

Health Matters

Health Consumers' Council (WA) Inc. Magazine

March 2020

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HEALTH CONSUMERS'
COUNCIL

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It's with cautious optimism that I welcome you to the March 2020 edition of Health Matters, which is dedicated to the patient experience.

With the spread of the COVID-19 virus, now is the time to focus on health and the safety of those around us. These are uncertain times, and it is difficult to think about anything else! However the content for this magazine has been in production for some time, so I hope that despite the unfolding pandemic, these articles on the patient experience will still prove to be informative and perhaps even a brief, welcome distraction from the current spread of COVID-19.

Given that the situation is changing so quickly, trying to provide you with up-to-date recommendations here would prove unhelpful. Instead, we offer this advice:

1. LISTEN TO THE EXPERTS

Try to limit your exposure to sensationalist news and personal Facebook posts giving advice on COVID-19, and instead look to the experts to get up-to-date advice. State and national authorities will let you know how to best look after your own health, as well as how to reduce the burden on healthcare and protect the most vulnerable in our community.

Trusted sources include the WA Health Department https://ww2.health.wa.gov.au/Articles/A_E/Coronavirus, the World Health Organization, and ABC news.

2. REMAIN CALM BUT CAREFUL

At the time of printing, the advice is to avoid large gatherings and minimise social contact to help slow the spread of the virus. While there is no need to panic, it is important to act now and to think carefully about your actions.

3. BE KIND AND KEEP THE COMMUNITY IN MIND

For many people the symptoms of COVID-19 will be mild, but there are many in our community who are in danger of becoming seriously ill if they contract the COVID-19 virus. We need to think of our community, our colleagues, our friends and our families, rather than just ourselves. We can all help reduce the impact of the virus by looking after our own health, following the current advice about

self-isolation and social distancing, and washing hands often. Although you may not be able to have close physical contact with your community, we do recommend you stay connected and reach out through the phone, text message, online forums and other online spaces to check in and reduce the impacts of social isolation. Try to approach the situation with a sense of compassion.

4. CONSUMER PEAKS RESPONSE

The Health Consumers across Australia are meeting on 19/3/2020 to discuss how we might collaborate to better understand the impacts of COVID-19 on everyday people (and not just on health). We have put together a short survey if you are interested in responding: <https://www.surveymonkey.com/r/COVID19WA>

Patient Experience

This edition of Health Matters coincides with Patient Experience Week, which is a movement aimed at celebrating the people in healthcare who impact on the patient experience every day. In 2020 Patient Week is celebrated from 30 March to 3 April in WA, although it is globally recognised from 27 April to 1 May.

While we understand events celebrating Patient Experience Week may be scaled back or cancelled due to COVID-19, it is perhaps now more than ever a chance to be appreciative for those working and volunteering in the healthcare system for the actions they take every day to create a better experience for patients.

When the situation allows for it, we encourage you to provide feedback on your experiences with the health system. Studies have shown that saying thank you can lead to a 50 per cent increase in helpfulness – so by expressing your thanks for a job well done, you could be helping to make the health system a little better.

As always Patient Opinion, or as we now call it, Care Opinion, is an easy way to share your feedback, “whether its good or bad”.



PIP BRENNAN
EXECUTIVE DIRECTOR
HEALTH CONSUMERS' COUNCIL

Championing the patient experience



A Q&A with The Beryl Institute President and CEO, Jason Wolf

Jason Wolf is a passionate champion and expert in patient experience improvement. As President and CEO of The Beryl Institute, Jason has led the growth of the organisation as the leading global community of practice and thought leader on improving the patient experience and establishing the framework for the emerging profession of patient experience.

In the lead up to Patient Experience Week, Jason spoke to us about the importance of working to continually improve the patient experience.

How and why did Patient Experience Week come about?

The first Patient Experience Week was held in April 2014. The focused week was inspired by members of The Beryl Institute community to celebrate healthcare staff impacting patient experience. Taking pause during this week provides a focussed time for organisations to celebrate accomplishments, reenergise efforts and honour the people who impact patient experience every day. The first annual event also encompassed the former Patient Advocacy Week sponsored by the Society of Healthcare Consumer Advocacy (SHCA) after SHCA integrated with The Beryl Institute in January 2014.

What has the uptake of the movement been like around the globe?

PX Week has appeared around the globe in a number of ways, from the great celebrations championed right here in WA by the Health Consumers' Council to efforts in the UK to recognise Experience of Care Week. While celebrations during Patient Experience Week are an underpinning of this movement globally, its observance

serves as more of an acknowledgement of the work it takes to effectively champion and sustain experience efforts across healthcare settings globally. What may be more significant than just the celebration of Patient Experience Week is the acknowledgement of healthcare consumers themselves, as reported in our study Consumer Perspectives on Patient Experience (2018).¹ This study included voices from Australia where 91% of consumers confirmed patient experience is extremely/very important to them overall and is significant to the healthcare decisions they make. This means that as we celebrate Patient Experience Week, every day provides an experience opportunity and comes with a clear expectation from those served by healthcare systems around the world.

In your view, what areas within health care have the biggest impact on patient experience?

I would suggest ALL areas of healthcare impact the experience people have. It is what led us to underline the importance of an integrated view of experience that acknowledges quality, safety, service, access, outcomes

and more are all part of the experience one has in healthcare. It is not bounded by the walls of a clinical encounter.

When looking at healthcare through the eyes of the patient or family member, we see that experience is directly affected by quality, safety and service efforts, and influenced for some by cost and broader public (population) health issues that play a role in both clinical and organisational decision making. From an operational perspective, quality, safety, service, cost and outcomes may be distinct areas of work, but they are not usually seen as distinct by the individual in a patient bed or at the bedside, in a waiting room or in the surgery suite, in a residence or in the recreation room. Although organisations may build efforts to address and improve each of these areas, the consumer of care in most cases does not distinguish between a quality encounter, safety protocol or service intervention as separate experiences, nor does he or she view cost—or, for that matter, broader population health issues that influence decisions—as separate.

In a similar light, we introduced the Experience Framework² last year to further reinforce the integrated nature of experience in healthcare today. The Experience Framework includes eight strategic lenses through which any experience endeavour should be framed. It reinforces the integrated nature of experience efforts and provides a means to identify where you are excelling or may have opportunities to address. It also offers a means by which knowledge, resources and solutions can be aligned.

The eight lenses and the rationale for why they are essential to the experience conversation are:

- » **Culture & Leadership:** The foundation of any successful experience effort is set on who an organisation is, its purpose and values, and how it is led.
- » **Infrastructure & Governance:** Effective experience efforts require both the right structures and processes by which to operate and communicate and the formal guidance in place to ensure sustained strategic focus.
- » **Patient, Family & Community Engagement:** Central to any experience effort are the voices of, contributions from, and partnerships with those receiving care and the community served.
- » **Staff & Provider Engagement:** Caring for those delivering and supporting the delivery of care and reaffirming a connection to meaning and purpose is fundamental to the successful realization of a positive experience.
- » **Environment & Hospitality:** The space in which a healthcare experience is delivered, and the practices implemented to ensure a positive, comfortable and compassionate encounter must be part of every effort.

