mind, the program from Diabetes WA was designed so that participants have a positive experience and feel supported through their journey. Diabetes WA will use these experiences to tailor the training GPs and Practice Nurses undertake to influence their interactions with patients about weight.

WA PRIMARY HEALTH ALLIANCE

The WA Primary Health Alliance has been investigating the barriers, enablers and experiences in talking to patients about weight and supporting patients to achieve and maintain a healthy weight. In addition to reviewing global and local literature, WA Primary Health Alliance interviewed local GPs to gather information on their current practice. They have also been listening to consumer feedback on experiences in attending GPs. Some of their findings to date are:

- General practice clinicians agree that they are well-placed and have a responsibility to help patients achieve and maintain a healthy weight
- There is a lack of confidence among general practices in engaging in conversations with patients about weight in a way that is sensitive and meaningful
- General practice clinicians identified that they are well-placed to provide patients with the ongoing support they need to achieve and maintain a healthy weight, however they require more tools and support to do this
- General practice clinicians are unsure where to find evidence-based tools to support their patients to achieve and maintain a healthy weight
- Patient mental health is a barrier to patients achieving and maintaining a healthy weight that is under-recognised (this was strongly reflected in the analysis of consumer feedback).

In a win for consumer consultation, it was noted that while patient mental health was mentioned by many consumers in their feedback to be a very common factor in maintaining a healthy weight, this theme was not evident in general practice data. It is imperative that general practice clinicians are aware of the role of mental health in weight management and refer their patients for appropriate treatment for these issues.

Other findings from our consumer and community research tell us that people don’t always feel comfortable talking about weight issues with their GP and sometimes it takes a while to find someone who they connect with on such a sensitive topic. The work underway with WA Primary Heath Alliance will mean that more GPs will have better resources and a better understanding of how to have these conversations.

Do you know anyone that would like to be involved in ensuring the perspectives of consumers and community members are heard?

We are especially interested in increasing the voices of Aboriginal people, children and families, people from culturally and linguistically diverse backgrounds, people living in rural and remote WA, people over 45, people with disability, and men who have lived experience of overweight or obesity.

Please email info@hconc.org.au to get involved. You can also join our mailing list for healthy weight at eepurl.com/aHephD

IMAGE © WA HEALTH, CURATED BY WEIGHT ISSUES NETWORK (AUSWIN.ORG.AU/)

Community health literacy sessions

One of the ways Health Consumers' Council is working to ensure diverse voices are heard by health services is by engaging with culturally and linguistically diverse communities though community conversations on specific health topics. Recently, we have been focused on health literacy sessions providing information on WA's health system.

Did you know that more than 60% of the Australian population has trouble understanding information provided to them by organisations? Additionally, many people have trouble navigating our state's large and complex health system.

That statistic is taken from across the whole population and doesn't take into account English proficiency, so you can imagine what it might be like for migrants, refugees and people with English as a second (or third) language trying to use a complex system of doctors, referrals, hospitals and allied health.

After taking a break from in-person sessions for COVID safety, we were delighted in September to get back out to communities to talk about health topics and support people from culturally and linguistically diverse backgrounds.

We conducted a session on Choosing the Right Health Service at a mother's group at Ishar Multicultural Women's Health Centre. This session was attended by 10 mothers (plus 10 babies, one child and two interpreters) who had varying levels of experience with the WA Health system and varying levels of English. While the mothers mostly had a good understanding of GP services, they were less clear about hospitals and pharmacies, so it was a real benefit for them to learn more about accessing these services. In particular, they heard about some of the online service provider search engines and reliable online and telephone advice portals.

We also conducted a number of sessions on Rights and Responsibilities in Healthcare in the City of Gosnells. In these sessions we discussed the Australian Charter of Healthcare Rights, which describes the rights that consumers, or someone they care for, can expect when receiving health care.

We focused on (telephone) interpreting and also on asking your doctor (or other health service provider) questions until you understand enough to give informed consent for a procedure or treatment. It's so important to feel comfortable asking questions, and we hope those who attended will be encouraged to seek more information when they need to. During these sessions we also looked at giving feedback, and how letting your doctor or health service provider know about your experiences, whether good or bad, can help these services to improve.

Our Real Life Church group (pictured) consisted of 12 participants, mainly with Chinese backgrounds, who have been in Western Australian for varying lengths of time. They meet weekly at the church to practice conversational English, and it was wonderful to join them to help facilitate conversations around health care. The aim of these sessions is to engage and empower consumers in management of their own healthcare. We encourage people to be active and informed decision makers – we are the Chief Executives of our own bodies!

Involving the community in health research

Research Priority Mapping Workshop

MAXINE POLLARD, CONSUMER AND COMMUNITY INVOLVEMENT COORDINATOR, CONSUMER AND COMMUNITY INVOLVEMENT PROGRAM (PART OF THE WESTERN AUSTRALIAN HEALTH TRANSLATION NETWORK)

When it comes to effective engagement between researchers and the community, involvement is key.

The most effective form of engagement between researchers and the community begins when health consumers have a voice in planning the research. In Australia we call this Consumer and Community Involvement.

In health and medical research, a multi-disciplinary approach is often used – that is, one that includes many experts in the planning and development of the research project to ensure it provides benefit to the community. It makes sense to treat individuals with a lived experience of illness as another expert that should and must be involved in the research process.

Medical research often focuses on the similarities found in the experience of a disease. Yet what is thought to be most important by researchers may be another thing to the majority of those who live with an illness. It is these complexities that can be the reason some research doesn't translate into practice successfully.

