

Health Matters

Health Consumers' Council (WA) Inc. Magazine
December 2018

Creating a Kinder Health System

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Celebrating People in Healthcare



HEALTH CONSUMERS'
COUNCIL
YOUR VOICE ON HEALTH

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Dates for Diary

6th January 2019

Cancer Care Costs survey closes (see updates on Page 19)

31st January 2019

My Health Record Opt Out deadline

20th February 2019

HCC: Introduction to Consumer Representation 10am - 2pm

February 2019 – dates TBC

School for Change Agents

3rd April 2019

HCC: Diversity Dialogues Forum (time TBA)

13th April 2019

HCC: Supporting Cultural Diversity in Healthcare 10am - 1pm

30th April 2019

HCC: Patient Experience Week event – details TBC

15th May 2019

HCC: Advanced Consumer Representation 10am - 2pm



HCC's new board members: (Back row) Samantha Bradder, Danae Watkins (Front row) Mallika Macleod, Rebecca Carbone



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Cover image: Stock

Foreword

Welcome to the summer 2018 edition of Health Matters, celebrating the innovative, compassionate, and hard-working people in healthcare. We look at some of the invaluable feedback that's been shared through Patient Opinion, congratulate the winners of the WA Health Excellence Awards, and share the highlights from our World Kindness Day event.

Person-centred healthcare

At HCC, our vision is for equitable, person-centred healthcare for all West Australians. One of the best ways to make sure healthcare remains focussed on the person is for consumers to share their stories – and this includes celebrating the people in health services who act with respect, kindness and compassion, or who involve consumers effectively in research and policy.

Since 2016 HCC has been announcing the winners of our Consumer Excellence Awards to coincide with Patient Experience Week in April. Events are already in planning for 2019's Patient Experience Week, and nominations for the 2019 Consumer Excellence Awards are now open.

Staff updates

2018 has been a big and busy year, and HCC wouldn't be where it is today without the hard work of our entire team – so thank you all for a job well done this year.

In mid-October, we appointed Rachel Seeley to the Marketing and Communications Coordinator role, as part of the Engagement Team.

We've also had some students and volunteers come on board recently – Kieran Bindahneem in Engagement, Sue Benson, Chris Lao and Alistair Morgan in Advocacy, and Bethany Lorian in Policy.

AGM

Our AGM was held on 21st November, and it was wonderful to see so many of our members there. HCC's chairperson, Cheryl Holland, spoke about our Strategic Plan and our focus for 2019, which will be on creating new opportunities. We look forward to working with ANSON on a Social Enterprise project, funded by Lotterywest. This will give us a chance to explore strategies to broaden our sources of income and increase our impact.



To support this process, we asked our members what really matters to them, their families and their communities, in terms of health care and health services. We heard a broad-reaching range of feedback, reflecting the diversity of the health system.

One of the key areas raised was access to services – access to prompt and affordable services, including dental care and mental health services, and access to services by people with specific needs, such as people with disabilities.

Another important issue was the patient's wish to be seen as a whole person – for consumers to be listened to and have their knowledge and opinions about care recognised. This tied in with issues of informed consent, which were also raised.

We have emailed members who couldn't attend the AGM, so they can contribute to the online brainstorm. The feedback provided will help HCC determine where our efforts can provide the most benefit.

We look forward to working with the four new board members elected at the AGM – Samantha Bradder, Rebecca Carbone, Mallika Macleod and Danae Watkins. We'd also like to thank outgoing board members Lee Griffiths, who has moved to Queensland, and Laura Colvin, who had to reassess her voluntary commitments after starting a new role.

Coming to the end of their 6-year terms were Tom Benson and Tony Addiscott, and we thank them for their contributions. Tony Addiscott was at the AGM to receive a certificate honouring his work on updated rules and improvements in our board's governance processes.

Happy holidays

With the end of year nearly upon us, the entire HCC team would like to wish you a happy and healthy holiday season.

Pip Brennan

Executive Director
Health Consumers' Council

WA Health Excellence awards

Recognising innovation and excellence



Overcoming inequities winner and Director General's Award winner – Improving access to hepatitis C treatment in WA prisons

A gala dinner held on 8th November celebrated the winners and finalists of the 2018 WA Health Excellence Awards. The event acknowledged the outstanding work being undertaken in WA's public hospitals and health services.

A highlight of the night was the Jill Porteous Memorial Award for Safety and Quality, which was awarded to Falls Prevention Health Network Lead, Dr Nick Waldron.

Dr Waldron played a pivotal role in piloting the use of the Goals of Patient Care tool in Armadale Health Service, which facilitates proactive shared decision-making to establish medical treatment goals and treatment limitations.

Dr Waldron was recognised for his leadership and dedication to improving patient experience and driving excellence within his health service and the Falls Prevention Health Network.

"Dr Waldron's win was very well deserved. He is a caring health professional who is a tireless advocate for patient centred care," HCC Executive Director Pip Brennan said.

There were four finalists in the category for Engaging with consumers, carers and the community. A couple of these focussed on providing a range of options for consumers to provide feedback and input to services. The winner of this category was a project from the Ward C16 team at Sir Charles Gairdner Hospital that enables family carers to feel more included and better prepared to provide care to relatives who are experiencing delirium.

The highest honour of the night, the Director General's Award, went to the Improving access to hepatitis C treatment in WA prisons project.