- » **Innovation & Technology:** As a focus on experience expands, it requires new ways of thinking and doing, and the technologies and tools to ensure efficiencies, expand capacities and extend boundaries of care.
- » **Policy & Measurement:** Experience is driven and influenced by external factors and systemic and financial realities and requires accepted and understood metrics to effectively measure outcomes and drive action.
- » **Quality & Clinical Excellence:** Experience encompasses all individual encounters and the expectations they have for safe, quality, reliable, and effective care focussed on positively impacting health and well-being.

Through the Experience Framework, we can create a more efficient connection of needs to knowledge, strategies to resources and opportunities to solutions, expanding the collective global dialogue through a common structure for focus and action. In having a means to align efforts at a macro level, we are well-served to drive specific efforts and address specific needs to the level required in any healthcare endeavour.

What key messages would you share with health service providers around patient experience?

I have written about this often and would suggest a few key points I offered both in our most recent research paper, *The State of Patient Experience 2019*, and in our 2018 study, *To Care is Human*. In *The State of Patient Experience 2019*, I wrote:

In moving to the future of healthcare grounded in experience, this calls on us to recognise and act on a few fundamentals, many that have been essential to our focus at the Institute and some we have discovered in our constant work to improve the patient experience and elevate the human experience in healthcare.

1. **Patient experience is not something healthcare does, it is who healthcare is.** It is when experience is simply seen as a thing to do, a box to check in a complex healthcare world, that its possibility is immediately weakened. Experience happens regardless of plan or process. It is who a healthcare organisation is and how it is perceived by others. It is incumbent on all in healthcare to build organisations that realise that every action, every encounter and every interaction create an experience for all involved. The choice then becomes to consistently create moments that will ensure the experience is one we aspire to offer.
2. **Patient experience is driven by all we do and, therefore, every effort must be approached with an integrated view of how it will impact the overall experience we provide.** This is the essence of the experience framework itself. It is in understanding

that all the elements it includes, the eight strategic lenses, while often operated distinctly in healthcare, must be seen as one integrated set of actions in ensuring an aligned and effective effort to drive experience and therefore the outcomes we look to achieve.

3. To succeed externally, we must focus internally.

The ideas that culture matters or that how we treat those who work in an organisation will impact the experience of those it serves are not new, yet healthcare leaders have been slow to turn this understanding into action. It is not an accident that the data from 2015 to today reveal a rapidly growing awareness of communication and employee engagement as the primary path to experience success. In fact, as revealed in the 2018 study *To Care is Human*, healthcare units who achieved high performance in experience all attested that after getting communication with patients and families down, the next critical element was to ensure the engagement, teamwork and well-being of those working in healthcare.³ If organisations are not willing to work on themselves first, they will never ultimately achieve the experience success they seek.

4. A commitment to experience will not (and must not) ever end. In hearing from many organisations over time since the first state of patient experience study in 2011, one of the greatest issues raised is that of sustaining success. This raises an opportunity for all organisations to consider. While many organisations initially related success to survey outcomes and percentile rank, they too seemed to feel that once they hit a certain level, they had achieved what they could. Many of those organisations assumed this achievement would continue; they shifted their focus or took their foot off the gas on their efforts. All of this led to diminished scores, questions about efforts, frustration and even more significant actions in changing staff or redesigning process. These organisations thought experience was something to be achieved. That presents a false consideration, as that idea means it is done, over, accomplished, but the need to ensure the best in experience never truly ends. It is about a relentless pursuit of excellence, about consistent delivery of intent and an unwavering commitment to the human experience at the heart of healthcare that will lead to the outcomes all aspire to realise.

How are patient experience and health outcomes related?

I would simply add here that if we see experience as the integration of quality, safety, service, access and outcomes, then experience is a measure of the outcomes achieved. If we help people get better through

improved care, that outcome is their experience. If we help them to live the remainder of their life, whether days or decades, with dignity and respect, that is their experience, and an attempt to distinguish experience from that undermines all we aspire to in healthcare.

Yes, there is prevailing research that shows high experience scores (for instance, represented by survey scores in the US) leads to better quality outcomes⁴, but this research only looks at experience as measured by the scores and does not acknowledge all we addressed above. The reality is that when people are engaged in care, feel listened to, are communicated to in a way they can understand and are treated with dignity and respect – all primary identified needs of healthcare consumers¹ – then we tend to see better outcomes. The discussion of experience undermining quality is a dangerous and misguided conversation that still relegates experience to satisfaction. We are not addressing how happy people are in tackling experience, but rather we are committing to their health, their well-being and their humanity and are committing to the best in outcomes for all we serve. Thus, experience is inextricably linked to outcomes. They are more than related; experience is the ultimate outcome of safe, quality, reliable and human care that all patients and families deserve.

What does the future look like when it comes to patient experience?

We are now in the midst of an inquiry on the future of human experience over the next decade as a call to action and an identified opportunity for healthcare organisations globally. I would encourage you to read and react to the dynamic and provocative path we offer, consider ways in which you can engage, where you can add practice or evolve systems and processes and how each of us can contribute to the future of human experience we all aspire to see and know all in our care deserve.

The *Future of Human Experience 2030* will be available from the Beryl Institute in April 2020.

REFERENCES

1. Consumer Perspectives on Patient Experience 2018 (<https://www.theberylinstitute.org/page/PXCONSUMERSTUDY>)
2. Experience Framework: <https://www.theberylinstitute.org/page/ExperienceFramework>
3. *To Care is Human: The Factors Influencing Human Experience in Healthcare Today* (<https://www.theberylinstitute.org/page/ToCareIsHuman>)
4. How U.S. Health Care Got Safer by Focusing on the Patient Experience. (<https://hbr.org/2017/05/how-u-s-health-care-got-safer-by-focusing-on-the-patient-experience>)

From 23 March 2020, Patient Opinion's name will become Care Opinion. After this time, when you go to visit the Patient Opinion website, you will automatically be redirected to the Care Opinion site at www.careopinion.org.au.

There you will see the updated Care Opinion name, logo and new colours but everything else stays the same. It will still be a transparent, moderated platform which creates a real-time feedback loop between the public and health services.

What's behind the name change?

Both Patient Opinion and Care Opinion have been operating in Australia since 2012, but they are now merging the new companies to follow in the footsteps of their parent company in the United Kingdom, Care Opinion, who have already made this change.

Patient Opinion becomes Care Opinion



Merging to be Care Opinion provides a single platform where people can post their stories of any care experience. That includes hospitals, aged care, disability, mental health and community/social services.

WA has led the nation in having every public health service as a subscriber to the Patient Opinion (now Care Opinion) platform, which means your feedback is monitored

and responded to. Now we call on every social service funded by the WA government to follow suit and commit to the process of transparently responding to people's stories of how they are experiencing services. This is how we continually improve, and how we celebrate the good practice of our dedicated health and social services staff.