This is where the consumer and community voice is critical. Where scientific minds must explore the broader public experience in order to find solutions that create meaningful change.

The Consumer and Community Involvement Program (CCI Program) links researchers with people with a lived experience of illness. One method used by the CCI Program is to bring researchers and consumers together to start a conversation that will guide the research planning process.

In November 2019, the CCI Program ran a Research Priority Mapping Workshop in partnership with MSWA and Edith Cowan University. The aim was to discover if research into neurological conditions that receive funding matches the priorities of people living with these conditions.

"You could see the researchers did come to the workshop with a different lens," said Kerry, a health consumer who attended the workshop to voice her experiences as a carer and patient of neurological conditions.

"We were more interested in seeing research address the practicalities of daily life with a neurological condition – on the importance of the things that we can control such as food and exercise, fear and anxiety. There was a shared feeling (between attendees) that this was often overlooked by medical teams.

"You could see that this surprised the researchers; that these aspects of nutrition and managing the condition rated so high on our priority list.

"It was exciting to see that they were willing to take this on board and look at their work from another perspective," she said.

The bright minds who pursue years of study and research in order to effect change need connection with the community to reinvigorate their work. While their many years' experience is vital in the quest for improving health, the personal experience of illness or disease can be beyond the reach of the scientific team.

This is precisely why the community voice is so important in health research. Sharing experience, humanising the research question, and asking critical questions about why the research is being undertaken and how it will benefit patients not only ensures the research is on track with the needs of patients – it relights that lightbulb moment for the researcher.

VISIT CCIPROGRAM.ORG FOR OPPORTUNITIES TO GET INVOLVED IN HEALTH AND MEDICAL RESEARCH IN WESTERN AUSTRALIA.

**The Consumer and Community Involvement Program recently changed its name from the Consumer and Community Health Research Network.*

Planning, design and delivery

How patience and persistence lead to meaningful engagement

The Fiona Stanley Hospital Emergency Department Consumer Advisory Group (EDCAG) was established in mid-2016, about six months after Fiona Stanley Hospital was opened.

Health Consumers' Council spoke to EDCAG consumer and Chair, Jane Pearce, and Fiona Staley Hospital Emergency Department Head of Service, Dr Vanessa Clayden, about the unique way the group has allowed consumers and staff to work together.

The EDCAG was set up in response to the NSQHS Standard 2 ('Partnering with Consumers'). The intention of this Standard is 'To create an organisation which has Consumers as partners in planning, design, delivery, measurement and evaluation of systems and services'.

"Because it was a brand-new hospital with a brand-new ED there was an opportunity to think differently about how to engage with consumers," Ms Pearce said.

"The initiative to set up the EDCAG came from a senior consultant in the ED, who has a keen interest in encouraging consumer engagement and has been a key driving force behind establishing and maintaining the EDCAG. He is deputy chair of the group.

"The Group has 6 consumer members and 4 ED clinical staff members, including the Head of Department and the Nurse Unit Manager. The Group sits within the governance structure of the hospital, reporting to the Consumer Advisory Council and hence to the Hospital Executive Committee. A consumer member chairs the Group, and a clinical staff member is deputy chair."

According to Dr Clayden, the EDCAG was a totally new concept for the staff in ED, and it felt like quite a novel approach to interface between consumers and clinicians.

"Sometimes when you're working in a service you can develop a fairly narrow, clinical view of situations, so everyone saw that it could be useful to benefit from the consumer point of view."

While work has continued under the broad terms of reference for the intention of the group, Dr Clayden said it had followed a natural course of looking at what both the consumers would like to focus on, as well as what people in the Department already had some awareness of.

From a consumer perspective, Ms Pearce said the most innovative aspect of the EDCAG's work is supporting consumer involvement in the planning, design and delivery of services.

The EDCAG's involvement in planning, design and delivery of services to date includes:

- Providing information for consumers about Emergency Department processes, including what to expect at triage and on admittance;
- Developing a leaflet for consumers explaining the rights and responsibilities of Next of Kin in the ED;
- Collecting narratives describing patients' and family members' first-hand experiences in the ED at Fiona Stanley Hospital, to be used as a resource in staff education seminars;
- The Patients at Risk project (PAR) was set up in response to the perception of ED staff that the needs of vulnerable patients could be met more effectively in the ED at FSH. After consulting widely both within the hospital and with outside agencies, the EDCAG developed Standards for the Care of Vulnerable Patients in the ED at Fiona Stanley Hospital which have since been adopted by the ED. A group of senior ED nurses are now working closely with EDCAG consumers to provide guidance on the contents of an education program to support staff to fulfil the requirements of the agreed standards.

"Consumers have regular contact with clinical staff members of the EDCAG through participation in every formal EDCAG meeting and occasionally as members of consumer working groups," Ms Pearce said.

> *"This regular contact has led to a close working relationship growing up between the consumers and the clinical staff members of the EDCAG. Establishing mutual trust has been very important, and the fact that staff members have been very receptive to consumers' perspectives, and that ideas are shared and discussed openly at meetings, are essential components of this.*
>
> *Consumers have also been encouraged to be autonomous from the start, and this enables the implementation of consumer-led projects and other initiatives that prioritise the design of care that is responsive to patient, carer, and consumer input and needs. Prioritising and supporting consumer autonomy have been crucial to the effectiveness of the partnership between staff and consumers."*

Ms Pearce described how the close involvement and endorsement of the work of the Group by senior staff has given a sense of legitimacy to consumers and has led to the role being recognised and widely accepted in the ED. The presence of consumers in key committees in the ED has brought consumer perspectives to the attention of senior medical staff as well as providing the consumers with essential insights into the work of the ED.