In the last two years, this project reduced the rate of hepatitis C in prisons by 5 per cent, showing the incredible results that can be achieved through strong partnerships across government and the not for profit sector. The project is led by the WA Department of Health and involves every relevant area health service, as well as the Department of Justice and not for profit organisation Hepatitis WA.

"Thanks to this innovative and dedicated partnership, WA is well on the way to achieving the goal of elimination of Hepatitis C. The team worked to overcome a significant barrier which prevented GP prescribing curative hepatitis C treatment to prisoners under Medicare and the Pharmaceutical Benefits Scheme. Breaking down these barriers and increasing access to treatment has created real, tangible results for some of our most vulnerable populations," Pip said.

WA's strong healthcare system, represented by the impressive line-up of entrants, finalists and winners, is a credit to the dedication of staff and their commitments to high quality care, a patient-centre service culture, and continuous improvement.

"The WA Health Excellence Awards are an important annual event recognising outstanding achievements in health care delivery, sustainable use of resources, quality and safety, and patient care," Pip said.

“It was fantastic to celebrate the dedication, innovation and compassion of those working hard in all of these areas.”

The Winners

Director General’s Award

Improving access to hepatitis C treatment in WA prisons

Sexual Health and Blood-borne Virus Program, Department of Health – in partnership with Department of Justice, Hepatitis WA, SMHS, NMHS, EMHS and WACHS

Mental Health Commissioner’s Award

Mental Health co-response

Mental Health Co-Response team – in partnership with WA Police

East Metropolitan Health Service

Jill Porteous Memorial Award

Nick Waldron

Consultant Geriatrician, Head of Department - Aged Care and Rehabilitation, Armadale Kalamunda Group

East Metropolitan Health Service

Category 1 - Managing resources efficiently and effectively

Pathology test reduction in ICU

Team: Fiona Stanley Hospital ICU, Fiona Stanley Fremantle Hospital Group – South Metropolitan Health Service

Category 2. Engaging with consumers, carers and the community

Supporting family/carers of older hospital patients experiencing delirium

Team: Ward C16 team, Sir Charles Gairdner Hospital, North Metropolitan Health Service – in partnership with Curtin University

“Breaking down these barriers and increasing access to treatment has created real, tangible results for some of our most vulnerable populations.”

Category 3. Achieving better health outcomes for Aboriginal people winner

Kidney care – closer to home

Team: Renal Service, Goldfields, WA Country Health Service – in partnership with Fiona Stanley Hospital Nephrology Unit and Purple House Alice Springs NT

Category 4. Developing sustainable solutions for out-of-hospital healthcare

Assisted automated peritoneal dialysis program

Team: Renal Medicine, Sir Charles Gairdner Hospital – North Metropolitan Health Service – in partnership with Fresenius Medical Centre Australia

Category 5. Overcoming inequities

Improving access to hepatitis C treatment in WA prisons

Team: Sexual Health and Blood-borne Virus Program, Department of Health – in partnership with Department of Justice, Hepatitis WA, SMHS, NMHS, EMHS and WACHS

Category 6. Improving safety and quality

Oral liquid opioids – from bottles to unit dose pods

Team: Fiona Stanley Hospital Pharmacy Department, Fiona Stanley Fremantle Hospital Group, South Metropolitan Health Service

Category 7. Promotion of preventative health

Alcohol screening and brief intervention project

Team: Clinical Service Planning and Population Health, South Metropolitan Health Service – in partnership with WA Primary Health Alliance, National Drug Research Institute

Category 8. Excellence in policy development

Guideline for the Health Management of Leprosy

Team: WA tuberculosis control program, Mental Health, Public Health and Dental Services, North Metropolitan Health Service

25 years of advocating for the consumer voice

2019: Health Consumers' Council's 25th anniversary

Health Consumers' Council is proud to be an independent, community-based organisation representing the consumer voice in health policy, planning, research and service delivery in Western Australia since 1994.

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.

The Commissioner of Health at the time, Dr Peter Brennan, summed up HCC's vision by stating that, "with regards to health care, the end product is better if the community have been involved in the decision-making process".

Although launched in 1994, HCC was formed through the former Health Advisory Network and Health Consumers' Network, with Professor Mark Livers as the chairperson and George Drimatis as the executive officer. There was a smooth transition between the Health Consumers' Network and the new, independent Health Consumers' Council. Writing in HCC's first publication the new executive director thanked them both for making HCC a viable, respected, forward-looking organisation.

In 1994, HCC had a board and two key staff – executive director Michele Kosky and office manager Sue Taylor. Prior to joining HCC, Michele had spent more than six years working for the WA AIDS Council, and was committed to consultation, cooperation and information.

Maxine Drake soon joined HCC as the Community Development/Education Coordinator, to promote the Council and assist health consumer representatives to participate in the consultation process.

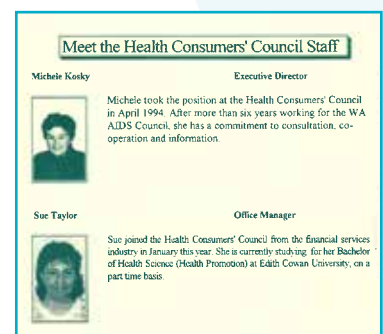
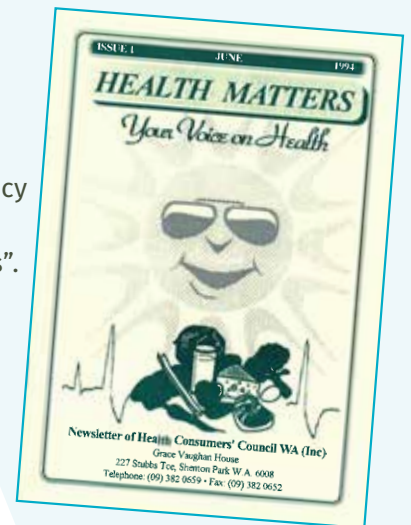
Maxine said at the time that it was clear she had "entered a dynamic agency with a band of inspiring and committed members".