We want to hear from you!



At Health Consumers' Council, we engage with people in our community in a variety of ways, from emails to social media and community events. To help us meet your needs when it comes to sharing information, events and opportunities, we would like to find out more about you and what's important to you.

We've put together a survey to help us better understand our community.



Everyone who takes the survey will have the chance to go into the draw to win an eco-friendly Health Consumers' Council prize pack. We also have 5 runner-up prizes to give away.

ONE (1) MAJOR PRIZE OF A GIFT PACK INCLUDING:

- » Health Consumers' Council mug
- » Notebook
- » Onya reusable produce bags
- » Silicone drinking straws
- » Vegan food wraps
- » Health Consumers' Council branded stationery

FIVE (5) RUNNER-UP PRIZES:

- » Health Consumers' Council mug

**Survey closes 15 May 2020, and winners will be announced shortly thereafter. Prizes can be picked up from HCC premises, or sent via post within Australia. Prizes cannot be exchanged or redeemed for cash.*

www.surveymonkey.com/r/HCCcomms

The art of compassion

Listening with empathy to guide treatment

DR ANDREW LEECH FRACGP MBBS BSC DCH

How do patients like to be understood and treated when they see a medical professional?

We are generally taught, as doctors, that taking a good history about symptoms, performing a physical examination, and offering evidence based, relevant treatment, makes a good doctor.

I now realise that medicine is a true blend of art amongst all the science. The balancing act between really understanding the patient as well as treating them is not an easy one. Medical schools are trying harder to teach this concept, but it comes with time, experience and feedback from your peers and from patients themselves.

The skill of understanding the person as a whole, and not just for their presenting complaint, probably takes a lifetime to master. We are complicated beings with many facets to what drives us. We depend on countless external and internal stimuli to function and thrive.

Despite all this, I have learnt that there are some beneficial skills that give patients hope, even when it may appear that all hope is lost. Active listening is a good start, but listening with empathy, understanding and compassion helps us to not only grasp the problem and build a therapeutic relationship, it helps guide treatment.

Patients definitely open up more when they are faced with some level of kindness. These may not seem like skills as much as a core human emotion that we all have the ability to possess. But the problem is we are busy, and amongst chaotic days filled with challenges it can be mentally fatiguing being a doctor, and therefore the emotional side of medicine can be stripped away.



In 2019, Dr Andrew Leech was recognised for his commitment to patient-centred care as winner of the Health Consumer Excellence Award for Compassionate Care. Dr Leech is passionate about family health and the integral role of a GP, and believes GPs are in a unique position to offer support to patients. Here, he talks about the art of compassion in healthcare.

I often feel we owe more than just our attention to patients. The Latin origin of the word doctor is 'to teach', and this rings true as we try to help educate our patients on the human body and why something might be changing for them. I think doctors can get caught up using quite funny language. We forget that this makes little sense. I am often caught out with this, only the other day the patient looked puzzled when I said they had a 'carotid stenosis'. Part of the art of medicine is in the communication and wording of how we educate, therefore it may take different words to get a point across, diagrams, handouts, even seminars or workshops, online resources and social media.

Patients are becoming increasingly 'educated' in this era of information technology. I feel my role in this is to weave through the information and present the most logical, evidence-based solution. Adding compassion to this discussion means patients often feel 'you get them', or at least that you're listening. We may not have all the answers, but if we walk this journey together then life might be just a little bit easier.



Nothing about us without us

Embedding the patient voice in health and medical research

'Nothing about us without us', encapsulates a critical part of the wheel that has often been overlooked in health care, not only in disability services but across the wider health system.

Yet times they are a-changin', and awareness is growing that without the patient and community voice, the wheels will limp along or grind to a halt – causing considerable waste and delays.

Most health and medical researchers and clinicians wholeheartedly agree that the patient voice plays an important role in designing healthcare and reforming policy; but how do we help to make sure patient and community engagement is meaningful for both parties?

Our voices are the voices of patients, family members, carers and all of us who one day may face a disease or injury. Our experiences of disease and illness are the oil that keep the wheel turning. So how do we ensure our voices are engaged at all stages of our health models? How do we bring this significant spoke to the very beginning stages of health policy to drive better and faster translation from bench to bedside?

One answer is through the Consumer and Community Health Research Network (CCHR), who are working to embed our voices in the very early stages of research development.

CCHR champion the consumer and community voice in health research across Western Australia.

"Our work directly connects the community with health and medical researchers," says Deb Langridge, Head of CCHR.

"The intersection of patient experience and lived experience happens when community members share their experiences with researchers to impact and improve research processes.

"This engagement can only add value and influence the final translation of research into patient care for generations to come."

CONSUMER AND COMMUNITY HEALTH RESEARCH NETWORK

As part of the Western Australian Health Translation Network (WAHTN), CCHR works closely with each of their partner institutions to advise researchers on how to create meaningful partnerships with community. They run events, seminars and workshops as well as a matching service that works across the entirety of the health and medical research cycle.

"We've found that engaging researchers is easiest when we make ourselves part of their habitat," says Deb.

"Our Consumer and Community Involvement Coordinators are therefore based at our partner institutions to help drive these collaborations."

A recent collaboration the team at CCHR has been involved with is an evaluation study of the St John WA Urgent Care Centres – three of which are currently operating in metropolitan Perth. Part of the evaluation is consulting with Community on how the centres are currently meeting the needs of Community. The St John WA team have been tasked with investigating how the Centres are currently meeting the needs of patients and where improvements could be made. Four new Centres have been proposed and consulting the patients who use the service is vital to ensure the new Centres meet the needs of Community.

If you would like to know more about the work the Consumer and Community Health Research Network do, you can visit the CCHR website at www.involvingpeopleinresearch.org.au

You can also get in touch with CCHR via one of their social media platforms, phone them on (08) 6151 1071, or email admin@involvingpeopleinresearch.org.au



A new plan for cancer care in WA

SUSANNAH MORRIS,
CONSUMER REPRESENTATIVE

In February 2020 on World Cancer Day, the state government released the WA Cancer Plan 2020-2025, a blueprint for the next five years for cancer services for Western Australians.

"We are looking to create a well-co-ordinated, high-standard, consumer-focused cancer care system which includes prevention, screening, early detection, treatment, survivorship, palliative and supportive care and research"

HEALTH MINISTER ROGER

Susannah Morris, a consumer representative on the advisory group for this plan, presented a powerful speech at the launch, talking about what the plan means for those who have, or will be diagnosed, with cancer. She shares an abridged version of this speech below.

As one person I cannot embody all the nuances of the experiences of those affected by cancer in WA. However, there is commonality at the core of every patient's experience of cancer: none of us "plan" to have cancer!

It is a major life event we don't study for, save for, make arrangements in advance for, and we certainly don't aspire to it. But it can affect us all, regardless of gender, age, race, education, income, geography or any of the socio-economic indicators frequently used to describe us.