"Opportunities for staff education have also developed as a result of EDCAG activities, whether formally (through the use of patient narratives) or more implicitly through having consumer contributions to staff discussions. This has resulted in a subtle but definite shift in culture towards an awareness of the importance of there being a consumer perspective across the ED. Consumer perspectives are now more explicitly 'on the radar'," Ms Pearce said.

Dr Clayden thinks that the consumers have also had a chance to learn a lot about the inner workings of an Emergency Department, including some of the limitations and the reasons behind them.

The recent involvement of senior nursing staff in implementing the PAR project is a further example of the value of a productive working relationship between staff and consumers.

"The group is very autonomous – they make progress and they report back to the CAG. It's one of the purest examples of a consumer perspective on what matters," Dr Clayden said.

"For lots of these very complicated examples [of patients at risk], there can be a utopian idea of what should happen. But in a high pressure setting of an ED, it's been interesting to see these two perspectives mesh. There's been an exploration of 'how can the staff lift to see if we can come closer to the ideal of what would be possible?'

"The group has felt very satisfied with the project, their recommendations and the Department's response."

By the same measure, the consumers feel that the PAR project has also been a positive experience for the ED nurses.

"I think they feel affirmed and supported by consumer endorsement of their own efforts to adopt a more person-centred approach to care in the ED, and are optimistic about the possibilities for change that consumer advocacy can create," Ms Pearce said.

"I also think the working group meetings have had the unexpected benefit of providing a space for nursing staff to talk about their work and share ideas with like-minded colleagues. The nursing staff are also embracing their roles as consumer advocates in the ED, and I expect they will become key agents for change as their involvement with the EDCAG deepens."

Importantly, Ms Pearce believes the strategies adopted by the EDCAG to involve consumers in service planning and designing care could be adopted by other consumer groups and staff members for designing and implementing consumer-led projects. The latest collaboration with nursing staff as members of an EDCAG working group shows the value of staff and consumer engagement in the co-design of services.

"Consumer engagement is a process that takes time and doesn't happen overnight, but with patience and persistence great things can be accomplished!"

And from the health service provider point of view, Dr Clayden said that while this type of collaboration may feel novel or confronting to begin with, "if you actually jump in with good intentions and an open mind, there is a lot to gain from having the consumer perspective on problems".

"With persistence and engagement from both sides, you can achieve quality improvement that is relevant to the consumers."

Consumer perspectives

Elizabeth Harris

My name is Elizabeth Harris, I am a 14-year-old Aboriginal girl. My Country is Bundjalung Country, but I was born in Perth. I am in Year 9.

I joined the Perth Children's Hospital Youth Advisory Council because I wanted to give a voice to other Aboriginal kids, since we don't very often get a say in the health system.

I also wanted to make sure that kids with disabilities were heard. I don't have a disability, but my older sister does, and I don't think many kids like her go to these sorts of things. I know I can't speak for what it's like for her, but I can make sure when we talk about things that I can bring up disability issues and ask if they've asked any disabled people about it.

That way, the health service will at least know they should be asking disabled kids. I have spent a lot of time going to appointments with my sister and visiting her in hospitals and it can be very boring for us both, so if I can help make it a bit less boring for some other family, that would be great.

At the YAC we do things like look at videos and resources they are making for youth and give feedback and let them know things that can improve. We also look at data and statistics and talk about why things are like they are, what might need to improve and how they can do that. We also talk about ways and ideas for the health service to engage and work with youth.

Most of the staff are pretty old, or at least, not very young, so they need help with that. They are really nice and supportive and make us feel welcome and that what we say is important. We meet every month, either at the hospital or on Zoom. I usually have to do Zoom as the meetings start really close to the end of my school and there isn't enough time to get there.

I like the food! But if I do Zoom, there's no food ☹. I like hearing the other kids views on topics, even when we don't all have the same opinion. I like learning about the health system. They also pay consumer payments, which is a lot more an hour than Maccas!

We don't really get to go to meetings like this as kids, and it makes me a bit sad that as an adult I might have to go to a lot of these things lol. Nah, its pretty fun, but I can't imagine doing lots of them every week!

Nothing really stands out yet [from the work I've been involved with so far] but I haven't been going very long, only 3 or 4 meetings, but I did sign up for 2 years so maybe ask me again when I am 16!

Consumer perspectives

Peter Hall

I am a 28-year-old man in Perth with Cerebral Palsy. When a good friend of mine passed away it empowered me to become an advocate for disabled people in the health system. I also joined the Western Australian Youth Parliament as Shadow Health Minister which was a great experience. Due to the complexity of my case, I only moved to the adult health system when I was 21, so I have a unique perspective on both the children's and adult health services.

The consumer rep role for me has included going to Melbourne to represent WA health consumers. It also involves advocating for people with all different types of disabilities, including intellectual and physical disability. For me it also means making sure I am available to consumers and my network whenever they need help.

I enjoy making a difference, meeting new people, and learning new things.

> *I like the power that being a consumer representative can have, being the dark horse in the room and asking the questions that might not otherwise be asked.*

Representation of diverse groups, like disability and LGBTQI people, is so important on these committees and councils. It is vital that lived experience of disabled people is at the tables where decisions are being made.

