

# Health Matters

Health Consumers' Council (WA) Inc. Magazine

December 2019

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2019  
*in review*



HEALTH CONSUMERS'  
COUNCIL

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Cover image: Health Consumers' Council: Consumer, Carer and Community Change Agent Networking Event

**Correction:** In the November edition, Carli Shears was incorrectly credited as the author of the article "Kimberley Aboriginal Suicide Prevention Trial: WA Primary Health Alliance, Country WA PHN, KAMS" on page 14. The information for this article was provided by the Suicide Prevention Trial team at WA Primary Health Alliance.

## Welcome to the final edition of Health Matters for 2019.

While we're already busy planning 2020, we also wanted to take the time to look back over the last year and the important issues faced by Western Australian health consumers. So we've dedicated this edition to the key systemic advocacy issues we've tackled and diverse engagement activities we've delivered over the past 12 months. We also take the time to celebrate our individual advocacy team, who continue to do a wonderful job supporting people who are either seeking access to health service or redress when things haven't gone as planned.

### AGM and Management Committee updates

We held a special AGM in celebration of our 25th anniversary on 12th November and would like to extend our thanks to all who came. It was wonderful to see some old colleagues there, and to celebrate the strong foundations they created for us to build on.

We welcomed four new Management Committee members; Steve Walker, Erin Moore, Tina Tuira-Waldon and Christine Sindely. We'd also like to thank outgoing board members Cheryl Holland, Nigel D'Cruz and Marlon Fernando for their contributions.

2020 will see an increased focus on re-developing our core contract with the WA Department of Health. At the AGM, we took the opportunity to ask our members for their ideas and feedback around three key engagement areas.

We asked what kind of online content you would like to see, in terms of consumer training; what people would like to see from our planned 2020 "State of Consumer Engagement" Forum, Culturally and Linguistically Diverse Panel, and training for staff



PIP  
BRENNAN

on benefits and how to engage with consumers; and what sort of content you would like to see in future editions of Health Matters. We had some informative discussions and gathered some interesting ideas which we will use to inform our strategic planning sessions scheduled for February 2020. We have a page on our website with Contract Review updates under the About Us section if you want to keep an eye on them.

### Reimagining our Health Care

We recently won a grant to develop an art project called "Reimagining our Health Care" which involved speaking to people with disabilities about their ideal health service. This was then turned into incredible artwork by prominent disability activist and artist Samantha Connor and displayed at Fiona Stanley Hospital for International Day of People with Disability.

Understanding, listening and communication were some of the key suggestions for creating an ideal health service experience – flip to the centre pages of Health Matters to see this amazing project.

### Happy holidays

With 2019 quickly drawing to a close, we'd like to wish you a happy and healthy holiday season. We know that this time is not always a happy time for all, but we hope you find support and time to relax and renew for 2020. We look forward to continuing to work with you next year to keep the consumer voice firmly at the centre of our health system – where it belongs!



L-R: Tina Tuira-Waldon, Christine Sindely, Samantha Bradder, Rebecca Smith, Danae Watkins, Mallika Macleod, Richard Brightwell

# Implants and medical devices

*The failures around true informed consent*

PIP BRENNAN, HEALTH CONSUMERS' COUNCIL EXECUTIVE DIRECTOR

Since the 1990s, the use of polypropylene mesh has been the preferred treatment for pelvic prolapse and urinary stress incontinence. Medicare Australia data from 1994 to 2008 showed that there was a 75 per cent increase in surgery for stress urinary incontinence during this period, an increase from 4000 to nearly 7000 cases a year.

Like all medical devices, pelvic mesh implants had been approved for use by the TGA on the understanding that detailed consent conversations would occur with clinicians and patients. The assumption was also made that any complications would be reported. Women did come forward as early as the 2000s, but the dots were simply not joined, and mesh implants continued to be the standard treatment for these non-life-threatening conditions.

## Senate Inquiry

But in more recent years, it became increasingly clear that there were a lot of issues with mesh. In 2014, the Australian Pelvic Mesh Support Group was formed by Caz Chisholm, and brought together around 800 mesh-injured women. After tireless campaigning, Caz Chisholm met with Derryn Hinch, who championed the establishment of a Senate Inquiry into pelvic mesh. He called it “the biggest medical scandal for Australian women since thalidomide in the 1950s and 1960s, when kids were born without arms and legs”.

Women who provided submissions and came to hearings to give testimonies told their devastating experiences of chronic pain and infections and life-altering injury and impact. They reported consent conversations littered with medical device company marketing lines, with common phrases such as “you’ll be like a sixteen-year old again”.

The hope was that the Senate Inquiry would raise awareness of the permanent, life-altering consequences for some women and call for a ban on its use. While there were 13 recommendations made, 12 of which were accepted by our nation’s Health Minister who publicly apologised, real change for women is yet to be fully realised.

The key recommendations relating to WA involve the services provided to women impacted by mesh. WA was the first state to develop a Mesh Clinic at our tertiary women’s hospital, King Edward Memorial Hospital. While there has been involvement and good will, true co-design of the clinic has not yet occurred, and further work is being undertaken to enhance the partnership for a woman-centred approach to their care.

A National Mesh Implant Forum was held in Melbourne in April 2019, to consider all aspects of Australia’s mesh implant crisis. The Forum was proudly convened by the Health Issues Centre, Health Consumers NSW, Health Consumers Queensland, Health Consumers’ Council (WA), Health Consumers Alliance of South Australia, Health Care Consumers (ACT) and Health Consumers Tasmania, with support from state governments. A report of this event is available on the Medical Devices page of our website. While this event prompted the release of a new plan for medical devices, the complexity of the issue requires ongoing coordination across states.

## Class Action Decision

More recently, in November 2019, a judgement was passed vindicating the more than 1200 mesh injured women who participated in the Shine class action against Johnson & Johnson. While HCC and the other state health consumer councils welcomed the announcement, we will reserve judgement until the size of the final settlement is announced.

It’s important to recognise the courage and voice of mesh injured women and their strength in undertaking this class action to its successful completion. Every aspect of women’s lives are impacted when there are



severe complications from mesh. Inability to work means significant economic disadvantage. Sexual dysfunction can mean the end of a relationship. Pain robs life of its quality. Accessing medical assistance is hugely problematic when there is a lack of acceptance that the symptoms are related to mesh, and the lack of actual services.