The team made great strides in enhancing community understanding of health issues.

By September 1995, as reported at the AGM, HCC had organised 24 education sessions on Health Consumer Issues, attended by more than 1000 people in total; held five public forums attended by 185 people in total, on topics such as health complaints legislation, and ethical thinking on health issues; produced two pamphlets to help consumers navigate WA's health system; and provided information, advice and referral to 171 consumers via phone.

In such a short time, HCC was already gaining interest as an organisation who gave consumers a voice that was coherent, thoughtful, and a force to be reckoned with.

You'll be able to read more about this important milestone in the next edition of Health Matters. If you have memories of HCC that you'd like to share, please email info@hconc.org.au



What kind of WA would you like to live in?

PIP BRENNAN, HEALTH CONSUMERS COUNCIL EXECUTIVE DIRECTOR

Supporting Communities Forum, WA

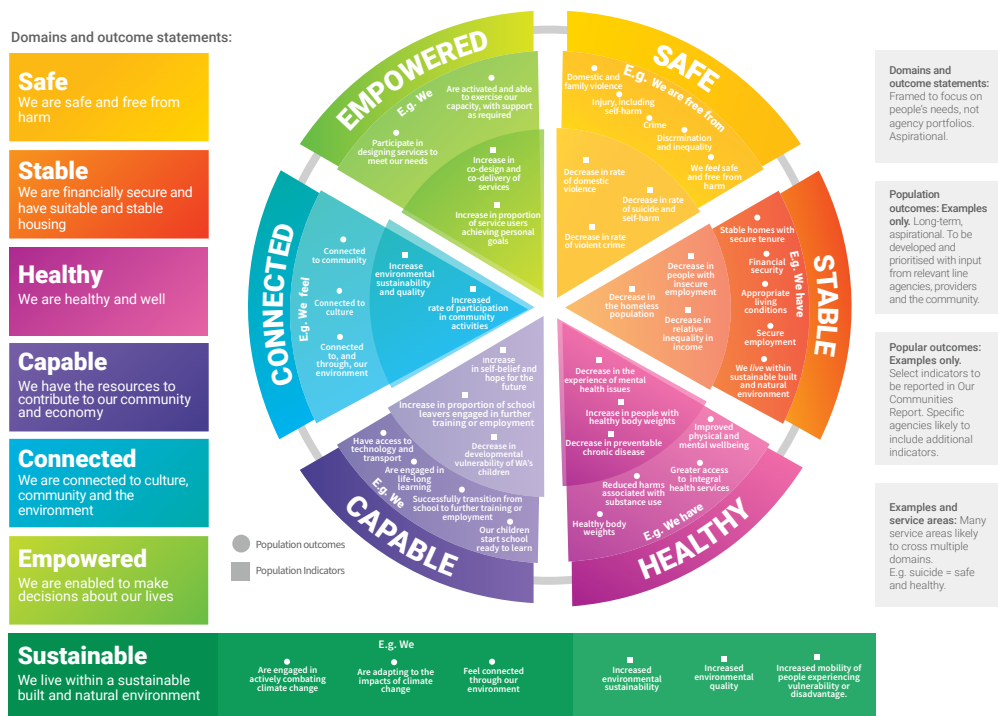
Some of you may be aware that there is a state forum of key government agencies and not for profit organisations who meet four times a year to support greater effectiveness of community services for West Australians in need. While there is a focus on improving the relationship and conversation between government and non-government providers, you can be sure that as a member of the Supporting Communities Forum, I constantly highlight the importance of involving people that use the services in the conversation from the beginning, and always.

One focus area of the Supporting Communities Forum is to develop an outcomes framework that speaks to the whole picture of what it is to be human – the

social determinants of health. This draft outcomes framework, pictured here and presented at Health Consumers' Council's AGM, has been developed by the WA Council of Social Services. Watch this space as there are very promising signs of our state coming together more effectively to provide the services West Australians need. The hope is that it will support the intent of the Sustainable Health Review to work beyond the walls of the health and hospital system to create a healthier Western Australia.

You can find out more about the Supporting Communities Forum at: <https://www.dpc.wa.gov.au/Councils-and-Committees/Supporting-Communities-Forum/Pages/default.aspx>

Outcomes Framework WA Prototype 3 November 2018



A first in Western Australia

Representation, advocacy and engagement



In a West Australian first, a newly incorporated, independent coalition has been created to provide stronger representation, advocacy and engagement, not only for consumers of alcohol and other drugs but for their families and supporters.

The Alcohol and Other Drug Consumer & Community Coalition (AODCCC) was officially established in June 2018, on the back of a Transitional Alcohol and Other Drugs Advisory Group hosted by Health Consumers' Council since 2015.

We spoke to AODCCC chairperson Juanita Koeijers about the organisation's journey so far, and how you can get involved.

"Organisations that represent the needs of health consumers, mental health consumers and carers have been in existence for many years and while most of us would fall into at least one of those categories, there has been nothing to fully represent the unique needs of people in relation to alcohol and other drugs," Juanita said.