Being a consumer representative has also meant that I have had another source of income, which protects me from the limitations of relying solely on Centrelink payments.

I have just left the Child and Adolescent Health Service Consumer Advisory Council after 15 years of service, and am looking for new opportunities to advocate for health consumers and continue to share my lived experience knowledge and learn more about our health system.

Vibrant discussions for culturally appropriate services

In August 2020 East Metropolitan Health Service (EMHS) hosted a forum for the EMHS Aboriginal Health Advisory Groups, creating an opportunity for Aboriginal patients, consumers and community members to describe their experience with maternity and outpatient services across EMHS.

The session was planned jointly between the team responsible for maternity service planning and outpatient reform and the Aboriginal Health Strategy team (AHST). The latter group was instrumental in ensuring that the session was culturally safe for those participating. One of their key recommendations was to have a table for men at the discussion, to ensure that the Aboriginal male perspective on maternity services was heard. This was particularly well received by participants, with several commenting it was a great opportunity to share their experiences.

The AHST also sought endorsement from the Aboriginal Health Advisory Council prior to proceeding with the workshop. Successful consultations with Aboriginal stakeholders like this one ensure the needs and interests of Aboriginal people are considered and appropriately incorporated into everything that EMHS does.

The forum in August focused on four key areas of discussion:

- How can we improve the experience of having a baby or attending a doctor's appointment?
- What can staff do to better engage and understand Aboriginal patients and consumer needs?
- How can we improve the quality and safety of the maternity and outpatient services?
- Is there any waste or unnecessary cost to our Aboriginal consumers?

Attendees unpacked each key area, identifying issues faced by Aboriginal people as patients, family members and/or carers. The discussion focused on:

- What was important to them in terms of the provision of culturally appropriate care
- What improvements could be made to staff awareness and understanding
- What they felt would add real value to EMHS services
- What measures were needed to ensure they felt safe while being cared for.

The forum generated a vibrant discussion between Aboriginal community members, allowing the EMHS teams to come away with a clearer understanding of culturally appropriate areas for service improvement for maternity and outpatients.

Feedback from the consumers at the forum highlighted that it was a truly collaborative session where they were able to both learn and share.

Aboriginal Health Advisory Council member Barbara McGillivray was delighted at the success of the event.

"It was one of the best sessions we have had. It was well organised and the collaboration was the best I've seen," she said.

Chairperson of the Bentley Community Advisory Group, Brenda, said the forum was a great way to bring this topic to the attention of the CAGs and share different points of views and opinions from the other CAGs.

Shaydeen, from the St John of God and Midland/Swan Hills CAG said "The focus groups with case study examples really helped to generate discussion and I loved the men's table to provide their point of view."

The forum marked a return to large group sessions following COVID, and EMHS Cultural Security Officer Ian Gentle said it was great to see community members back at EMHS.

"They have all come back enthusiastic and shared some really good insights and feedback."

The outcomes from the workshop were collated and shared with the relevant leadership teams, who are eager to understand key areas of importance to the local Aboriginal community and collaborate with stakeholders to provide culturally sensitive services wherever possible.

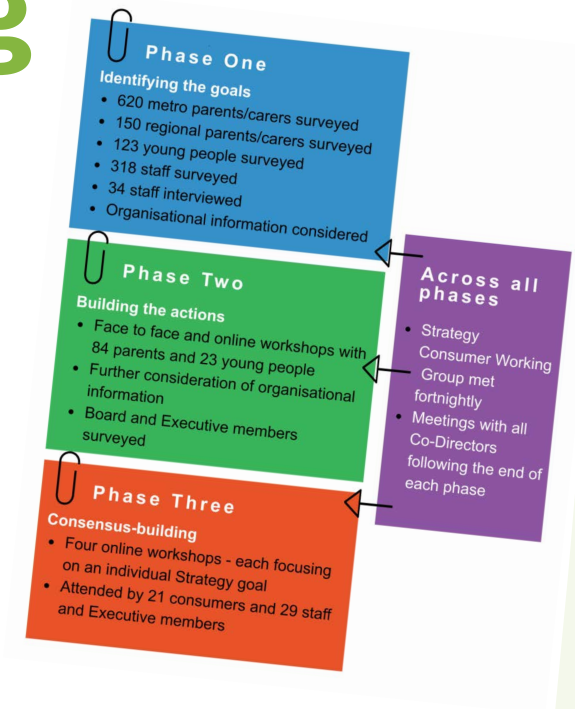
Planning for maternity services within EMHS is ongoing and the findings will be presented to the maternity leadership group to strengthen actions prior to finalising the EMHS maternity service plan.

Healthy kids, healthy communities

Compassion | Excellence | Collaboration | Accountability | Equity | Respect

Neonatology | Community Health | Mental Health | Perth Children's Hospital

CAHS improving engagement



Phase One
Identifying the goals
- 620 metro parents/carers surveyed
- 150 regional parents/carers surveyed
- 123 young people surveyed
- 318 staff surveyed
- 34 staff interviewed
- Organisational information considered

Phase Two
Building the actions
- Face to face and online workshops with 84 parents and 23 young people
- Further consideration of organisational information
- Board and Executive members surveyed

Phase Three
Consensus-building
- Four online workshops - each focusing on an individual Strategy goal
- Attended by 21 consumers and 29 staff and Executive members

Across all phases
- Strategy Consumer Working Group met fortnightly
- Meetings with all Co-Directors following the end of each phase

The Child and Adolescent Health Service (CAHS) has partnered with consumers and staff to establish the CAHS Consumer Engagement Strategy 2020-2022 and continue its journey of improving the way the health services engage with children, young people and families. The development of the Strategy focused on identifying how CAHS could more successfully partner with its consumers across the three main ways that they engage with the health service:

- partnering in clinical care, treatment and support
- sharing feedback, and
- participating in planning, designing, implementing and evaluating services.