## The challenge of mesh removal

The Royal College of Obstetricians and Gynaecologists named the challenge that while Australian clinicians were easily able to implant mesh, their removal skills are patchy. Partial removals are favoured by clinicians, but consumers want full removal, to ensure they are not constantly suffering from infections and inflammation.

Some women have been advised that full mesh removal would mean a colostomy for life. Women have voted with their feet and travelled to the US to access specialist mesh removal care which has freed them from the awful choice between mesh removal and a functioning bowel.

Removal surgery is lengthy and complex, and the outcomes are uncertain. There is no guarantee the debilitating pain will cease once the mesh is removed.

## It's not just mesh we need to worry about

That's why we have called on the Government, through its regulatory agent the TGA, to ensure that innocent people are never again left hostage to the unscrupulous greed of medical device manufacturers. Because one thing that has become increasingly clear is that there is an even bigger issue in Australia, and that is a systemic failure when it comes to implants and medical devices.

Testing, regulation and monitoring of all medical devices has been severely lacking, and just as the true extent of mesh injuries took time to come to light, we are now seeing an alarming rate of injury related to other implants and devices used regularly by medical professionals – hernia and bowel mesh, metal hip replacements, metal knee replacements, IUDs, pain pumps, insulin pumps, breast implants and obesity surgery devices are just some.

When Health Issues Centre Victoria initiated their Mesh Device and Implant Failure study late in 2018, they noted that a sizeable 183 patients had already reported major problems with their hernia mesh implants – 70 per cent of reporting were men.

The vast majority (87 per cent) of respondents in their survey believed they were not given enough pre-operative information on risks, impacts and options to enable informed consent to a hernia mesh procedure. Compounded with lack of testing, regulation and monitoring, a lack of informed consent is a massive concern.

When risks and complications are minimalised, trivialised or not mentioned at all, patients are unable to make truly informed decisions about their care.

We believe that reform is needed in the way medical devices are tested and approved, in the way that they are monitored once on the market (starting with a complete record of everyone who has them placed) and the need for vast improvements around informed consent and adverse event reporting.

In late 2019 the Allergan company voluntarily recalled their un-implanted Biocell macro-textured breast implants and tissue expanders due to a risk of breast implant associated anaplastic large cell lymphoma (BIA-ALCL), a rare cancer of the immune system. Another company also cancelled their product (Emergo Airxpanders Aeroform tissue expanders).

A month later, the TGA published its decision to recall and suspend a number of other breast implants and tissue expanders – the full list of these can be found at <https://www.tga.gov.au/hubs/breast-implants>

## It's OK to say no

Before you agree to any test, treatment or procedure, make sure your doctor has talked to you about the rationale for the proposed treatment, alternative options, potential complications, and all the associated risks. You should be told about the likely successes and potential complications as they relate directly to you, as there are individual circumstances which can impact treatments.

Informed consent is a fundamental consumer right. And to exercise that right, we need to know that it's OK to ask questions, and it's OK to say "can I think about this", "I need more information" or even "no" to suggested treatments.



# Voluntary Assisted Dying and End of Life Care

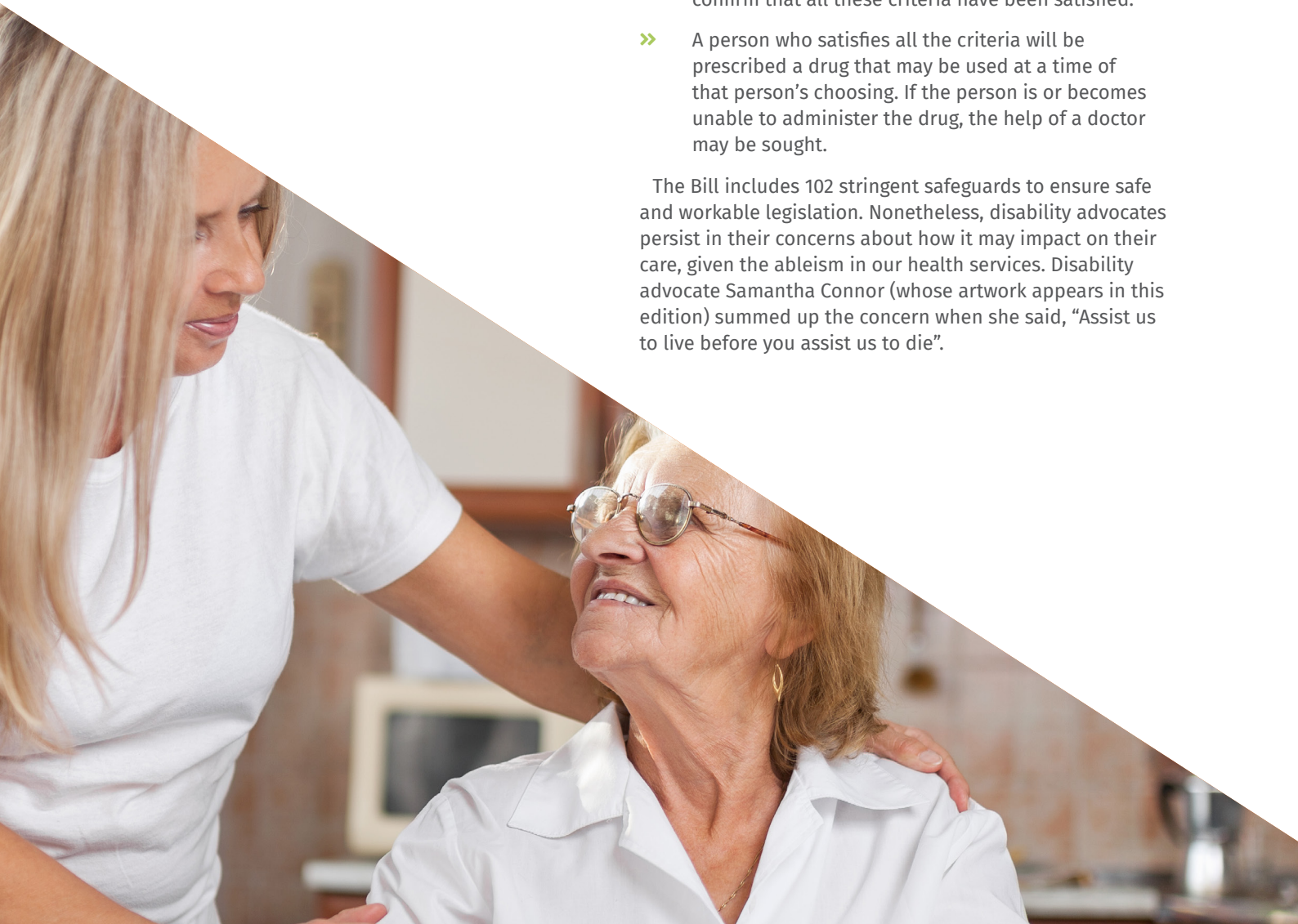
*WA the second state to pass VAD legislation*

After much debate and consultation this year, the Voluntary Assisted Dying Bill 2019 was developed for introduction to Parliament. This passed into law on 11th December 2019, and after an 18-month implementation phase, it will allow eligible people at the end of their life access to voluntary assisted dying.