In 2016 I was that person diagnosed with cancer: the person without a plan; the person not believing it was happening to them.

I am now in my fourth year of a treatment pathway through surgery, chemotherapy, radiotherapy, endocrine therapy, and recently, more surgery. I have traversed between the public and private systems, the primary, tertiary, and the not-for-profit health and supportive-care sectors. My needs have been addressed by surgical oncologists, radiological oncologists, medical oncologists, pathologists, immunologists, infectious diseases specialists, anaesthetists, nurses, physiotherapists, occupational therapists, radiologists, sonographers, psychologists, plastic surgeons, dieticians, and GPs.

My case is not unusual: getting well and living well after a cancer diagnosis takes a lot of care. That care costs a lot both to the public purse and to private individuals and their families, financially, practically and emotionally. That care requires continuity and coordination: that care requires a plan. We cannot plan for care without working with the people that it is for.

Since 2016, I have become an advocate for, and representative of, others with cancer. It is my honour and privilege to be the Health Consumers' Council of WA's consumer representative on the Advisory Group to this Cancer Plan.

My role has been to draw on general experiences and themes that emerged from the consumer engagement to help the consumer voice be heard in the development of the Plan. I have been heartened and impressed by the Advisory Group's recognition of the importance of that voice.

So, what does this plan mean for those affected by cancer in WA? Whatever your interest in the plan, please take the time to look at cancer care through a consumer lens. Think, what would a cancer diagnosis mean for you, and, how will this plan help?

For many of us, the good news is a cancer diagnosis does not mean the end. Major advances in life expectancy mean we need to think about living with cancer and the effects of our treatment, not simply dying of cancer, our initial gut fear. The outcome measure of our care is therefore not simply about our quantity of life but our quality of life through treatment and beyond: that depends on the care pathway we traverse.

From the moment of diagnosis, when we are at our most vulnerable, those affected by cancer face huge challenges navigating information regarding diagnosis, treatment and prognosis.

Before diagnosis, many view the health system as a single service in the landscape of our lives, there if needed, but hopefully not visited too often. After diagnoses, however, consumers find the health system far more complicated. Cancer is not one thing, nor are there single treatment options.

We may need to choose between different care pathways regarding where and how we are treated. We may need to know whether alternate avenues offer different experiences and outcomes, physically, psychologically and, all too often, financially, through unanticipated costs or earnings forgone.

So, from diagnosis on, information is key to consumer experience. We may be young or old, geographically, ethnically and/or linguistically diverse, endowed with different resources or facing multiple socio-economic challenges in our lives. Regardless of our differences, however, few of us would choose to venture forth into new territory with blindfolds on, without a guide, map or journey plan.

That is why the Cancer Plan matters to consumers. It's not just a document to inform the actions of health planners and providers. It's a resource to help and empower us navigate the care pathway we will traverse and the information we may need when choosing forks in the road.

Consumers need a plan that recognises our needs and perspectives may differ from those of providers. We see ourselves as whole people diagnosed with potentially life-threatening conditions, needing treatment and help to navigate through to the longest and best-quality life we can have. We need a plan for our care in its entirety, not a series of separate plans and bottom lines for each provider.

We want a coordinated and continuous care pathway to meet our needs holistically, with information about our case moving with us. We may need ongoing medical, psychosocial and supportive care beyond

the cessation of the acute treatment phase of surgery, chemotherapy and radiotherapy. In the medium to long-term we may be living, and, alas for some, dying with chronic conditions as a result of our cancer, its treatment and its side-effects.

Minimising the burden of cancer for individuals and the community requires partnership and information flows: not just between different providers in the health system but between providers and consumers, and, that information needs to flow both ways.

We need to recognise where consumer and provider perspectives on care may differ. Consumers could be treated in the recommended time-frame, recurrence risks reduced and life expectancy increased: for the provider an apparent success story. Yet, the consumer may feel lost in an unending saga of physical or cognitive impairment resulting from their treatment. Consumer reported experience and outcome measures (PREMs and PROMs) can therefore capture these different perspectives and help identify the impact of healthcare interventions on people's lives.

I would, therefore, like to thank Minister Cook and the Department of Health for the Cancer Plan and Sustainable Health Review which have committed to transparent and public reporting of Patient Reported Experience Measures (PREMS) and Patient Reported Outcomes Measures (PROMS). These will inform providers making improvements to future provision whilst assisting those affected by cancer to live well.

For those of you that have been, or will be, diagnosed with cancer I hope you can take heart about all that is good in WA cancer care: where there are areas that need improvement your voice has been, and will continue to be, heard.

“None of us “PLAN” to have cancer!” SUSANNAH MORRIS





Finding support during a life-changing experience

What it's like to have rare cancer as a teen

Tilly Gorce was 18 years old when she was diagnosed with a rare, aggressive cancer. To mark Patient Experience Week and the release of the WA Cancer Plan 2020-2025, Tilly shared her experience with us.

When did you first notice a change in your health, and what was your journey to cancer diagnosis like?

In 2013 during my last year of school I noticed a small lump forming in my left ring finger. It didn't really bother me that much, but by 2014 the lump had got quite a lot bigger and my mum said I should get it checked out.

After an x-ray, an ultrasound and finally an MRI, a surgeon concluded he would need to operate to check out the lump properly. The biopsy surgery took place on 1 October and the surgeon explained that he didn't like the look of the lump and could only remove part of it so it could be biopsied. It was then that I started to feel worried.

I went to see the surgeon about a week later to have my stitches removed and he told me that if the initial pathology results were confirmed it was possible that I would need my finger removed, and possibly part of my hand.

On 22 October we got a call to see the surgeon and my worst fear came true. The pathology had confirmed that the lump was an epithelioid sarcoma, a rare, aggressive, malignant tumour and the only treatment was a radical amputation.

I was in a complete state of shock. It was a complete blur and I just couldn't make sense of the situation. I felt just completely overwhelmed and consumed by the fact my life had been turned completely upside down.

What was it like as a young person going through the healthcare system? What support did you have during this time?

I felt bewildered most of the time so thankfully my parents were there to support me and talk to the doctors on my behalf because I had no idea what I should be asking or what to expect.

I remember talking to one health professional about support organisations and I was told that there were lots of them but it was only a finger that I was going to be losing so I should just put it behind me and get on with my life. I was so upset to be told this and my mum who was there at the time just couldn't believe it either.

My GP and surgeon were wonderful during the whole ordeal. They both attended the State Sarcoma Service meetings to hear my case being discussed and were both very supportive in providing feedback about what would happen next.

The day for my surgery was set and I knew I had to find a way to get through it, so I organised a 'farewell to finger' party with some of my close friends and family. We organised finger food, a finger painter (she painted everyone's left ring finger in support of me losing mine!) and a finger tree where people put the imprint of their left ring finger on the tree to look like leaves.

The fateful day finally arrived, and I just felt numb, thinking that the 11th of November would be a day that I would always remember.

One thing I really appreciated that day was how amazing the staff were at the hospital where my amputation was performed. They took such good care of me on what was one of the most difficult days of my life.