Development of the Strategy

The Strategy was led by the CAHS Consumer Engagement Team and was developed in three phases, each involving consumers, staff, and representatives from non-government organisation partners. A Consumer Working Group also met fortnightly to help shape how the Strategy was developed.

Members of the working group shared the following reflections on being involved in the Strategy:

"It's an honour to be consulted about the shaping of healthcare in Western Australia and the Child and Adolescent Health Service. It's great to have a voice and to know what's happening." – A parent of five

"It is important to have the family of the young person involved to work together to deliver the best outcome for the child." – A parent of two

"It allows for those who don't feel brave enough or don't have the platform to speak to be represented. This representation prevents different perspectives from being lost or misheard. Different perspectives are eye-opening!" – A young person

Phase One

Phase One involved a consumer survey which received responses from 620 metropolitan parents and carers, 150 regional parents and carers, and 123 young people. The team also conducted interviews with 34 staff and received 318 responses from a survey that was sent to all CAHS staff.

From this, the strengths and gaps in consumer engagement across CAHS were identified, and four goals for the Strategy emerged.

Phase Two

In Phase Two, the **actions** based on the feedback received in Phase One were built upon with the involvement of 84 parents and 23 young people through face to face and online workshops.

Phase Three

Phase Three brought together 29 staff and 21 consumers via online workshops to develop the final wording for each of the four Strategy goals and a prioritised list of actions to sit under each goal.

In total, over 1000 consumers were engaged during the three phases.

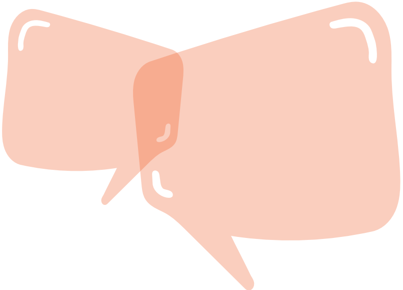
The four goals are:

- **Goal 1:** Work together with children, young people and families in the care we deliver.
- **Goal 2:** Partner with children, young people and families in ways that work best for them.
- **Goal 3:** Communicate compassionately with children, young people and families according to their unique needs.
- **Goal 4:** Provide clear guidance for working together with children, young people and families.

TO LEARN MORE ABOUT THE GOALS AND ACTIONS, OR IF YOU ARE INTERESTED IN BECOMING A CONSUMER REPRESENTATIVE AT CAHS, PLEASE VISIT CAHS.HEALTH.WA.GOV.AU/FOR-FAMILIES-AND-CARERS/CONSUMER-ENGAGEMENT/CONSUMER-ENGAGEMENT-STRATEGY OR EMAIL CAHS.CONSUMERS@HEALTH.WA.GOV.AU

Communication key to patient engagement strategy

KERRY HODGKINSON, NURSING DIRECTOR – STRATEGY, ROYAL PERTH BENTLEY GROUP



Royal Perth Bentley Group (RPBG) is in the process of developing a contemporary patient engagement strategy to inform and improve health care delivery. This strategy is an integral part of care delivery under the Deliver What Matters Most pillar.

It is integral to comprehensive care, ensuring patients, consumers, carers, families and the health care teams work in partnership to achieve the best possible outcomes for the patient.

Engagement has been defined as "actions individuals must take to obtain the greatest benefit from the health care services available to them", and this emphasises the role individuals have at improving the effectiveness of the healthcare system.

It is important to have the consumer voice at the table as health care services are being planned, reviewed and delivered, bearing in mind 'expertise lies at both ends of the stethoscope'. A such, the strategy aims for consumers to have more capacity to influence health outcomes.

As part of the strategy, we are developing a model for how effectively we use patient feedback to inform improvement to service, and to achieve this a comprehensive analysis of patient feedback is being undertaken. We are also undertaking a comprehensive stocktake of external stakeholders and aim to facilitate a genuine partnership between patient and consumer engagement, as identified in the RPBG Nursing and Midwifery Strategic Priorities to Build a Better Future.

In 2019, the Nurse Unit Manager (NUM) of 4ABG was nominated for a WANMEA Award for her passion for improving patient care and satisfaction, as demonstrated by her actions after a complaint was made by a patient's parent. The complaint was about wait times on the ward and poor communication which led to a negative experience. The NUM took on board the feedback and arranged for the parent to present her views and concerns directly to staff during a ward education session.

This provided an opportunity for staff to receive direct feedback from the consumer perspective and to engage directly with the family. It provided perspective of the patients' journey and showed how small actions from staff can have a large impact.

Following the session, the NUM and her staff reviewed the roles and responsibilities of staff in the unit and created a rotating Communications Officer role. Each day a Registered Nurse is allocated to the role, with it being their responsibility to update patients every hour regarding their upcoming surgery.

The Communication Officer role promotes an avenue for open discussion with the nursing staff and allows patients to address any concerns or questions they may have. This reassures the patient and to date has seen an improvement in positive feedback collected on the ward by 55%.

This is just one example of what we are hoping to achieve across the organisation through the patient engagement strategy.