Key things to note about the legislation, with acknowledgement to Dying with Dignity Western Australia:

- » To be eligible for voluntary assisted dying a person must be 18 years or older and have decision-making capacity.
- » The request must be voluntary and must be made without coercion or duress. The person must also be suffering from an advanced and progressive terminal, chronic or neurodegenerative condition that is causing irremediable and grievous suffering that cannot be alleviated in a manner acceptable to the person, and which is expected to cause death within the foreseeable future.
- » Two independent doctors must assess the person to confirm that all these criteria have been satisfied.
- » A person who satisfies all the criteria will be prescribed a drug that may be used at a time of that person's choosing. If the person is or becomes unable to administer the drug, the help of a doctor may be sought.

The Bill includes 102 stringent safeguards to ensure safe and workable legislation. Nonetheless, disability advocates persist in their concerns about how it may impact on their care, given the ableism in our health services. Disability advocate Samantha Connor (whose artwork appears in this edition) summed up the concern when she said, "Assist us to live before you assist us to die".



## More focus and funding on palliative care

The journey to the destination of Voluntary Assisted Dying began in earnest with the Joint Select Committee report on End of Life Choices. The My Life My Choices report from this committee is a weighty 600 pages, and a 16-page summary of the report and the response from the current government is also available.

Key recommendations from this report include the review, from a consumer perspective of the three existing models of palliative care. While Voluntary Assisted Dying will be an option for some, the majority of West Australians will benefit from increased funding and consumer and carer input into service design. This review of models of palliative care is now starting to be addressed in earnest by the WA Department of Health.

In August 2019 there was a Ministerial Summit on Palliative Care, which featured an excoriating carer's story of her husband's protracted suffering before his death. Kathy Eager, a key researcher from the Palliative Care Outcomes Collaborative, provided the keynote presentation and echoed the cry of the room, that this event needed to be considered a "Base Camp" rather than a Summit, as the journey to review and improve our state's palliative care is only just beginning.

In December 2019, there was a follow-up World Café event convened by the WA Department of Health, which was attended by about 15 consumers and carers, to start the thinking about the review into palliative models of care. An independent reviewer will be nominated in 2020, and the hope is that consumer and carer involvement will continue to be paramount in this project.

The lack of community understanding and fear of accessing palliative care continues to be an issue, and the formation of community messages is also flagged as part of this project.

If you would like to get involved, email us at [info@hconc.org.au](mailto:info@hconc.org.au) and put Palliative Care in the subject line.

## Advanced Care Planning

Meanwhile, Palliative Care WA continues its important work on raising community awareness on Advanced Care Planning – a document that tells your doctor and family about how you wish to be treated if you can no longer speak for yourself or make your own decision – and the importance of having the conversation about end of life wishes. They released a campaign in October "You Only Die Once", and further work is planned on community education in 2020.

## We will be holding a workshop in February 2020 on Advanced Care Plans and My Health Record:

If you would like to attend, please register at

[www.eventbrite.com.au/e/advance-care-planning-and-my-health-record-community-workshop-tickets-85599651863](https://www.eventbrite.com.au/e/advance-care-planning-and-my-health-record-community-workshop-tickets-85599651863)

### Advance Care Planning and My Health Record community workshop

📅 THURSDAY 6 FEBRUARY 2020

🕒 10AM TO 2PM (LUNCH PROVIDED)

📍 CANCER COUNCIL WA'S SEMINAR ROOM, 15 BEDBROOK PLACE SHENTON PARK

➔ *please enter via the upper carpark*





# People power

## Empowering consumer voices within WA health

CLARE MULLEN, HEALTH CONSUMERS' COUNCIL  
ENGAGEMENT MANAGER

2019 has been the first full year of our refreshed consumer and community engagement program.

As we've worked with both consumers and service providers, we've experimented with a range of engagement activities alongside existing approaches.

We believe in the power that lies in bringing people together. What we try to do is create ways for people to connect, provide them with the time, space and access to information that can support them to continue to speak up and influence change in the health system.

This year we've done this in a range of ways: bringing people together face to face with consumer engagement events and training sessions; informing people through our regular e-news and Health Matters magazine about key issues in the health system; and using social media to forge valuable connections. In all these ways, we aim to "hold the space" to enable consumers to support each other and draw on shared knowledge to empower them within the system.

From the individual through to health services and the wider health system, information, connection and time have been the key focus as we facilitate and encourage greater participation in health and an increased voice for consumers and community members to influence the shape of our state's healthcare.

Here are some of the highlights from the cross-system projects, groups and discussions we've supported and facilitated this year.

### Partners in Change – Obesity Collaborative

Since 2018, we've been working with the Health Department and the WA Primary Health Alliance to ensure the consumer voice is front and centre of policy and service planning in the area of overweight and obesity. This culminated in the publication of the WA Healthy Weight Action Plan 2019-2024 in November.

It was important to us that these conversations were informed by powerful, real-life experiences of people who have taken action to manage their weight.



We believe the Action Plan outlines a plan that is not "business as usual" for the health system. The inclusion of actions that seek to establish collaborative structures to enable the next steps recognises that something different to the traditional hierarchical approach to implementation is required for this complex issue.

### Ambulance Project

In partnership with The Behaviour Change Collaborative, we were commissioned by the WA Department of Health capture consumer experiences of ambulance services in Western Australia.





## Ambulance Project

## Empowering Health Consumers with Disabilities

We did this through an online survey gathering more than 450 responses and hosted forums in Perth, Bunbury and Broome. Patients, carers, and anyone who had phoned an ambulance service for someone else spoke about their experiences, which will inform the procurement of ambulance services in our state.

In 2020 we will work with consumer peaks and other key community organisations to provide feedback on the Draft Statewide Ambulance Services Policy.