"The incorporation of the AODCCC is a step toward stronger representation, advocacy and engagement for AOD consumers across all sectors."

On 1st November the organisation held its hugely successful first AGM, and elected a governance committee. The feedback at this event showed members of the community were embracing the opportunities that AODCCC hopes to offer.

"I am encouraged by the diversity on the board and the spirit of cooperation that was evident at the first meeting. There was an atmosphere of mutual respect which augurs well for the future... I can see the AODCCC really kicking some goals sooner rather than later," one member said.

Another member summed up what the AODCCC is doing with one word – "inspired".

As for Juanita, it is her hope that the AODCCC provides a consumer-led space for problem solving, advocacy, and peer-based capacity building, calling on the

variety of perspectives, voices and experiences within the alcohol and other drug landscape.

As an independent body, AODCCC hopes to provide a safe place for unfiltered conversations that reflect the true state of the AOD sector and provide a greater understanding of the current impact of the stigma on community inclusivity.

One of AODCCC's first points of call will be to establish relationships across health, mental health and the AOD sectors to facilitate engagement of a broad consumer demographic.

Juanita noted the pivotal role that HCC played in getting AODCCC to where it is today, providing continued support to the group who continued to meet in the hopes of establishing a consumer body.

The significance, and potential, of this first of its kind coalition is huge, and HCC congratulates AODCCC on becoming a catalyst for the consumer representing the diversity of voices in AOD.

AODCCC Membership

AODCCC membership is open to current and past consumers of alcohol and other drugs, and/or related services, their family members, significant others and supporters. If you're interested in becoming a member, please contact aodcccwa@gmail.com or visit the Alcohol and Other Drug Consumer & Community Coalition Facebook page.

Adverse childhood experiences

This article contains information about adverse childhood experiences, self-harm and suicide which may be triggering to survivors.

Using lived experiences to promote prevention and healing

Childhood experiences, whether positive or negative, can have a huge impact on a person's future, including their lifelong health. Because of this, early experiences are an important public health issue.

Adverse childhood experiences, known as ACEs, are stressful or traumatic events, such as abuse, neglect and household dysfunction, experienced before the age of 18. There are strong links between ACEs and the development of a wide range of health issues throughout a person's lifespan.

In WA, two women have come together in an effort to make WA the first ACE-aware state in Australia. Nurse Practitioner Stephanie Dowden and Kit Scott are on a mission to improve the lives of others by raising awareness around the impact ACEs can have on a person's health and wellbeing. By encouraging everyone to learn about ACEs and understand their impacts, there is hope we can unite to build a more supportive, connected community.

As a health consumer with a lived experience of entrenched domestic family violence, poverty and ACEs, Kit Scott is dedicated to using her experience to help others.

"Prior to my breakdowns I was a successful international fitness professional and personal trainer, but after my breakdowns I realised I had been an exercise addict who was using exercise to numb my body as a form of self harm, as I didn't have the skills to deal with my mental and emotional pain in healthy ways," Kit said.

In 2015 Kit was diagnosed with depression, mood swings and a benign pituitary brain tumour. It wasn't until she began looking into ACEs that she was able to see this was all related to deeply suppressed emotional pain and unhealed childhood traumas.

"For me, it's about healing and acknowledging that once we know better, we can be and do better."

Kit and Stephanie have hosted two community meetings to shine a light on ACEs. Through a growing Facebook group ACE Aware WA, they are sharing resources and making connections that are helping those living with ACEs feel less alone.

"I look forward to working with others putting in place better help, prevention supports, education, recovery and healing that will leave this world better than how we found it," Kit said.

Stephanie has her own children's clinic in Cockburn and uses discussions about ACEs to help families understand the impact of their own, and their child's, ACE scores on their parenting, well-being, health, child behaviour and development.

"Although many health professionals fear that discussing ACEs will lead to high levels of distress and 'lift the lid on trauma', I have found the opposite to be true," Stephanie said.

"However, it's vital to take time for these conversations, to listen, not judge or blame but reflect, be supportive and work together to find a better future."

If you are affected by this story, you can seek 24/7 support from: Lifeline 13 11 14 www.lifeline.org.au

ACE Aware WA meeting
Wednesday 9th January 2019,
4pm-6pm
Cockburn Integrative Health,
Level 1, Group Room –
11 Wentworth Parade, Success
Free to attend, all welcome

At HCC, we strongly believe our health care system is better when the people using it are meaningfully involved in its development. One way we can help to create a safer, kinder and more person-centred health system is to share our stories.

The human voice can be a powerful motivator for change. **Stories really can – and do – change the world.**

Patient Opinion is one way that you can share your story and make a difference. Patient Opinion drives safe and quality conversations between the public and our health services. Your stories help health

providers understand how people experience the care they receive, and can give doctors, nurses and organisations an insight into what improvements could be made to better support patients.

On average, 50 per cent of the stories shared are positive, and Patient Opinion provides the opportunity for more frontline staff to receive feedback on the wonderful work they do. We believe that recognising good practice is an important part in encouraging more of it.

www.patientopinion.org.au 1300 662 996

“She had a genuine desire to alleviate any discomfort”

The smallest acts of kindness can make a big difference. When **atlaswj76** had imaging undertaken at Esperance Health Campus, the reassurance and communication from staff member Beth made all the difference.

“She recognised I was uncomfortable and was compassionate and had a genuine desire to alleviate any discomfort. Beth’s bedside manner is impeccable.”