An expression of interest for committee members for the engagement project working group will be coming out soon for interested parties who are innovative, compassionate and want to improve the experience for all who use RPBG services.

Telehealth and chronic conditions

An intentional, respectful and collaborative approach

Stay Connected with Telehealth

ConnectGroups
helping support groups & individuals

The WA Primary Health Alliance funded Stay Connected with Telehealth program was a three-month initiative led by ConnectGroups, the Peak body for Support Groups in Western Australia. ConnectGroups was tasked to:

1. Build consumer knowledge and awareness of telehealth within targeted Support Groups with diagnosed chronic conditions and their wider membership
2. Increase the uptake of telehealth by those targeted health consumers
3. Increase consumer confidence to request telehealth to maintain engagement with their GP and other specialists.

ConnectGroups was well placed to lead this program because of its oversight and access to chronic conditions-focused Support Groups. ConnectGroups deployed a strategy engaging six Support Group champions (SGC) across five diagnosed chronic conditions to directly reach groups' membership (representing 5,000+ health consumers) and engage in positive telehealth messaging, building reassurance and competency in consumers to engage with GPs through telehealth, and promoting the imperative of partnership and safety around the self-management of their chronic condition.

A total of 474 members from across five chronic conditions responded to the first survey to understand baseline levels of telehealth awareness in this cohort. 119 members responded to the post education campaign which measured confidence to positively engage with the service. Baseline results revealed that a majority of health consumers did have awareness of telehealth though there was a substantial percentage who did not or were uncertain of the availability of telehealth at their GP practice. Furthermore, 34% of respondents indicated better knowledge of telehealth would encourage them to use it.

Measurements about consumers' engagement with the education campaign indicated that 89% felt the campaign was useful and provided sufficient information to better understand telehealth. 100% of respondents requested that telehealth continue to be made available after September 2020. The metrics clearly indicate consumers' positive experiences engaging with telehealth following the education campaign.

Engaging in a co-designed and co-produced approach to program delivery with the SGCs proved an effective strategy to rapidly access health consumers who live with distress and disruption, in an intentional, respectful, collaborative manner that led to the successful program outcomes. The program demonstrated the value of engaging the Support Group sector and converted their unique insights and experiences in health access and disparities into quantifiable findings around the importance of telehealth as an ongoing feature of the healthcare system.

> *"Working with ConnectGroups on the telehealth project has been a fantastic initiative and the Young Adult Diabetes Committee have been incredibly proud to have been a part of it. The project has highlighted the importance of telehealth for people living with chronic illnesses and how vital this service truly is. Working with the entire committee has been powerful in bringing together our voices for a common goal; a core value of the Young Adult Diabetes Committee. We truly hope that we have been able to voice the opinion of all people living with diabetes and can continue to improve the lives of those living with all chronic illnesses."*
>
> SUPPORT GROUP CHAMPION

There are lots of ways you can get involved and have your say on health in WA. Join us in a private Facebook group to connect and discuss, or stay up to date via email.

FACEBOOK GROUPS:

Source – Connect, Learn, Share

www.facebook.com/groups/hccsource/

A community for upcoming, experienced and/or active Consumer Representatives in WA to connect, learn from one another and to share information and resources.

Partners in Change – healthy life for longer

www.facebook.com/groups/248123835784261/

A space for community discussions around living a healthy life for longer, with an initial focus on the WA Healthy Weight Action Plan.

Health Consumers' Council WA Aboriginal Health

www.facebook.com/groups/2551000611789401

A place for all of those with an interest in Aboriginal health to connect, looking at the work HCC is doing, information for health consumers, and engagement opportunities.

Maternity services

www.facebook.com/groups/WAMaternity/

A group to harness the power of social media to ensure women and their families have a say on maternal health issues in Western Australia.

Empowering Health Consumers with Disabilities in Western Australia

www.facebook.com/groups/1238258316345979/

A group for people with disabilities, their families, support workers and carers who have used the health system in WA, offering information, education, peer support and above all empowering health consumers.

MAILING LISTS:

Health Consumers' Council e-news

For a monthly update on everything happening at HCC, plus the occasional breaking news or event update: www.hconc.org.au/resources/enews/

Consumer representative opportunities

For a weekly email outlining consumer participation opportunities

http://eepurl.com/cREYkn

Healthy Weight Action Plan

http://eepurl.com/dHephD

To stay connected around the topics of healthy weight and ways to get involved in the WA Healthy Weight Action Plan

CaLD Panel

www.hconc.org.au/cald-community-panel/

Opportunities for people from culturally and linguistically diverse communities to have their say on health services in WA

Health Engagement Network

www.healthengagement.org.au

An emerging community of practice for health service staff and consumer representatives to promote best practice and build capability.

Community kindness and patient feedback

Peel Health Campus has produced a series of videos sharing their stories of caring for people. One of the key themes among the Community Kindness Video Series is how meaningful change can be made when consumers are listened to and their feedback is used to improve services.

In particular, the video Improving Dementia Patient Care explores the importance of listening to patients and their families to achieve best practice outcomes. This video was released to coincide with Dementia Action Week 2020 in September.

According to the organisation Dementia Australia, dementia affects close to half a million Australians – but that number is set double in the next 25 years. Dementia Action Week 2020 will demonstrate that many people living with dementia can continue to live well for many years after their diagnosis. Many continue to make significant contributions to our community, they engage, make their own choices and live rich and active lives.