### Empowering Health Consumers with Disability

In 2019 we worked with People With disabilities WA to deliver a project which examined health literacy materials to see if they were disability friendly. The project delivered nine training sessions on Disability Health Rights for people with disabilities, and their carers, family and support people. Through these discussions, we developed a series of accessible booklets and videos on better healthcare for people with disabilities, which are available at <https://www.hconc.org.au/projects/empowering-consumers-with-a-disability/>

One impact of this project was the increased knowledge and understanding of HCC staff about the needs and interests of people with disability as they access the health system. While we have lots to learn, this experience will help us continue to promote the voice of people with disability in future HCC activities.

In 2020 we are looking to continue to work with people with disability and health service staff to improve health service communications and engagement opportunities for people with a disability.

### Engaging with culturally and linguistically diverse communities

We made some big strides towards improved health literacy for people from culturally and linguistically diverse (CALD) backgrounds in 2019, thanks to Cultural Diversity Engagement Coordinator Karen Lipio. Karen finished up her time with HCC just before the Christmas holidays, and we'd like to acknowledge the impressive work she has done in this role, including establishing strong relationships with local governments and other partners, and establishing the culturally and linguistically diverse panel that will help us to continue to ensure diverse voices influence the future shape of health services. We look forward to continuing this work with Nadeen Laljee-Curran, who has been appointed to the role for 2020.

## Community Conversations

If we want WA's health system to be equitable, we need to make sure that diverse voices are heard. At a series of community conversations throughout the year, Karen asked people from a range of CALD backgrounds "what matters to you?" regarding the health system. From these sessions we discovered that while many people are grateful for the opportunity to access high quality, low cost healthcare in WA, they don't often feel comfortable providing feedback on their experiences. We have been particularly focused on discussing how providing feedback can be a valuable way of helping health services continue to provide high quality care.



Community Conversations

## Health Rights and Responsibilities

Refugees and asylum seekers arriving in WA face many barriers in accessing our health system, from language difficulties to not knowing which service to use. This year, we partnered with Red Cross to deliver health literacy information as part of their orientation program, to help people from refugee or asylum seeker backgrounds choose the right health service at the right time, know their health rights and responsibilities, and feel confident in providing feedback.

## Health literacy resource

Based on conversations throughout the year, we began developing a comprehensive health literacy resource to support our in-person work. The resource will provide accessible information to help people new to WA navigate our health system. It's currently in development and we'll be asking for feedback from South Metropolitan TAFE Adult English Migrant Program students in 2020.

# Engagement Framework

## Not just another Engagement Framework...

While there are many Engagement Frameworks around, we think the Mental Health Commission's **Working Together: Mental Health and Alcohol and Other Drug Engagement Framework 2018-2025** is an important resource. Developed through a co-design process, its visual representation extends and builds on the traditional engagement continuum. It has ambitions all the way to citizen-led change and shows it in a picture which communicates this immediately.

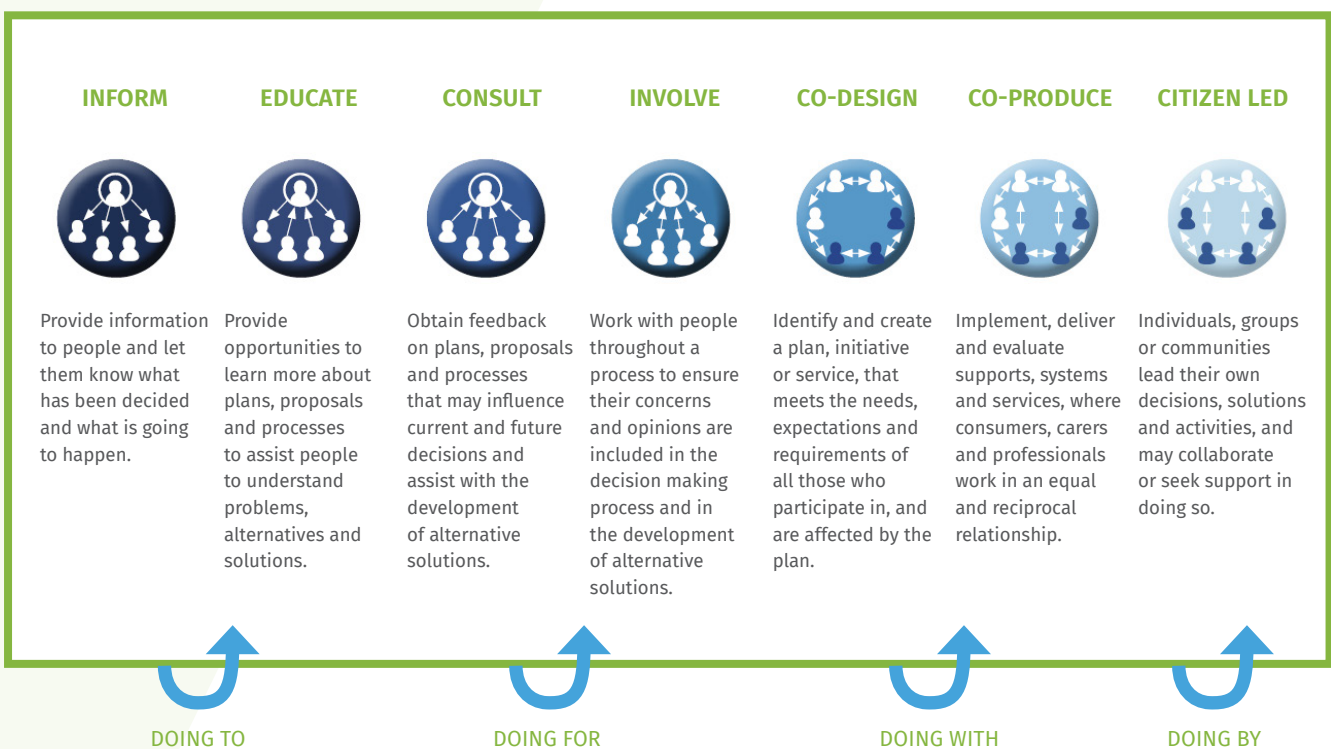
It articulates the "doing" relationship which speaks to the powerful dynamic and the opportunities that consumer involvement offers our health and human services:

- » Doing to (informing, educating)
- » Doing for (consulting, involving)
- » Doing with (co-designing, co producing)
- » Doing by (citizen led)

This framework has been central in the initial conversations that are now taking place with the Sustainable Health Review Implementation Unit and will inform the ongoing co-design process of implementing new ways of engaging in 2020.