What was recovery like for you?

The first two weeks after the amputation were lonely and isolating. I was at home on the couch most of the time with only my family for support. So my parents said that I really should contact CanTeen to see how they could support me, despite being initially discouraged by a health professional. That was the best thing I ever did.

The relief talking to a CanTeen counsellor was enormous and I haven't looked back since. I've connected with some amazing young people who were also living through cancer experiences and this immediately made me feel less alone and more like I could get through what was such a life-changing event.

You've said before that cancer is different in a young person's world. Can you share more about this?

I think given my age at the time of diagnosis, I really had no idea how to navigate the health system all by myself. You really need an advocate to help you and, in my case, it was my parents and then CanTeen helped me gain an understanding of how to speak up for myself and my health care needs.

Young people experiencing cancer are also going through all sorts of other things in their lives and can sometimes feel vulnerable so being with people your own age, who you can relate to, is so important and comforting.

Why did you decide to speak out to help raise awareness of young Australians affected by cancer?

As a Youth Ambassador for CanTeen I feel it is important to speak out about how cancer affects your life. Whether it's trying to finish a study course, getting back into the workforce, becoming independent, keeping up financially when you can't work because of treatment or recovery... these are all very real issues that are going in a young person's life and emotional and practical support are essential to help you get back on your feet.

When the opportunity came up via CanTeen to tell my story as part of the WA Cancer Plan 2020-2025, I was so happy to do so, not because of what I have experienced but because it was an opportunity to represent so many other young people who have had to get through life after cancer has come knocking at their door. No one plans for cancer, especially not young people, therefore it's important to raise awareness so young people know that there is support out there if they need it. It's also essential that health services are well equipped to consider the way a cancer experience may be affecting a younger patient.

What does life look like now, post-cancer?

I'm very pleased to say that I am now five years cancer free and feeling great about my life. When I was studying at school, I had no real clear idea about where I was heading and strangely enough getting cancer helped me focus on a totally unexpected career path. I'm studying laboratory medicine and hope to one day carry out research in the area of sarcoma. I'll be in quite a unique position having been a cancer patient and will be able to work from both a researcher and patient perspective which I feel is a real advantage and I feel really humbled to do so.

I can safely say that I have found my new normal thanks to all the support and opportunities provided by CanTeen. I'm actually proud of my hand now and don't mind showing it to the world – it's a cancer-free hand!

Strengthening the voice of culturally and linguistically diverse people



At the start of the year, Nadeen Laljee-Curran joined our engagement team as Cultural Diversity Engagement Coordinator.

Nadeen initially came to HCC in 2017 as a Master of Public Health student volunteer and she has now returned as the Cultural Diversity Engagement Coordinator with the Engagement team. Her personal experience with her own health and the health system has made her passionate about patient centred healthcare, health literacy and patients understanding and managing (where possible) their own healthcare. Nadeen had a corporate career before she decided to study public health and pursue her passion and what she considered to be a more meaningful career.

Nadeen has a Bachelor of Science from Cardiff University and a Master of Public Health from the University of Western Australia. Nadeen was born in the UK to Indian parents who had migrated to the UK from Africa. She considers herself Indian, English and Australian and is conscious of some of the issues around migration, resettlement, culture and belonging. She is keen to do what she can to help migrants to understand their rights and fully benefit from health services.

Through her new role, Nadeen aims to strengthen the voice of people from culturally and linguistically diverse backgrounds living in WA. She will be facilitating workshops for these communities as well as working with service providers on cultural sensitivity in health.

Culturally and Linguistically Diverse Community Panel

One of the projects Nadeen is keen to grow is the Culturally and Linguistically Diverse Community Panel. We recognise that the voice of Culturally and Linguistically Diverse people is often left unheard and that there is, particularly in certain areas, a poor uptake of health services. To help address this, we're planning to trial a new approach for HCC. We'd like to establish a Culturally and Linguistically Diverse Consumer Panel.

This will be an informal group for individuals who are happy to receive information about consumer

representative opportunities. We may also sometimes bring people together to hear about people's lived experience and that of their communities when accessing health services.

Community members on this panel will be contacted when we have opportunities that may be of interest, for example when we are asked to

collect feedback on particular health services and/or plans and policies.

Community members might receive invitations to consultations or surveys, to be part of working groups and committees in healthcare or invitations to provide input and feedback on our projects and activities targeted to assist those from culturally and linguistically diverse backgrounds.

Join our CaLD Panel

SIGN UP ONLINE AT

<https://mailchi.mp/hconc/calddpanel>



Health literacy

Something else the team has been thinking about is health literacy for the CaLD community. Health literacy is about how people understand information about health and health care, and how they apply that information to their lives, use it to make decisions, and act on it.

We're interested to find out how people from diverse communities understand and process health information and how they use this information to make decisions or act for their own healthcare or that of family and community members.

If English literacy is the first hurdle, then where do people stand in terms of trying to integrate resources and concepts about health, and do they have the required vocabulary and knowledge of our state's health system?

Health Consumers' Council, as well as a number of other wonderful not for profit organisations, are available to help. But we need to know if we're addressing the right topics and how many people we're reaching. Are there enough resources available for CaLD people that explain the health system? If not, is there a gap we can fill?

If you are a CaLD community member, or an organisation working with CaLD communities, and you would like to give your opinion on what resources you use and/or where the gaps are, we would love to hear from you – please go online to answer this short survey: www.surveymonkey.com/r/CaLDhealthlit

“When I arrived in Australia from the UK, I confidently booked a GP appointment. After all I had a Medicare card (due a reciprocal agreement between the UK and Australia) and English is my first language, so I didn't have to worry about asking for a translator. I went ahead and saw the GP and when I was done, I walked out of the surgery. The receptionist chased me into the street – I hadn't paid! But I didn't know I had to pay, because I thought it was covered by Medicare. In the UK when we are done with the doctor we don't need to back to reception, we are done as it is all free. I was so embarrassed.”

NADEEN, CULTURAL DIVERSITY
ENGAGEMENT COORDINATOR

Partners in Change - Healthy Weight Action Plan

Since 2018, Health Consumers' Council has been working in partnership with the Department of Health and the WA Primary Health Alliance (WAPHA) to ensure the consumer voice is front and centre of policy and service planning in the area of overweight and obesity.

After months of work, including a consumer survey, focus groups and community conversations – as well as forums involving health professionals, policy makers and other staff, the Minister for Health launched the WA Healthy Weight Action Plan 2019-2024 on Tuesday 26 November 2019. It's available at https://ww2.health.wa.gov.au/Articles/U_Z/WA-Healthy-Weight-Action-Plan

Currently, approximately 67% of the WA adult population lives with obesity or overweight. The impacts of overweight and obesity are many and varied and people experience them differently – differently from each other and differently at different points in their lives. Many people live with overweight and obesity quite happily. Many others have struggled with their weight for years and describe a sense of resignation that anything will ever work in their efforts to manage their weight. Others again have had positive experiences in taking action to manage their weight, describing success in their efforts.