Improving Dementia Patient Care

youtu.be/7atY4Fl53lE

> “Peel Health Campus provides care to many patients with dementia. Hearing from the families of those patients has enabled us to make our care and programs more supportive for them and their families. This video story highlights the power of listening to feedback and the value of collaborating with families who are affected by the disease.”

YOU CAN TAKE A LOOK AT ALL OF THE VIDEOS PRODUCED FOR THIS SERIES AT

www.peelhealthcampus.com.au/lib/Community%20Kindness%20Video%20Series

Health in a Virtual Environment

From a newly constructed Command Centre at Royal Perth Hospital, East Metropolitan Health Service (EMHS) will launch the Health in a Virtual Environment (HIVE) service in December.

HIVE is a remote monitoring system using artificial intelligence and staffed 24-hours a day by clinical experts in critical care. HIVE will provide another level of observation and clinical assistance for patients identified by their treating team who may benefit from receiving extra care and monitoring, supporting the delivery of consistently amazing care.

Three HIVE staff can monitor up to 150 patients at the same time. HIVE utilises a two way audio-visual communication between the bedside and HIVE command Centre. Patients and staff can see and communicate directly with clinical staff on duty within the command centre. For the initial go-live, HIVE will only activate the audio-visual system upon the request of the bedside clinical staff, or in the event of a medical issue arising with the patient that requires immediate intervention.

However, if the patient or family requests the bedside staff to contact HIVE on their behalf, this would be very welcomed. At all other times, the audio-visual system is turned off and clinical staff at the bedside and Command Centre are trained to involve the patient and family in all patient-related discussions.

The HIVE will initially focus on improving inpatient care in Royal Perth and Armadale Hospital, however in the future EMHS plans to use this capability combined with mobile and wearable technologies to support patients going home earlier and empower patients with chronic health problems to co-manage their health in the community.

Consumer advisory committees at Armadale and Royal Perth Hospitals, along with Aboriginal consultation groups, were consulted at the early stages of project. On 28 August, consumer representatives from across EMHS were involved in real HIVE simulations to ensure that the patient experience is as positive as the staff experience, and to identify any modifications required prior to the go-live date at the end of 2020.

Consumers who participated in the simulations described the HIVE service as safe, secure, comforting and reassuring for patients, family, carers and loved ones.

ARMADALE KALAMUNDA HEALTH SERVICE CONSUMER ADVISORY COUNCIL CHAIRPERSON, DOROTHY HARRISON SHARED

"I felt very comforted".

"My nurse was reassured by the (HIVE) support person as to what she had done in my immediate situation and also (HIVE) could do additional things like call doctors if I didn't improve immediately.

"A family member at the bedside of a HIVE patient would be very reassured by the fact that higher level medical advice is available immediately and is being given to them straight away."

Dates for the Diary

Community conversation follow up - Sustainable Health Review

Monday 26 October 2020, 4:30pm-6pm

This session is an opportunity for consumers, carers and community members to reflect on the updates that were presented in a community conversation presented by Health Consumers' Council on 19 October and discuss how they and other consumers, carers and community members can be involved going forward. This session will take place via Zoom.

Register at www.eventbrite.com.au/e/community-conversation-follow-up-sustainable-health-review-tickets-125862178163

Diversity Dialogues: Mental Health and the CaLD Youth Community

Wednesday 11 November

The discussion is part of HCCs Diversity Dialogues series. Diversity Dialogues comprise a panel discussion whith panellists from a range of cultural backgrounds sharing their knowledge and (lived) experiences around culturally aware practice, building culturally inclusive services and discussing the importance of cultural awareness in best practice.

Our panel will discuss some of the complex problems faced by multicultural youth in Australia around mental health issues and navigating treatment with family and health service providers. More details will be available at www.hconc.org.au/what-we-do/upcoming-events/ or you can contact Nadeen@hconc.org.au to register your interest.

Health Consumers' Council

Annual General Meeting

Monday 23rd November 2020

TIME: Registration Commences at 4:00pm, event commences 4.30pm

LOCATION: Burswood on Swan, 1 Camfield Place

Registration is essential at www.eventbrite.com.au/e/hcc-2020-agm-tickets-125831119265 or by calling **(08) 9221 3422** by Monday 2nd November 2020.

Supporting Cultural Diversity in Healthcare Workshop

Thursday 3 December, 10.30am-1.30pm

Location TBC

To assist healthcare workers and providers to deliver services that are equitable, the Health Consumers' Council has developed this workshop to enable health workers to provide culturally inclusive services that support patient-centred care.

Find out more at www.hconc.org.au/what-we-do/diversity-culture/supporting-cultural-diversity-ffs/

Email Nadeen@hconc.org.au to register your interest (WA Health staff prioritised)

Updates

COVID-19

When COVID-19 hit, one of the first things to go was consumer and carer engagement. At first this seemed perfectly understandable – after all, desperate times called for desperate measures. But as time went on, it began to feel like COVID-19 was a welcome excuse for the health system to carry on without us.

HCC began facilitating online workshops and sessions to fill this void until the Community Advisory Council and District Health Advisory Council meetings resumed. We also joined forces with our state consumer peak bodies to host a number of events to explore COVID-related topics. Queensland showed the way in terms of maintaining engagement with consumers, and attending their Clinical Senate meeting on ethical decision making frameworks was a highlight. We enjoyed the opportunity to work with Health Issues Centre in Victoria on several of their online events including one on Telehealth and the COVID-Safe App, and one on Planning for Recovery.