"Consumer, family, carer and community engagement offers a pathway toward better quality health care, more efficient health care and service provision, and improved population health."

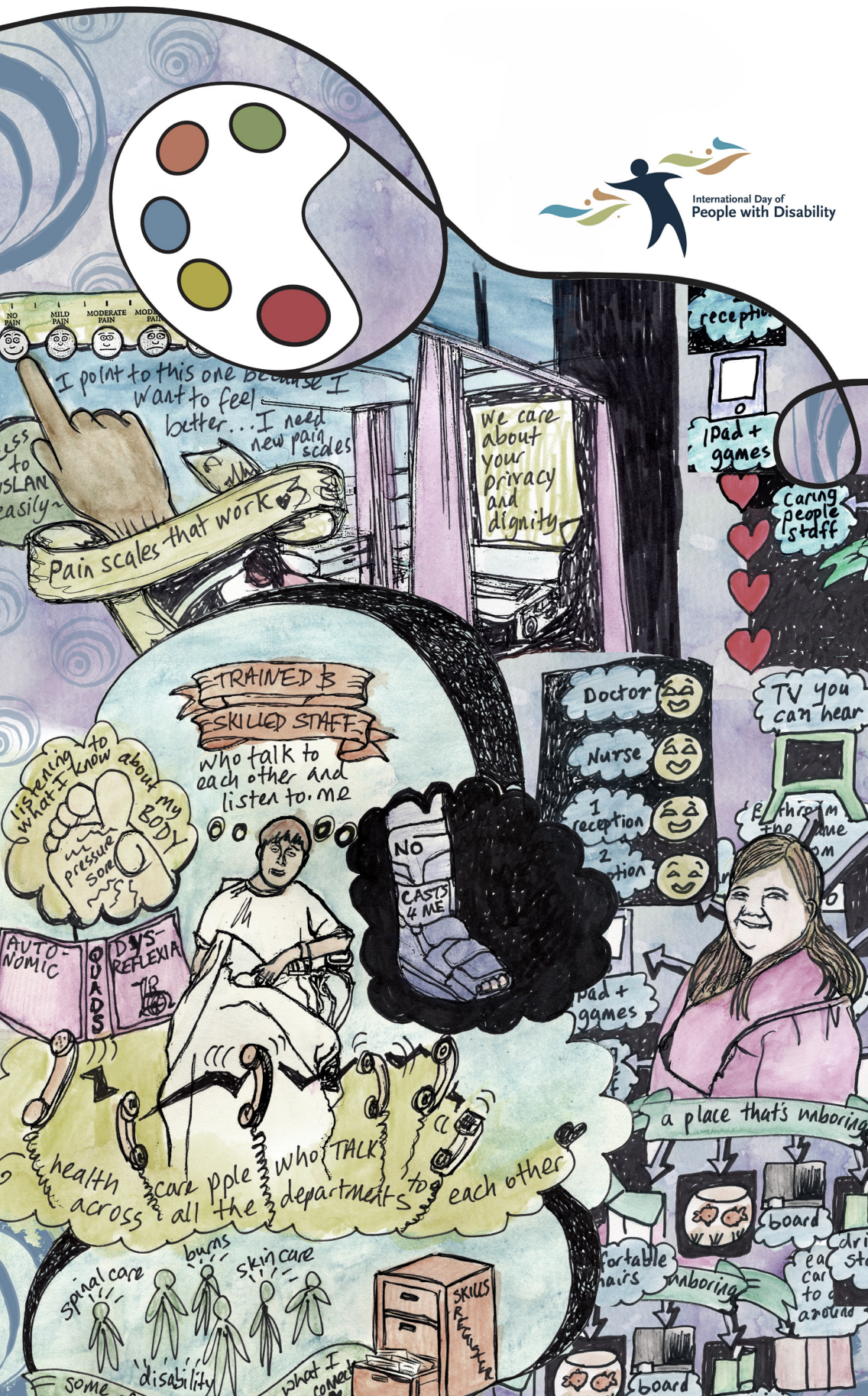
"Aiming for approaches that will maximise engagement opportunities for more equal and reciprocal relationships, the sharing of roles and responsibilities, including decision making, is likely to result in positive changes."





ARTIST:  
SAMANTHA CONNOR





## Partnerships

2019 has been an important year for HCC in terms of Aboriginal engagement, and we've been involved in a diverse and exciting range of projects and discussions. We maintained an ongoing commitment to representation on committees related to child and adolescent health, prison health, and sexual health and blood borne viruses.

We recently signed a Memorandum of Understanding with the Aboriginal Health Council of WA to support the ongoing partnership projects we aim to undertake.

We are also working with the National Justice Project's George Newhouse, AHCWA and Bila Muuji to develop and pilot advocacy training for those Aboriginal community members and staff working with Aboriginal people. The purpose of the training is to upskill key people in health consumer rights and how to navigate the system, so they can in turn support people in their communities and services. We are actively seeking opportunities to roll this training out across the state.

We have been strengthening links with the FSH Aboriginal liaison service, and have been meeting with consumers to help them understand My Health Record so they can make informed choice about how they use it.

For Mental Health Day we again partnered with Yorgum, Yokai, and Derbarl Yerrigan Health Service to convene a yarning and drumming circle. Mental health starts where we live, learn, work and play, so it was a great opportunity to meet up with people in our area.

## Traditional Healing

Patient Experience 2019 focused on the Aboriginal Patient Experience, and a key focus area identified by attendees was the opportunity to expand consumer access to traditional healing. South Australia has seen a successful partnership between the SA Local Health Network and the Anangu Ngangkari Tjutaku Aboriginal Corporation (ANTAC) to map out the clinical and corporate governance requirements to facilitate access to traditional healing modalities. These are offered on a fee for service basis, for both Aboriginal and non-Aboriginal people. Active discussions are in progress with health service providers in WA to support similar initiatives in our state. We are hoping to partner on consultation events in 2020 to move this idea towards reality. It is a complex area and this will be a careful and considered journey towards understanding how we can link in with what's already happening and make for a clearer path between consumers and traditional healing services.

## Patient Opinion

We have worked with the Justice Health and Patient Opinion to create an alert for when stories related to Aboriginal and Torres Strait Islander people are uploaded. We convened a meeting with key people in health around justice in health services more generally and will continue to monitor systemic issues across the system.