Esperance Health Campus

“It made a traumatic and exhausting event for us so much more bearable”

No parent ever wants to see their child in pain, but it’s good to know that when accidents happen, compassionate care is available. When **echopt9’s** toddler broke their arm, they were taken by ambulance to Perth Children’s Hospital. **echopt9** said the level of care they received made this traumatic event so much more manageable.

“All who attended to our toddler were wonderful in every way, including level of care, attentiveness and communication. It made a traumatic and exhausting event for us so much more bearable. Top staff and top facilities!”

Perth Children’s Hospital

er health system

y can make a difference

Patient Opinion wouldn't exist without the hard work of the organisations who listen and respond to patient stories.

Thank you to the organisations who have embraced Patient Opinion and are contributing towards an improved health care experience. These three organisations were identified by Patient Opinion to be using the service well in WA:

East Metropolitan Health Service

- 221 stories shared about their organisation to date
- 31 stories that have led to a change planned or made
- 217 staff listening to stories

South West Health

- 204 stories shared about their organisation to date – 171 in 2018 alone
- 65% of all their stories are positive
- 108 staff listening to stories

Midwest Health

- 201 stories shared about their organisation to date
- 18 stories that have led to a change planned or made
- 148 staff listening to stories

“From the moment I walked in the staff were friendly and professional”

Going to hospital for a day procedure can be nerve-wracking. Being treated with respect and kindness goes a long way in soothing these nerves. At Busselton Health Campus, **One happy customer** was treated with dignity and respect by everyone – from the nurses, personal care assistants and admin staff, to the doctors and anaesthetist.

“From the moment I walked in the staff were friendly and professional. The theatre area was clean and bright, and I can't thank the staff enough for making me feel comfortable and welcome...”

Busselton Health Campus

“Nothing was ever too much trouble for anyone...”

Thankful partner took the time to provide invaluable feedback after a heartbreaking experience. After spending four weeks on the ward, **Thankful partner's** partner passed away.

“I would like to thank ALL staff in all areas, ED and [Ward] 10C and ICU, from kitchen staff to cleaners, to social workers, to allied health, to ward clerks, to nursing staff and the medical team, even the chaps in the café...nothing was ever too much trouble for anyone...I was most impressed and grateful for the care and attention we received.”

Royal Perth Hospital

World Kindness Day

Embracing a culture of kindness in healthcare

Kindness can happen anywhere, and at any time, but it is especially nice when acts of kindness happen in our own community and workplaces.



Kindness in healthcare is something that often gets taken for granted. When we are ill, or going to a health service provider for advice, we all want to be treated with kindness. However all too often in healthcare, kindness can be missing, just when it's most needed.

In 2016 in Victoria, the Gathering of Kindness movement was born. A 'taster' World Kindness event was held by HCC in April 2018, during Patient Experience Week. The plan was always to celebrate World Kindness Day on 13th November by holding a second event focusing on kindness, and people from Culturally and Linguistically Diverse (CaLD) backgrounds.



HCC partnered with WA Primary Health Alliance, Ethnic Communities Council of WA, the Multicultural Services Centre WA, Ishar Multicultural Women's Health Centre, WA Country Health Service, and the Multicultural Youth Network WA, and invited CaLD specific health service providers and community members to come along and network, discuss and reflect on the impact of kindness in healthcare for CaLD populations.

The act of kindness can look different across different cultures, and so health care providers need to have a shared understanding and value of what kindness in healthcare means.



On the day, we were lucky enough to hear from both community members and health care service providers, as they shared stories of kindness in healthcare and the importance of creating a culture of kindness to deliver more equitable healthcare.

The Welcome to Country by Len Yarran from Wadjak Northside Aboriginal Community Group included the story of a very early act of kindness, when the traditional owners of Australia shared their most precious resource, water, with the white settlers.

Ruth Lopez and Alex Xiao from WA Department of Health shared a snapshot of WA's population diversity. In looking at who exactly we are talking about when we talk about kindness in healthcare and supporting cultural diversity, they provided fascinating insight into the current population of WA.

To ground the day, a panel of CaLD consumers discussed their experience of kindness in healthcare, chaired by Arlene Quinn from Perth Playback Theatre. Vithan Thillairajah from the Youth Affairs Council



shared his insights into the importance of education and mental health to support CaLD communities. A Macedonian mother of three shared her experience of how Ishar Multicultural Women's Health Centre had supported her when she had really needed it, and literally changed the course of her life. Siyat Abdi from the Ethnic Disability Advocacy Council shared stories of the importance of community support and how members of a community can rally around to support those in need.

– and that included not relying on family members to translate important health information for each other. One panel member working in the school setting noted that it was a less intimidating environment for people to attend for health interventions.

Perth Playback Theatre then took to the stage to reflect the stories and comments from the panel members and others in the audience. The feedback from the event was overwhelmingly positive about this part of the day.



Dr Bernadette Wright facilitated a panel discussion with health professionals who provide support to CaLD communities. Sarah Cheria, Brenda Kamau, Tessa Scholefield and Leanne Mirabella shared their insights and strategies for providing culturally safe care. The importance of flexible services with the ability to provide care to any and all family members was key. Access to interpreters was also agreed to be critical

“[Perth Playback Theatre] were absolutely amazing. Loved how they could play back stories from the audience with such emotion and capturing those stories is quite a skill.”

The day closed with an interactive reflection on the learnings from the day.

Stall holders included Breastscreen WA, Ishar, Ethnic Communities Council WA and Multicultural Services WA, Wadjak Northside and HCC. The event was supported by major funding from WA Primary Health Alliance through the Australian Government's PHN Program.