The Plan includes strategies for action over the next five years to tackle the complex causes of overweight and obesity and aims to drive long-term change across WA. In his statement launching the plan, the Minister stated that the goal is for WA to become the State with the highest percentage of population with a healthy weight in **ten years**.

Since the Minister launched the Action Plan, HCC staff have been meeting with the team at the Department of Health and WAPHA to discuss the ways in which the plan will be brought to life. The main focus of the discussions so far has been how the Obesity Collaborative (action 1.1) and the Community for Change (action 1.2) will work in practice.

HCC believes it is important that the conversations are informed by real experiences of people managing their weight.

On our website you can read a summary of consumer engagement activities, a presentation that Pip Brennan gave at the Obesity Forum in 2018, and watch two videos where consumers share their stories – <https://www.hconc.org.au/issues/partners-in-change-obesity-collaborative/>



A bold plan for change

HCC believes the Action Plan outlines a plan that is not “business as usual” for the health system. We are particularly interested in the inclusion of the actions that recognise a new way of working is needed to really impact on this complex health issue. We look forward to the establishment of the WA Obesity Collaborative and the Community of Change that will provide platforms for people with lived experience, health professionals and policy makers to work together to take positive action.

Aboriginal Health

From health rights, to health apps

In late 2019, we held two Health Rights sessions at Wadjuk Northside focusing on My Health Record.

The first session was for Elders, and it was interesting to learn that many carry a hard copy of their health records and care plans with them. It was also noted that the online nature of My Health Record was an issue, with limited access to internet and computers acting as a barrier for many.

A second session, held with a Mums and Bubs group, showed a higher acceptance of My Health Record, with less concerns around security and more ability to readily access the records online.

This started some good conversations about not only the importance of health records, but the different ways people keep and share their information.

The past couple of weeks have seen the cancellation and postponement of many of the events which showcase the excellence and innovation shown by Aboriginal health sector. One of those events was the annual WA Aboriginal Community Controlled Health Sector Conference – Healthy Country, Healthy Communities and the Youth Conference, which are hosted by the Aboriginal Health Council of WA. This decision, like so many now, was made due to the rapidly evolving COVID-19 situation in Australia. While it is disappointing to not have the opportunity to attend this year, the health and safety of Aboriginal consumers, workers and all our communities is the highest priority and we will all be looking forward to these events next year.

In March Prime Minister Scott Morrison handed down the 2020 Closing the Gap Report. It was, in his words “stark and sobering”, with only two of the seven targets being on track to be met this year. It was also the last Closing the Gap Report under the old agreement, with a new agreement being developed in partnership by the Council of Australian Governments (COAG) and the Coalition of Peaks, who represent more than 50 Aboriginal and Torres Strait Islander groups. Pat Turner, CEO of the National Aboriginal Community Controlled Health Organisation, expressed her hope that future reports would be a cause for celebration.

In February we partnered with WA Health to host a couple of consumer workshops focused on their experiences of giving feedback to the Health Service Providers. We had around 18 Aboriginal consumers attend a 3 hour workshop where we talked about some of the barriers to giving feedback, what makes that process easier, what works well and what needs to be done to encourage Aboriginal consumers to let the services know about their experience. The feedback from the workshop is now with WA Health, and we look forward to sharing that information with WA health consumers when it becomes available. And we thank all the consumers who gave up their valuable time and so willingly shared their stories with us.

WA Health is currently trialling their Manage My Care app. This app is currently being used in Fiona Stanley Hospital and Royal Perth Hospital, and is designed for outpatient appointments and referrals.

An Aboriginal consumer shared the following feedback on the app:

“My daughter used RPH a lot and I find the app really useful. It doesn't have her clinics on it yet, so I can't change the appointments, but I can see all her upcoming appointments for the next month and all her past appointments for this year. I can also see all her referrals on it. What I also like is that we can add our own notes under each appointment so that we don't have to remember these things when we go back to our GP. It's really good to have a record and not have to remember when we last saw a specialist.”

THE APP CAN BE DOWNLOADED FROM THE **APP STORE** OR **GOOGLE PLAY**. YOU CAN ALSO GO AND HAVE A LOOK AT THE **MANAGE MY CARE WEBSITE** FOR FURTHER INFORMATION.

https://healthywa.wa.gov.au/Articles/J_M/Manage-my-care

More than just bad period pain

A changing tide for the treatment of endometriosis

RACHEL SEELEY

Most people are shocked or in disbelief when they get diagnosed with a serious illness. But for me, being diagnosed with endometriosis when I was 23 was a huge relief, because I could finally put a name to the awful, painful thing inside me.

Endometriosis is a chronic disease where cells similar to those that line the uterus (the endometrium) are found in other parts of the body. There is no known cure for endometriosis and the cause is unknown, but it affects 1 in 10 women, girls and trans men. Symptoms can vary greatly but include pelvic and lower back pain (not just during the menstrual cycle), bladder and bowel problems, nausea, bloating, fatigue, and heavy, painful periods.

For many reasons, including the common misconception that period pain is normal and a lack of understanding of the disease all the way from the community through to the health system, it takes an average of seven to twelve years to get a diagnosis.

When I was in school, I absolutely dreaded getting my period. I was plagued with pain the week before, during, and the week after every period, bleeding for ten days every couple of weeks. I dropped out of swimming lessons, I tried to avoid sleepovers, I bled through my night-time uniform of two pads, two pairs of underwear, boxer shorts, pyjama pants and a towel, and I took so many sick days the school became concerned.

ENDOMETRIOSIS

two types of surgery

★ Always remember to speak with your surgeon about what makes sense for you, your body, and your specific case.

ABLATION LIKE SLASH-AND-BURN		vs	EXCISION LIKE A TROWEL	
<p>Burning or vaporizing endometriosis at the surface with a laser or heat gun, leaving roots and other scar tissue behind.</p> <p>Can cause additional scarring and allow lesions to grow back, similar to how slash-and-burn can damage the land and only temporarily clear brush.</p> 			<p>Physically cutting out endometriosis lesions at the root and not leaving the disease behind.</p> <p>Can be performed with surgical tools, a laser used as a knife, and robotic-assisted methods.</p> 	
<p>✓ PROS</p> <ul style="list-style-type: none"> Typically costs less, and is more likely to be covered by insurance Shorter recovery time Provides short-term relief Less invasive More surgeons trained in ablation 	<p>✗ CONS</p> <ul style="list-style-type: none"> High rates (40%-60%) of recurrence 1-2 years after surgery Underlying endometriosis and scar tissue not treated Higher and earlier recurrence rates of endometriomas Higher potential for complications & pain Higher risk of heat damaging underlying tissue or organs Burning means no specimens for pathological diagnosis 		<p>✓ PROS</p> <ul style="list-style-type: none"> Long-term relief rates in skilled surgeons as high as 75%-85% Ensures total removal of endometriosis detected by surgeon Allows for pathological diagnosis of tissue Significantly lower rates of endometrioma recurrence Higher precision means especially able to treat severe endometriosis 	<p>✗ CONS</p> <ul style="list-style-type: none"> Typically more expensive and less likely to be covered by insurance Even if 90% of disease is removed, complete remission not guaranteed More invasive Less doctors specialize in excision Recovery can be longer