Here in WA we enjoyed pivoting to online, particularly in relation to how equitable it is for our country colleagues to participate in meetings when everyone is online. We began to partner with the health system on developing Fireside Chats with senior health leaders, to provide some means of continued engagement and communication. Recordings of these sessions are available at www.hconc.org.au/issues/covid-19/

A key question COVID left for the consumer engagement community is – what needs to change, to make this kind systemic shutting out of the consumer and carer voice unthinkable?

It is pleasing to see that the Sustainable Health Review has been named as the blueprint for WA's Health system recovery. We hope to tackle this key question in partnership with the health system as implementation of the Sustainable Health Review begins to gain momentum.

Recommendation Four – Citizen and community engagement provides a platform to drive these discussions and shared initiatives between consumers, carers and health professionals.

Additionally, results are now available from the Survey of Consumer and Community Involvement Program Community Members' Attitudes to COVID-19 Research and Consent. The purpose of this survey was to gain an understanding of community attitudes to involvement in medical research and forms of giving consent, on admission to hospital during the outbreak of the COVID-19 pandemic in Perth in April 2020. You can read the full report at cciprogram.org/wp-content/uploads/sites/2/2020/07/CCIP-Consent-Survey-Report-Final-200715.pdf

Digital Health Strategy

This too has been reactivated, and represents Recommendation 22 of the Sustainable Health Review. Consumer and carer engagement is starting to be activated, and very early plans are afoot to develop a Consumer Charter on Digital Health.

Palliative Care, National Goals of Care, and Advance Care Planning

The first phase of the National Goals of Care project is now complete, and a briefing was held for health service staff on 17 September.

A consumer video has been produced to give consumers information about goals of care. You can view it at youtu.be/mcRxdSo050s. HCC staff were involved in providing feedback on the key messages and objectives as well as a draft of the film. The draft *National technical guidelines for Using My Health Record to store and access advance care planning and goals of care documents* is currently being finalised.

During the early stages of this project, we identified the need for tailored information for people with disability about goals of care and advance care planning, to support them to be proactive in these conversations.

We are now working with People With disability WA and Palliative Care WA, as well as a group of consumers with disability, to review and adapt existing information about goals of care and advance care planning for people with disability.

HCC also provided a submission to the Joint Select Committee on End of Life Choices, for an enquiry relating to the recommendations in the *My Life, My Choices* document, as well as to equity in palliative care service provision between metro and country areas.

On 26 November a Palliative Care Summit will bring together palliative care, aged care and community service professionals, researchers, volunteers, policy makers, students, carers and community members. The theme is Joining the Dots – Pathways, Challenges and Emerging Innovations in Palliative Care in WA, and you can find out more at palliativecarewa.asn.au/events/2020-palliative-care-summit/

Sustainable Health Review

The Sustainable Health Review has been reinvigorated, and is nominated as our state's COVID-19 Recovery Blueprint for health.

- There is an Independent Oversight Committee, one of whose members is Margaret Doherty, a highly respected and effective consumer, carer and family advocate.
- The Program Steering Committee consists of all the Chief Executives of the Health Service Providers (North, South, East, Country and Child and Adolescent Health Services) and the Assistant Directors General in the WA Department of Health. They are generally the Executive Sponsors for Recommendations. They report to both the Minister for Health and the Independent Oversight Committee.
- The Program Board consists of the Recommendation Leads for all 30 recommendations.
- The SHR Partnership Group has many of the Program Board members, non-profit peak organisations and individuals with lived experience. It provides advice and tests concepts for planned strategies to address the Recommendations.

The Assistant Director General of WA Health – the Clinical Excellence Division's James Williamson, is the Executive Sponsor for Sustainable Health Review's Recommendation Four, which aims to drive greater consumer engagement. Some of you may recall that Recommendation Four relates to Citizen and Community Engagement. Pip Brennan is Co-Lead on this Recommendation, alongside Theresa Marshall from North Metropolitan Health Service.

The Working Group has met pre- and post-COVID and includes representation from carers, Consumers of Mental Health WA, and WA Health Translation Network's Consumer and Community Involvement Program staff, to discuss consumer engagement into the future. On 19 October we will hold an online session for anyone who is interested to hear an update on the Sustainable Health Review focusing on Recommendation Four. We will be asking you how you might like to be involved with this key piece of reform.

Cancer Plan and election asks

Work is now underway to develop an implementation plan for the WA Cancer Plan 2020-2025. Susannah Morris is the consumer representative on the Strategic Advisory Committee, and HCC's Executive Director Pip Brennan is involved in another committee looking at commissioning services.

HCC Deputy Director Clare and Susannah attended a meeting on resolving state-wide issues relating to this plan, in particular some recent changes to the role of the Cancer and Palliative Care Network. It was discussed that there would be value in creating opportunities for relevant clinical leads from health service providers to get together to discuss such issues. A number of clinicians highlighted just how fragmented care is for people accessing cancer services.

In September, in a joint event with Cancer Council WA, Pip and Clare hosted a consumer event to inform election asks in this area. Some of the issues discussed included cancer care navigators, a desire to make temporary telehealth MBS item numbers permanent, increased resources for the psycho-oncology service, limited daily parking fees for cancer patients and carers at hospitals, peer support, services for Aboriginal people, and support and services for young people including those who transition to adult health services.

Cancer Council WA will use this to inform their election asks, but it is also useful to inform HCC's and CCWA's ongoing systemic advocacy work.

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Opening hours

Monday - Friday 9.00am - 4.30pm
Closed Public Holidays

HEALTH CONSUMERS' COUNCIL