# An ongoing commitment to Aboriginal health



## Health Justice Partnerships

Health justice partnerships link people accessing health services with the support of a lawyer if required. We reached out to the Health Justice Partnership team based in NSW who connected us with a partnership already up and running in Joondalup, and we have found another example in Armadale. We will re-convene in 2020 to continue discussions and see if more partnerships can be formed.

# Working together

## to address barriers in healthcare

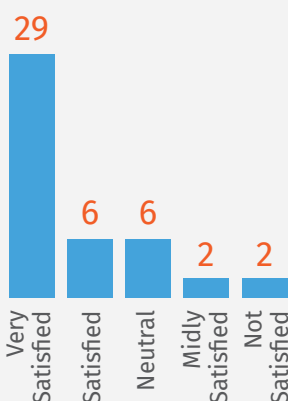
It can be difficult to navigate the Western Australian Health System, or to give feedback if you are unhappy with any aspect of your healthcare experience. Our Advocacy Service provides flexible, individualised support, including providing information about your health rights, helping you to get linked with a service, attending appointments with you, and assisting you to make a complaint.

### Our advocacy service

- » Assists people with problems in the health system
- » Is available to people anywhere in Western Australia
- » Is staffed by advocates who are experienced in consumer rights, knowledge of the health system and consumer responsibilities, and are generally not trained in medicine or the law

*“Advocacy is important, particularly when people don’t have family or other support.”*

### How satisfied were you by the way the advocate handled your case?



*“Really felt heard and supported - it was wonderful.”*

*“I felt better having the advocate involved, Carly made a world of difference, even though she was not able to get the desired outcome. Carly brought an objective point of view to the discussions with health providers. Having an advocate with me made my experience less traumatic”.*

### Advocacy Case Type

Advocacy Case Type	Health	Mental Health	Total Advocacy	Information and Linkages	Total Individual Support
2015	491	128	619	513	1132
2019	326	218	544	1066	1610

### You Said, We Did!

During the year we held a consumer focus group to gather ideas around how we can improve our advocacy service.

It was reassuring for us to realise that our processes already included some of your suggestions and we have since implemented more.

What we are doing differently following your feedback?

- » Offering consumers (where appropriate) the opportunity to meet their advocate face to face to discuss their issue.
- » Using the word ‘feedback’ rather than ‘evaluation’ when referring to obtaining your views on our service.
- » Referring to your complaints as ‘issues’ rather than ‘cases.’
- » Letting consumers know we have the time to listen to their story/issue.
- » Providing more specific explanation as to why we seek consumer feedback.
- » Sharing the RUAH Directory resource with our consumers, which is regularly updated and packed full of useful information around where/how to access other help and support. You can find the directory at [www.ruah.org.au/directories/](http://www.ruah.org.au/directories/)
- » Letting consumers know that our Advocates can attend medical appointments with them.
- » Asking if consumers do/don’t want their feedback shared with the Advocate and ensuring confidentiality for those that don’t.

The service improvement journey is never finished! We would like to run a forum in May 2020 and do a deeper dive on the questions we ask in our feedback forms. If you would be interested in being part of this, just email [info@hconc.org.au](mailto:info@hconc.org.au) and put Attention Carly Parry in the subject line.

# Sustainable Health Review

## Supporting a focus on patient experiences

The Sustainable Health Review Final Report was released in April 2019. Among other points noted in the Minister for Health's media release was that "A continued focus on patient outcomes and experience should be supported...by involving consumers and carers in planning, design and evaluation of services"<sup>1</sup>. The specific Recommendation that this referenced was Recommendation 4, Enduring Strategy 1:

**Commit to new approaches to support citizen and community partnership in the design, delivery and evaluation of sustainable health and social care services and reported outcomes.**

When The Sustainable Health Review Final Report was released, it was likened to "a diet plan, not lost weight". In other words, the work is all in the implementation, the completed report is just a document.

To date, it could be argued that instead of losing weight, the system may possibly have gained weight. From April until November there has been a focus for WA Health on developing the internal mechanisms to undertake the work of implementation. A commitment to develop a three year plan which draws together the Safety and Quality Review, the Sustainable Health Review, the Digital Health Strategy (which was finally released in November 2019) and the Health Leadership Strategic Intent document.

However, the year is closing out with positive and productive conversations about Recommendation 4 and a plan of action is starting to emerge. The Priorities in Implementation dot points appear below, expanded out where necessary, with short notes on our current knowledge of what is going on.

<sup>1</sup> <https://www.mediastatements.wa.gov.au/Pages/McGowan/2019/04/Sustainable-Health-Review-provides-ambitious-blueprint-for-the-future-of-health-care-in-Western-Australia.aspx>

No.	Description	HCC Comments
1	1.1 Expansion of Patient Opinion, Care Opinion	In 2020, Care Opinion and Patient Opinion will merge into one website, in line with UK/ Scotland. Events will be held on 11 and 12 May for health services and non-profits.
1	1.2 and real-time consumer feedback mechanisms;	There will be many things already in place in Health Services. This project would be a great opportunity to link with consumer advisory groups across the state.
1	1.3 Introduction of deliberative approaches where citizens are engaged in a detailed review of a given topic to inform decision making.	This may be a longer-term ambition, but it lends itself well to contentious topics.
2	2.1 Transparent public reporting of patient and carer reported experience and outcomes (PREMs and PROMs) by July 2021 with ongoing development of measures in line with emerging best practice	Transparent reporting of safety and quality data is imminent. PROMs and PREMs may need closer examination to see if it will provide the outcomes we are seeking, and if it still accords with best practice.
3	3.1 Greater shared decision making between patients, carers and clinicians through open and honest conversations on treatment options, evidence, benefits and risks.	This links to recommendation 9 on Realistic Medicine, and is both a workforce and health literacy initiative.
4	4.1 Consumer and carer voices embedded into health system governance structures.	Current structures could be enhanced and better supported through training of both consumers and staff, and support to develop and report on strategies, or even consideration of Chairs becoming independent co-located staff members embedded in the organisation.
4	4.2 Make consumer/carer/clinician partnerships and co-designed projects a normal part of business.	There are important opportunities to leverage existing consumer and carer advisory groups.
5	5.1 Introduction of community-based and online approaches to better link people to support and navigation assistance, including a pilot of Community Booths.	The Community Link Booth at Fiona Stanley Hospital is now well into implementation, and is providing rich learning and evaluation opportunities. An independent evaluation process is being enacted through this current project.
6	6.1 Engagement and support for carers embedded through early recognition in patient administration systems.	This links with the digital health strategy and update of electronic systems. Staff training is also key. The Prepare to Care resource needs to be more widely accessible.
6	6.2 Enhanced training to support and strengthen carer resilience and overall health and wellbeing.	Carers WA already provide these services, and ideally would lead this work.