Sources: The National Institute of Health, Endometriosis Australia, Center for Endometriosis Care

endographics.org
@endo_graphics

It took me around eight years to get a diagnosis, as I had been seeing doctors for these symptoms since I was 15. Being diagnosed was a relief, but I quickly realised how hard it was to find correct information on endometriosis. One doctor would tell me I might never be able to get pregnant, while another would say my fertility wouldn't be impacted at all. At the same time, I went online and was reading horrifying accounts of women experiencing horrendous pain and multiple surgeries, and became incredibly anxious about what my diagnosis actually meant. It was difficult to make sense of, and it was hard to find support outside of my family. If people didn't know anything about the disease, if doctors asked me how to spell it, and if my symptoms didn't fit neatly into a box, how was anyone going to help me? It was confusing and frustrating, and I can't count how often I was told by medical professionals that I was a mystery, that I was just sensitive, or that periods were just painful for some people. Many doctors' appointments ended with me sobbing to my mum on the phone because I'd been told there was nothing they could do for me.

What's worse is that I came to believe this, and thought I had to just live with the pain. I feared more surgeries (I had a second laparoscopy a year after diagnosis), more painful physical examinations, and more uncomfortable scans that didn't show anything abnormal anyway. By age 28 I'd tried a dozen different medications all meant to stop the endometriosis from returning – instead, they gave me acne, headaches, weight gain, night sweats, night terrors, mood changes, more bleeding, and a cyst in my breast, and the endometriosis returned anyway.

For years I didn't bother mentioning it to doctors when I was seeing them for something unrelated – I knew I'd either have to explain to them what endometriosis was or, even more frustratingly, be told by a GP during a consult for a flu, or by a nurse during a blood test for low iron, that getting pregnant would clear it right up. Just to be clear, that's a myth.

In 2016, when I could no longer ignore that I was having the same symptoms again, I joined a local support group and learned a lot about treatment options and specialists, and finally it seemed like this disease made sense. I was no longer a mystery – in fact, many of my symptoms were common among the members of the group, even if they baffled doctors.

I had my third surgery for endometriosis at age 32, but this time I was confident about the outcome. I saw one of the very few endometriosis specialists in Perth, and I had expert excision, which is considered the gold standard of treatment. This time, instead of just burning the endometriosis they could see on the surface of my organs, they completely removed the disease from my pelvic side walls, uterosacral ligaments and around my ureter, and detached my ovary from where it had become tethered.

I was also diagnosed with adenomyosis, which is known as the sister disease of endometriosis, and is when the lining of the uterus (endometrium) grows into the muscle walls of the uterus. The only cure for adenomyosis is to remove the uterus (hysterectomy), and there is very little in the way of treatment options for it.

Even after this surgery and more than a year spent seeing a pelvic physiotherapist, I know pelvic pain will be something I'll face for much of my life, whether it be because of the adenomyosis, because the endometriosis could possibly return, from ruptured cysts on my ovaries, or from overactive pelvic floor muscles that have become sensitive to pain. But these thoughts no longer terrify me because I now feel confident about my ability to choose the best treatment options and I trust myself to make decisions for my own health.

In 2018 the government launched the National Action Plan for Endometriosis and admitted there are many myths surrounding endometriosis and its treatment, and that this misinformation continues to be delivered by both healthcare professionals and the general public. Together with a public apology from the health minister, this felt like a huge win.

Because what has become incredibly clear to me is that people with endometriosis face huge deficiencies in care. We can't blame any individual health care provider for that, but we do need support to change an inadequate system that tells people pain is normal, that offers us outdated drugs that only mask symptoms, and that offers surgical treatment that is substandard or incomplete. I know there are many theories about causes and treatments, but I am convinced now that a doctor who spends most of their days delivering babies shouldn't be in charge of removing diseased tissues from bladders, bowels, ovaries, and anywhere else that endometriosis occurs. Women with endometriosis shouldn't have surgeries where the doctor removes "as much as they can", they should have access to specialists who can remove the disease in its entirety.

I don't know what's next from here, but I do know we're on the brink of major changes in the way people with endometriosis are cared for. And it will be our voices and the choices we make for our own treatment that will pave the path for this change.

IF YOU'RE IN PERTH AND ARE LOOKING FOR SUPPORT FROM OTHERS WITH ENDOMETRIOSIS, VISIT

www.endoperthsisters.com



Listening and respect

People with intellectual disability share what they want from the health system

The patient experience can be very different for people with disability. This became increasingly clear during the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, which is examining issues relating to the health care of disabled people.

At the time of writing the Royal Commission was still ongoing and a report had not been presented. In the first days of the public hearing, the Commission heard the harrowing and devastating stories of the experiences of people with disability in our healthcare system.

The Commission heard shocking statistics on the rate of preventable deaths of Australians with intellectual disability (38% of deaths, more than double that of the general population). The hearing was also a chance for people with intellectual disability to share what they want and need from the health system.

The common themes were respect, and listening to what the patient wants — two things that should go hand-in-hand with good healthcare but often become barriers for those with differing communication needs.

The Council for Intellectual Disability wrote about the public hearing, and highlighted several personal experiences:

“Tara Elliffe is a member of CID and also works at the NSW Ombudsman. Tara told the Commissioners how doctors should communicate with people with intellectual disability. They should listen carefully, use simple words and pictures and easy read. They should talk to the person not their parents. Tara concluded, ‘just listen to us!’”

“Day six of the hearing started with Jacquie Mills from Perth telling the Royal Commissioners about issues for people who have complex communication needs, such as her son. Jacquie has been able to develop her son’s communication over time so that he can now indicate where he feels pain and answer questions on his iPad. But doctors have spoken about her son in front of him as if he didn’t have a life of his choosing. Doctors need training in working with people with complex communication needs.”

“As with other parents who have given evidence, Jacquie emphasised the challenges families can face in navigating the health system. Advocacy support can make all the difference.”

At the time of printing, there were no planned public hearings for WA. However, submissions can be made via <https://disability.royalcommission.gov.au/share-your-story>

Resources There are resources available to help people with disability get the support they need when accessing healthcare.