Health Consumer Excellence Awards

2019 – **Nominate now!**

The Health Consumers Council Excellence Awards were created to honour the everyday heroes in health in WA, from the administrator to the clinician. We also recognise health consumers who go out of their way to make a difference to our health system.

“There are a lot of unsung heroes in WA health care and health services,” Health Consumers’ Council executive director Pip Brennan said.

“If you’ve received outstanding care in WA, this is your chance to publicly recognise and thank the people who are making a difference, and ensuring consumers receive amazing care across all areas of health services.”

Winners and finalists will be announced at an awards ceremony held on Tuesday 30th April 2019, as part of Patient Experience Week.

In 2019, Patient Experience Week will be focus on the experiences of Aboriginal and Torres Strait Islander people using health services.

Health Organisation Award

This category is for health organisations working effectively with consumers to improve services. The award recognises health organisations that demonstrate an ongoing partnership with health consumers to improve health outcomes and the patient experience.

Health Professional Award

This category is for health professionals demonstrating excellence in patient care. The award recognises health professionals who demonstrate ongoing commitment to improving health outcomes and/or the patient experience.

Health Consumer Award

This category is for consumers demonstrating excellence in contributing to the improvement of the patient experience. The award recognises a health consumer who demonstrates commitment to improving health outcomes and/or the patient experience.

Rosemary Caithness Award

This award is for either a consumer or service provider and acknowledges outstanding service to health consumers. This award is highly selective and typically the recipient has supported health consumers over many years. The Health Consumers’ Council will only award the Rosemary Caithness Award should there be a worthy recipient in any given year.

Aboriginal and Torres Strait Islander Award

This award is to acknowledge outstanding service to Aboriginal/Torres Strait Islander health consumers. The candidates can be an Aboriginal/Torres Strait Islander person or organisation. They can be a health professional, consumer, other individual or organisation.

Compassionate Care Award

This award is to acknowledge people providing direct patient care who demonstrate compassion. We are looking for compassionate individuals working in any capacity in a health service or organisation. We are also looking for compassionate teams of health care providers who demonstrate effective multi-disciplinary care. Evidence of compassionate care in the form of feedback letters from consumers and cares will strengthen the nomination.

***Nominations close 31st March 2019**

<https://www.hconc.org.au/health-consumer-excellence-award-nominations/>

Improving the patient journey from country to city

JESSIE MAY, ARCHE HEALTH LIMITED

A unique role in Aboriginal health care

I am an Aboriginal Nurse, Midwife and Child Health Nurse, from the Ngarinman tribe of the Amanbidji region. I am very proud of my Ngarinman culture, and I live – straddle – between this and the Western culture, working very comfortably in both these worlds.

I hold a Bachelor of Arts in Social Sciences with majors in Aboriginal Anthropology and Sociology, and a Master of Public Health and Tropical Medicine, and am in the final stages of completing my Doctor of Philosophy Degree, although this is currently on hold.

I have been working in Perth since the 1980s in Aboriginal Health, however I visit my homeland regularly. Currently I am working as a Specialised Care Coordinator at Arche Health's Country to Perth Primary Healthcare Linkage in partnership with Aboriginal Hostels Limited.



Health travel

Our local health system still has gaps and inadequacies, which allow Aboriginal country patients to fall through the cracks in accessing optimum health care. There is a high need for advocacy and primary care support while they are in Perth.



Jessie May

My principal role involves supporting patients on hospital discharge to access primary health care support; ensuring the client is registered on the Closing the Gap Initiative; ensuring access and compliance with medication; and focussed emotional and social support while in Perth.

It's been both humbling and rewarding to see our people recover and go back home safe and healthy to their lands and loved ones.

The Country to Perth Primary Healthcare Linkage is funded by the Commonwealth through the WA Primary Health Alliance (WAPHA).

Join the SHQ Publications Committee

Expressions of interest to help shape and improve SHQ's services

For more than 30 years, Sexual Health Quarters (SHQ) has been providing sexual health services, information and training for people across WA.

Following the implementation of its successful new consumer engagement framework in May 2018, SHQ is taking the next step in the organisation's consumer engagement journey.

SHQ is committed to hearing the views of consumers to help shape and improve services, and is seeking expressions of interest from consumers to be part

of its Publications Committee in 2019. This person/s would be responsible for providing feedback regarding new and existing SHQ publications to ensure they meet the needs of community members.

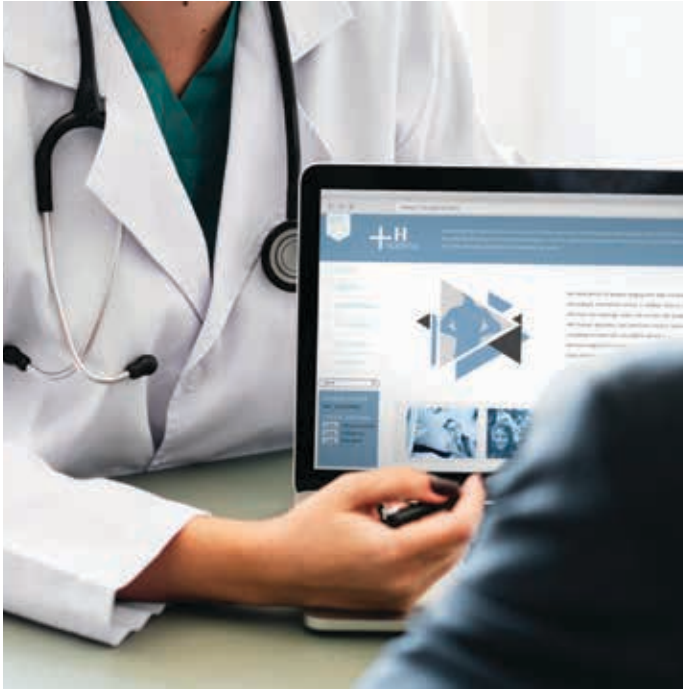
SHQ is seeking representation from a diverse range of groups, in particular young people. The role will involve attendance at 2 or 3 meetings each year and feedback via email.