# A new maternity app

*Help to navigate WA's maternity system*

As many of you may already know, the journey to patient advocacy and passion for informed consent for our Executive Director Pip Brennan started with pregnancy.

This was when she realised that conversations surrounding pregnancy didn't really provide the full picture, they were more about asking which doctor you'd like to go with rather than discussing all of the options – which can range from midwifery to obstetrician-led models of care, depending on the individual's needs and circumstances.

These types of conversations don't paint the full picture of what maternity care in Western Australia can and does look like, which is why we're really excited about a new app, Pregnancy WA. The aim is to help WA families to connect more easily with the services in their area that suit their situation.

The app will also support informed decision making about models of care, and the many different choices that need to be made during pregnancy. It is a partnership project with WA Country Health Service with funding from WACHS Country Health Innovations, with app developers Lateral and Reach

Health Promotion Innovations. Work is now well-underway on the prototype.

Discussions have been going on for some time to get it to this point, and Change, Choice, Continuity's Kylie Ekin has been central in ensuring the consumer voice is at the centre of development. App testing will be happening in early 2020 and we will keep you posted.

Don't forget we have a Facebook group to join if you want to stay in touch about this project: [www.facebook.com/groups/WAMaternity/](https://www.facebook.com/groups/WAMaternity/)



# Digital health

PIP BRENNAN, HEALTH CONSUMERS'  
COUNCIL EXECUTIVE DIRECTOR

## Where are we at?

### My Health Record

Since January 2019 when the opt-out period ended, 90 per cent of Australians have ended up with a My Health Record. Like all our state counterparts, we were funded by the Australian Digital Health Agency to circulate information materials on My Health Record via our networks. We have noted that some social media posts have attracted concerns from consumers, and have communicated these to the Australian Digital Health Agency.

We also undertook a survey to explore the issues important to consumers, and gain an understanding of real-life experiences of using My Health Record. We are currently compiling the results of this survey, and you will be able to find them at <https://www.hconc.org.au/resources/my-health-record/> in 2020.

On 11 December the CEO of the Australian Digital Health Agency, Tim Kelsey, announced his resignation. A new appointment will be made early next year.

### WA's new Digital Health Strategy

As noted on page 16, this strategy was released in November 2019, almost a year to the day of the last stakeholder engagement HCC was able to be part of. Now the Strategy has been released, it's clear that the main goals require an electronic medical record. The scale of this undertaking is not to be under-estimated. The WA Health Information and Communication Technology Consumer Reference Group re-convened in November 2019 and there are hopes for more robust engagement and a co-design process with consumers, clinicians and administrators to drive this project forward in the way it needs to go.

### Data and Privacy

Meanwhile, WA's Department of Premier and Cabinet has completed the Privacy and Responsible Data Sharing consultation, and submissions received are now being analysed and legislation drafted. It may surprise you to know that we are the only state without privacy legislation.

I contributed to an independent submission which was supported by Professor David Watts, former Victorian Privacy Commissioner, and Dr Bridget Bainbridge, whose inputs were kindly supported by the Minderoo Foundation.

The submission argued for an innovative approach to the drafting, rather than merely "cutting and pasting" other state's legislation, first written in the 1980s. Our world has changed beyond recognition since then, and Europe has led the way in developing the General Data Protection Regulations which seek to uphold civil rights. The argument was made to aim for something along these lines that will allow us to more easily participate in international research.

### Data is the new oil

It has often been noted that three enormous enterprises, Amazon, Google and Facebook, do not charge for their products. That is because the data they harvest from their platforms is far more valuable and marketable than membership fees. It is vital that as citizens we do not "give away the farm" when it comes to our health data. There have been alarming precedents in other countries where health data has been swapped for "innovation" –

A graphic consisting of a black rectangular area with white, hand-drawn style text that reads "DATA IS THE NEW OIL...". The graphic is set against a background of green geometric shapes.

so that the costs of developing a platform, for example, are not met by the public purse. But what is the cost of this in terms of loss of privacy, in leaving ourselves open to having our data re-packaged and sold back to us?

Meanwhile, there is a confusion in the public mind about how much data is shared between government agencies. There is an expectation that data is shared much more than it really is. The excuse of “privacy” is often invoked by government agencies keen to control what information is shared and avoid contentious issues reaching the light of day, or stymie the ability of people to seek redress.

While in WA it was noted that our lack of privacy legislation is hampering data sharing, in all other jurisdictions where privacy legislation exists, it is invoked as a reason not to share data. As always, culture is a key driver of how policy and legislation is enacted.

In Australia there is no independent, publicly funded app for My Health Record. There are three commercial providers who provide apps, and as we saw in 2019 with the Health Engine debacle, in some states our data was being on-sold to third parties – which consumers had consented to with one click, without any real understanding of what we were consenting to. The phenomenon of signing away our rights is endemic. The Norway Consumer Council worked out that it would be quicker and faster to read the New Testament than it would be to wade through the terms and conditions of 33 apps on your average smart phone.

## What to do?

As always, a “buyer beware” approach is important. If something is free (Facebook for example), then you’re for sale. Many of us make this call because what we receive is worth the (largely invisible) cost of obtaining something we want right now, which is the functionality of what the app offers.

Does this topic interest you? If you would like to stay in touch with projects and initiatives in data and IT, email us at [info@hconc.org.au](mailto:info@hconc.org.au) with Digital Health as the subject line.

You might also want to listen to this episode of Big Ideas exploring this complex topic: <https://www.abc.net.au/radionational/programs/bigideas/digital-disruption/11697214>



# 25th anniversary celebration

*A quarter of a decade advocating for the consumer voice*

There's been a lot to celebrate since we began advocating for consumers at an individual and systemic level in Western Australia in 1994.

From each individual advocacy case that has the potential to change the picture for an individual health consumer, to the large-scale projects and policies that help change the landscape around health conversations and ensure consumer voices are heard, we're proud of the hard work done by each and every staff member, volunteer and board member in the last quarter decade.