The Council of Intellectual Disability has Easy Read information about seeing a doctor, going to hospital, medications, and mental health. They are available at <https://cid.org.au/resource-category/health/>

The Council of Intellectual Disability’s My Health Matters folder can help people with disability explain to doctors and other health people what is important to them. My Health Matters is an Easy Read folder, made by people with intellectual disability for people with disability. The folder helps people with disability communicate in a way that suits them. It lets doctors know if they prefer to use an app, picture board, sign language or their voice to communicate. The Health Matters Folder is available at <https://cid.org.au/resource/my-health-matters-folder/>

Health Consumers’ Council and People With disabilities WA have booklets and videos to help people with disability access health care. They cover topics like rights, ideas for getting better care, where to go for help, medical records and information sharing, and navigating the health system. These are available at <https://www.hconc.org.au/issues/empowering-consumers-with-a-disability/>

Updates

National Goals of Care – My Health Record and Advance Care Planning

We've been involved in looking at how to get more people using My Health Record for Advance Care Planning (ACP). As well as being involved in committees, Pip Brennan has been appointed as the co-chair of the National Goals of Care Collaborative. This national piece of work is being headed by WA. A key point of interest from a consumer perspective, is that this project considers Advance Care Plans, Goals of Care, and consumer values statements as key end of life documents to have on a central repository such as My Health Record.

In February we held an event with Palliative Care WA and Carers WA to inform and educate people about advance care planning, goals of care and how to upload Advance Care Plans and other documents into My Health Record.

My Baby WA app

Over the last few months we've been hard at work partnering on an app to support informed maternity choices. We're excited to now be able to share that the app will launch in April, under the name My Baby WA.

My Baby WA is for all WA women and families, and has been developed in partnership with the WA Country Health Service. It will help you find WA-specific information on pregnancy, birth and early parenting; maternity service provision including finding services close to you; a pregnancy timeline of recommended appointments, screening and reminders; and a baby bump photo gallery.

Providing consumer feedback to health services

During February, we hosted several workshops to look at the consumer experience in providing feedback to health services, including making complaints. We looked at how feedback is collected, provided, and used for improving health services.

The sessions revealed that many people are unclear on the process for providing feedback and concerned about the impact their complaint may have on them, particularly in small country towns. We also held discussions around the reliance on written feedback which can exclude some people, and positive cases of providing feedback which were described as empathetic and responsive.

These sessions were commissioned by the Patient Safety Surveillance Unit at the Department of Health and the department is in the process of collating the feedback which will be used to inform how they collect and use consumer feedback and complaints in future.

Sustainable Health Review

On 28 February 2020 Pip Brennan was invited to be Co-Lead on Recommendation Four “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”. The other Lead will be Ryan Sengara, who some will recall was the Secretariat Lead for the Sustainable Health review. The Co-Leads will drive the implementation with the Executive Sponsor, Nicole O’Keefe, Assistant Director General, Strategy & Governance Division of the WA Department of Health. Pip will be the first external partner co-lead – an important step in mobilising the implementation of the Sustainable Health Review.



Pelvic Mesh

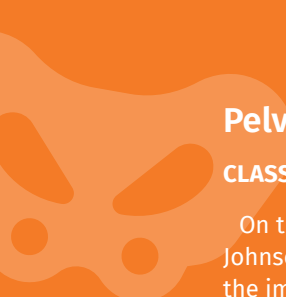
CLASS ACTION

On the 21 November 2019, Federal Court Judge Anna Katzmann delivered her decision on the Johnson & Johnson Class Action in relation to mesh and tape implants. She determined that the implants were “not fit for purpose or of merchantable quality” and further that Johnson & Johnson and their manufacturers Ethicon Sàrl and Ethicon, Inc. were negligent and driven by “commercial opportunities”. This has been a very long time coming, having begun on 4 July 2017 and become the largest women’s health action in Australian history. You can read more here on the website of Shine Lawyers, who filed the class action: <https://www.shine.com.au/service/class-actions/johnson-johnson-ethicon-class-action/qld-wa>

WA PELVIC MESH COMPLICATIONS CLINIC

On 17 December 2019, a Ministerial Roundtable was held to continue to progress the implementation of the Recommendations from the Senate Inquiry into pelvic mesh. A key commitment was a new approach to the King Edward Memorial Hospital Mesh Clinic, and the first meeting was held on 17 February. This is an ongoing key priority for HCC, recognising there are emerging concerns with many implants, such as Essure contraceptive devices, textured breast implants, hernia mesh implants and many more. What is particularly complex and distressing in relation to pelvic mesh is the difficulty in fully removing the mesh once implanted, and the difficulty for women accessing the care they need. The WA Pelvic Mesh Support Group continues to be a key partner with the King Edward Memorial Hospital Community Advisory Committee, to keep the consumer front and centre of clinic planning.

You can find out more about the Clinic here: <https://www.kemh.health.wa.gov.au/-/media/Files/Hospitals/WNHS/For%20Patients%20and%20Visitors/Patient%20resources/422%20WNHS%20Pelvic%20mesh%20clinic%20flyer%20FINAL.pdf>



Dates for the Diary

PLEASE NOTE all dates are subject to change as the Coronavirus situation unfolds and we comply with government rules for health and safety. We are exploring online engagement options to ensure we can stay in touch and keep the consumer voice at the heart of our healthcare system. We will update you as we find out more.

Supporting Cultural Diversity in Healthcare Workshop

Thursday 30th April, 10am – 1pm (WA health service staff session)

Wednesday 24th June, 10.15am – 1pm (Open session)

To support health providers in delivering services that are equitable, Health Consumers' Council has developed this a workshop focused on providing culturally inclusive services that support patient-centred care.

The workshop will provide participants with the opportunity to:

- » Recognise potential barriers people may have in accessing health services
- » Increase understanding of cultural competency
- » Gain awareness of own culture and attitude towards cultural differences
- » Gain knowledge and sensitivity of different cultural practices
- » Develop strategies to deliver a culturally competent service
- » Develop ability to use cross-cultural skills

To find out more, visit <https://www.hconc.org.au/what-we-do/diversity-culture/supporting-cultural-diversity-ffs/> or contact Nadeen on nadeen@hconc.org.au or call 9221 3422

Consumer rep networking sessions

Please save the date for our upcoming networking sessions. More information will be available closer to the dates.

- » Tuesday 30th June, 10am – 12pm
- » Wednesday 23rd September, 1.30pm – 3.30pm
- » Friday 4th December, 10am – 12pm

To find out more, visit <https://www.hconc.org.au/what-we-do/diversity-culture/supporting-cultural-diversity-ffs/> or contact Nadeen on nadeen@hconc.org.au or call 9221 3422

Introduction to Consumer Representation

Wednesday 14th October, 10:15am – 2:15pm

This highly interactive 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

You can find out more at <https://www.hconc.org.au/consumer-representative-introductory-skills/>

Or register to attend at <https://www.eventbrite.com.au/e/introduction-to-consumer-representation-training-october-tickets-79486340785>

Advanced Consumer Representation

Thursday 22nd October, 10:15am – 2.15pm

This session is for consumer reps with at least 6 months experience on a working group, committee or Board, and will help you take your consumer representation skills to the next level.

You can find out more at <https://www.hconc.org.au/consumer-rep-advanced-skills/>

Or register to attend at <https://www.eventbrite.com.au/e/advanced-consumer-representation-training-october-tickets-79486659739>

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Opening hours

Monday - Friday 9.00am - 4.30pm
Closed Public Holidays



HEALTH CONSUMERS'
COUNCIL