For more information or to apply, please email info@shq.org.au or call Rebecca Smith on 9227 6177.

The implant files

PIP BRENNAN, HEALTH CONSUMERS COUNCIL EXECUTIVE DIRECTOR

A global investigation



The impact of pelvic mesh is an issue Health Consumers' Council has been actively working on since 2017.

I joined The Australian Commission on Safety and Quality in Healthcare Reference Group convened to look at the issue. At that time, I believed the common misconception that implants and devices are rigorously tested before they are put into our bodies.

However, this just isn't the case, and this is a global issue – as we've seen, when a device is approved in one place (such as Europe) it can facilitate approvals in the rest of the world. While every medical treatment involves some possible risk, we believe consumers have the right to fully understand those risks before deciding whether the treatment is right for them.

For the last few years, the International Consortium of Investigative Journalists (ICIJ) have been looking into the issue of device and implant regulation. The Consortium includes 250 journalists across 25 countries. The ICIJ has uncovered some alarming trends in relation to how devices are regulated, and statistics in relation to patient harm.

The two-part ABC Radio program Background Briefing noted that Dutch members of the ICIJ were shockingly able to get approval for a mesh implant that was made of the netting from a bag of mandarins at the supermarket. This has driven a tightening up of the regulations in Europe, but concerns remain across the world about patient (and doctor) understanding of just how experimental these devices are. It is particularly concerning that in many cases, their safety can only be determined after they have been implanted in a patient.

You can find this episode at <https://ab.co/2KSYVHT>

While we know that some medical devices and implants have helped many people, when they do go wrong they can have disastrous consequences. The problem is, surgeons aren't compelled to report problems with devices and there is no register for most implants, so it can take a long time for problems to be identified.

Our Victorian counterpart, Health Issues Centre, is running an anonymous survey on medical devices and so far have received feedback in relation to hernia and bowel mesh, cochlear implants, metal hip replacements, total knee replacements, IUDs, insulin pumps, pain pumps, resuscitation devices, ventilators, breast implants, shoulder replacements, obesity surgery devices, stents and intraocular lenses.

You can take part in the short survey here: <https://www.surveymonkey.com/r/SKRYTGN>

HCC supports Health Issues Centre in advocating for the health system and consumers by addressing the shortcomings experienced in relation to medical devices and implants. By sharing your stories and personal experiences, you can make an invaluable contribution that will help HIC capture an accurate picture of the prevalence of medical device failure.

If you need any further information on this issue, please call HCC on 9221 3422.

Community wellbeing

JASMINE UITERMARK THAUNG, CARERS WA

Celebrating the unique contribution of carers

A carer is someone who provides unpaid care and support to family members and friends who have disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue, or who are frail aged.

Over 2.9 million Australians provide help and support to a family member or friend, and while this does come at a cost to the carer, the impact on lives and communities is invaluable.

Carers play a unique role in ensuring the health and wellbeing of members of our community. They provide comfort, encouragement and reassurance to the person they care for, as well as overseeing their health and wellbeing, monitoring their safety and helping them retain their independence and quality of life.

This incredible work should be acknowledged not only for the many ways it improves the life of the person being care for, but also for the impact it has on the person doing the caring. They're often less likely to be employed, or less likely to participate in the labour force, due to their time spent caring.

Additionally, carers in Australia make a \$60 billion contribution by providing care that would otherwise need to be funded by budgets dedicated to health, mental health, ageing and disability.

Gaye Philp is one of Australia's carers, a single mother who fostered two children. The eldest child, Jay, now 29, has complex needs due to a variety of conditions including autism and a congenital heart disorder. Jay moved into his own home in August this year, but Ms Philp remains his health guardian to assist with health and welfare decisions.

"Jay lived with me from the age of 4 months until he was 18 and then...I think he had about 7 years in group homes and they were all disastrous through poor compatibility and providers not really being trained. I got called in a lot to support him," Ms Philp said.

In May 2015 after a number of psychotic episodes in his latest group home, Jay returned to live with

his mum after developing uncontrolled diabetes, a psychotic disorder and severe sleep apnoea.

"We got some support in while I was working which was really quite tricky, I had to take time off work often because of his health issues..." Ms Philp said.

"There's a huge cost in the amount of work I've been able to do and also to my own health and wellbeing," Ms Philp said.

Caring, while incredibly rewarding, can also be a high-stress role and carers are seen to have one of the highest incidences of depression and burnout. That's where Carers WA comes in, working to achieve an improved quality of life for family carers in our state.

For Ms Philp, she believes both the healthcare and wider community need to be aware of the economic advantage carers give society.

"I've been the main provider for the family, the only driver, the only person who has been helping family access support services, get treatment at GPs and clinics. Had the State had to pay for that, it would have cost them a lot," Ms Philp said.