HCC was officially launched on World Health Day, which fell on 7th April 1994. More than 100 people attended the launch, including representatives from the Health Department, community groups and professional organisations.



HCC quickly gained a reputation as an organisation which gave consumers a voice that was coherent, thoughtful, and a force to be reckoned with.





The foundations were laid by early consumer leaders and Board Members such as Mitch Messer, Ann White, Karen Carey and Anne MacKenzie, to name a few. Staff members such as Michele Kosky and Maxine Drake have created an enduring platform of individual and systemic advocacy and consumer engagement that we have been able to grow over the last 25 years.

**Ann White**



**Maxine Drake**



**Michele Kosky**



**Mitch Messer**



# Patient Opinion

in Western Australia IMPACT REPORT FY 18/19



**992**

STORIES SHARED

**86%**

STORIES THAT RECEIVED A RESPONSE

**34**

STORIES LED TO CHANGE

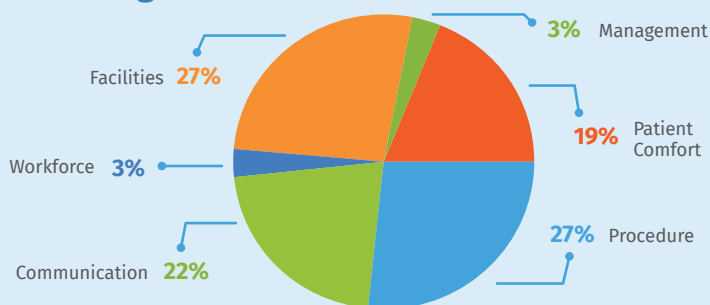
**52%**

ENTIRELY POSITIVE FEEDBACK

**237,340**

TOTAL PUBLIC VIEWS

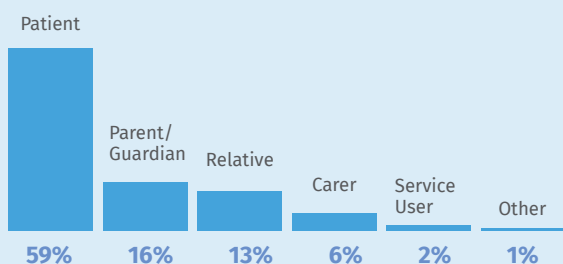
## Change Actions Taken



## Common Concerns



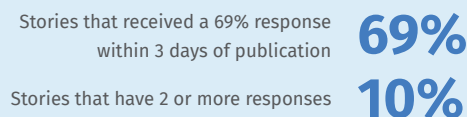
## Story Author Identity



## Top Change Actions



## Story Responses



## Big News!

In 2020, the Patient Opinion and Care Opinion platforms will merge. This means that Australia will have a consumer-driven, transparent, moderated platform for both health and human services.

HCC very much hopes that the not for profit community sector will be interested in adopting this platform to support their contractual requirements to involve people who use services in the quality improvement cycle.

The WA Council of Social Services is convening a session at the Peaks Forum on 11 May 2020 when the CEO of the original Care Opinion Platform, James Munro, will be visiting Perth alongside Care Opinion Australia's CEO Michael Greco.

# Dates for the Diary

## Advanced Consumer Representation

Tuesday 25 February, 10.15am – 2.15pm

Register at: <https://www.eventbrite.com.au/e/advanced-consumer-representation-training-february-tickets-79486816207>

The advanced workshop will take your skills to the next level, providing an increased 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 session will also cover topics raised by participants, including meeting effectiveness, productive conversations and self-care.

*A second round of intro and advanced training will be held in October 2020.*

## Consumer feedback sessions

Giving feedback about our experience of healthcare and health services is a powerful way that consumers, carers and family members can play a part in ensuring the delivery of high quality safe health services.

We're working with the Patient Safety Surveillance Unit in the Department of Health to learn more about how consumer feedback is collected, provided, and used for improving health services.

As part of this project, we will host a number of consumer feedback sessions to find out what people's experience is of giving feedback, including complaints. This information will be used to inform how WA Health collect and use consumer feedback in future.

### In person sessions:

Wednesday 12th February, 1pm – 4pm at Citiplace Community Centre, Perth (open invitation)

Wednesday 19th February, 1pm – 4pm at Citiplace Community Centre, Perth (targeted sessions for Aboriginal health consumers)

### Online sessions:

Thursday 13 February, 9:30am – 12:30pm (open invitation, via Zoom)

Tuesday 18th February, 9:30am – 12:30pm (targeted sessions for rural and remote Aboriginal health consumers, via Zoom)

For more information and to register: [www.hconc.org.au/projects/consumer-feedback-improving-how-its-collected-and-used-for-improvement/](http://www.hconc.org.au/projects/consumer-feedback-improving-how-its-collected-and-used-for-improvement/)

## Consumer, Carer and Community Change Agent Networking

Our networking events are an opportunity to meet and connect with fellow consumer, carer, community and family change agents.

The next event will be held in March 2020.

More details will be available soon – please join our consumer rep networking Facebook group <https://www.facebook.com/groups/hccsource/> or join our consumer rep networking mailing list <http://eepurl.com/cREYkn> for updates.

## Introduction to Consumer Representation

Tuesday 11 February, 10.15am – 2.15pm

Register at: <https://www.eventbrite.com.au/e/introduction-to-consumer-representation-training-february-tickets-79485969675>

The highly interactive introductory workshop will give you the opportunity to hear, learn and think about important information for consumer representatives including:

- » The roles and purpose of a consumer representative
- » The benefits of consumer representation
- » Barriers to participation for consumer representatives
- » Overcoming barriers to participation
- » Maintaining effectiveness as a consumer representative

## Advance care planning and My Health Record

Thursday 6 February, 10am – 2pm

Cancer Council WA's Seminar Room, 15 Bedbrook Place Shenton Park

Register at: [www.eventbrite.com.au/e/advance-care-planning-and-my-health-record-community-workshop-tickets-85599651863](http://www.eventbrite.com.au/e/advance-care-planning-and-my-health-record-community-workshop-tickets-85599651863)

Advance care planning can help you to plan ahead, so your family, friends and doctors will know what you want if you can no longer speak for yourself.

This is a partnership event with Carers WA, the Advance Care Planning Consortium (via Palliative Care WA) and the WA Department of Health.

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## Opening hours

Monday - Friday 9.00am - 4.30pm

Closed Public Holidays



HEALTH CONSUMERS'  
COUNCIL