Fortunate in finding her way through the maze of services and supports due to a history of working in disability services, Ms Philp expressed that she was grateful for the skills she had which helped her as a carer and expressed anguish for those who did not possess the same knowledge.

"I saw so many people who had no idea how to navigate the system and it was so tricky," she said.

To Ms Philp, it is incredibly important for healthcare professionals and service providers to value carers' expertise and to acknowledge the extensive support they provide for loved ones.

If you know a carer or are a carer whose role is not being adequately recognised, or need assistance in navigating the caring role, please contact Carers WA.

1300 227 377 or info@carerswa.asn.au

Consumer stories driving change in obesity services



The Obesity Collaborative Summit

The Department of Health and the WA Primary Health Alliance have convened a new Collaborative tackling the critical health issue of overweight and obesity. Health Consumers' Council was asked to help to bring the consumer perspective into the room at the Obesity Collaborative's Summit in October 2018.

We received more than 700 responses to a survey, heard stories through an online brainstorm, and had people share their experiences through writing and video. The key issues raised showed that more than 40 per cent of respondents had tried more than five times to lose weight in the last 12 months; that people often know what to do but need help doing it; and that there are many and varied reasons as to why people are overweight.

We shared these key experiences at the Summit, where Minister for Health Roger Cook reiterated the importance of this issue for individuals and the community. The Department of Health is reviewing the outputs from the Summit and HCC will continue to ensure the consumer voice is central to these discussions.

You can find out more at <https://www.hconc.org.au/projects/partners-in-change-obesity-collaborative/>

Senate inquiry on end of life choices

The state-based inquiry into end of life choices handed down its report in August 2018. The report focussed on three key areas of care at end of life: advance care planning, palliative care services, and voluntary assisted dying.

Palliative Care WA has been leading the charge in the communication of the recommendations and driving the impetus for their implementation. The organisation has held forums to debrief the recommendations and seek advice from the sector as to what needs to be prioritised by our state's Minister for Health.

Palliative Care WA's final forum, addressing Voluntary Assisted Dying, will take place on 12th February 2019. To book, contact Palliative Care WA or go to <https://bit.ly/2Rehijc>

There is an inevitable media emphasis on the Voluntary Assisted Dying recommendations, but in truth it is the palliative care recommendations which will impact many more people.

HCC supports the notion of Advance Care Planning but acknowledges that the reality of developing a Plan is fraught with complexities. We noted with interest the initiative of Professor Charlie Corke, Senior ICU



Specialist at Barwon Health in Victoria, to create a hyper-real sculpture of a woman receiving the typical level of care that results from the lack of an Advance Care Plan or detailed conversations between loved ones. This sculpture was on display in Melbourne and provided an opportunity to begin conversations about end of life care choices.

Professor Corke developed the My Values website to act as a voice when people can't speak for themselves: <https://www.myvalues.org.au/>

Updates

Federal Senate Mesh Inquiry

In early October 2018, Federal Health Minister Greg Hunt issued a national apology to the many women whose lives have been devastatingly impacted by pelvic mesh implants. WA's Mesh Clinic has continued to work with the WA Pelvic Mesh Support Group and the King Edward Memorial Hospital Community Advisory Council, however there are still concerns about access to removal of mesh. An audit of women who have had mesh implants is in progress in WA, and HCC is working with consumers and WA Health about what this will look like.

Sustainable Health Review

The Sustainable Health Review has been a major focus for 2018, and the report is expected to be publicly released in early 2019. One of the key aspects on the agenda is prevention, echoing a nationwide call for a renewed focus on prevention to reduce the upward trend in health costs.

Fiona Stanley Hospital Family Birth Centre

The Consumer Reference Group has been meeting regularly with Fiona Stanley staff to ensure that the centre has women's and families' voices firmly in the centre. The project is progressing towards a planned launch in mid-2019, with the job descriptions for the midwives finalised, a flurry of interest from staff, and a consumer representative to sit on the interview panel when recruiting for the roles.

Cancer Care Costs

HCC has partnered with Cancer Council WA on a new project to find out whether people are making informed financial decisions about where to get their cancer care. A short survey has been developed, and closes on 6th January 2019:

<https://www.surveymonkey.com/r/CancerCareCosts>

Health Engagement Network

The Network is an online community for people interested in the practice of consumer, carer and community engagement. The Network has over 200 members from across the whole health system in WA.

When we asked what people want to get out of being in the community, responses included working with like-minded people around the challenges of a complex health system, sharing ideas about consumers and community engagement, and keeping up to date with health initiatives.

Planning for 2019 is underway – to join the Network, head to www.healthengagement.org.au

Empowering Health Consumers with Disability

HCC has partnered with People with Disabilities WA (PWdWA) to deliver the project Empowering Health Consumers with Disabilities.

We have established a Focus Group made up of people with disabilities and have held our first meeting. From this group, we will select a number of trainers to deliver sessions to people with disabilities, their families, carers, and health and disability providers. Our second formal meeting was held on 14th December.

My Health Record

The Federal Government recently extended the opt-out period for My Health Record to 31st January 2019.

It also passed changes to the legislation surrounding My Health Record that addressed some of the concerns expressed in recent months: greater privacy for those 14 years and over; prohibited access by insurers and employers; increased protections for people at risk of family and domestic violence; and the ability for Australians to permanently delete their records, and any backups, at any time.

**For more information, please visit
www.hconc.org.au or call (08) 9221 3422
Country callers 1800 620 780**



**HEALTH CONSUMERS'
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Monday - Friday 9.00am - 4.30pm
Closed Public Holidays