

Health Matters

Health Consumers' Council (WA) Inc. Magazine
September 2017, Issue 2

Celebrating 25 years of commitment to Women's Health

Page 20

Senate Inquiry: Number of women in Australia who have had transvaginal mesh implants and related matters

Page 4

When you, or someone you love, is diagnosed with breast cancer

Page 6

Changes to our National Cervical Screening Program

Page 24



**Women's
Health**

Contents

Issue 2

- 3 Foreword
- 4 Senate Inquiry: Number of women in Australia who have had transvaginal mesh implants and related matters
- 6 Breast Cancer Network Australia (BCNA)
- 8 When Your Breast Cancer has Spread
- 8 Obituary: Vale Christina Lyall
- 9 Injury Control
- 10 Equitable Healthcare for Migrant and Refugee Women?
- 12 State News
- 14 Culture & Diversity and Consumer & Community Engagement Programs
- 17 The Pressing Issues in Women's Health
- 20 Ishar Multicultural Women's Health Centre
- 22 Annual General Meeting
- 23 Expressions of Interest
- 24 Upcoming changes to Australia's National Cervical Screening Program
- 26 BreastScreen WA informs women about their breast density



HEALTH CONSUMERS'
COUNCIL
YOUR VOICE ON HEALTH

Health Consumers' Council

GPO Box C134, Perth WA 6839

Phone (08) 9221 3422 **Fax** (08) 9221 5435 **Country Freecall** 1800 620 780

Email info@hconc.org.au **Web** www.hconc.org.au

ABN 87 841 350 116

Cover image: Stock

Foreword

Welcome to **Issue 2** of Health Matters.

This edition focuses on women's health and brings a range of important updates on topics, especially the pelvic mesh scandal which has been dominating the media news cycle for much of 2017.

There is plenty to report in both State and Federal news as the ongoing review of seemingly every piece of policy continues.

Lotterywest Grant

We were delighted to receive a Lotterywest Grant to upgrade our computers and continue developing our database. This development will include an integration with our website, which is also going to undergo a facelift. We also received funding for training for Staff and Board. I was lucky enough to attend the Cranlana Leadership Colloquium which brings together leaders from government, not for profit and corporate sectors to reflect on the morals and ethics of leadership.

Staff

This month has seen more comings and goings. We said farewell to Ashleigh Roccisano, who was working on engaging with country consumers and placed Aboriginal Advocate Tania Harris in this role to oversee the project completion. We have employed Kerrie Mocevic to support the advocacy team. Welcome, Kerrie!

Also on the move is Lucy Palermo who has decided to focus on her MBA studies full-time. Lucy has worked tirelessly over her four years at HCC to continue to raise HCC's profile through marketing and communications and we wish her all the best.

Caitlin Hausler initially started at HCC as a trainee and has now completed the Certificate III Business Administration. Caitlin is our Receptionist, the first face of HCC and we are delighted to have her stay on with us as a staff member.

Students and volunteers

HCC engages with students and volunteers often, and value their contribution to the organisation. Since our last edition we have welcomed Renee Jarrett, who has joined the Refugee and Humanitarian Entrant Health Research Allied project. Kaitlin Johnston has been working on Advocacy outcomes, Meagan Twyeffort has been collating information about women impacted by the urogynaecological mesh implants and Rodrigo Baratela has been working on our membership surveys.

Pip Brennan

Executive Director
Health Consumers' Council



Senate Inquiry

Senate Inquiry – Consumer Story

Carolyn Chisholm, Founder, Australian Pelvic Mesh Support Group. Winner of HCC's Consumer Excellence Health Consumer and Rosemary Caithness Awards, 2017.

The emotions come flooding back to me as I recall the first reply I received from Senator Derryn Hinch in response to my desperation to see him about the catastrophic injuries that pelvic mesh implants were inflicting on women. I had already written to The Minister for Health and the Minister for Women in March and August of 2016. I had a meeting with three other mesh injured women in May 2016 with the TGA, calling for a suspension on mesh, without success.

So I wrote on October the 3rd 2016 – “Hi Mr Hinch, I understand completely how your time is not your own anymore and it is difficult to find a time to meet with you. I'd like to explain my situation in the hope that we can meet this week. I am available all of this week. I can book a flight at the last minute. The women in my group have paid for my flight to see you. Is this week possible? I can fly to Melbourne tomorrow and fly back to Perth Wednesday. If we can't meet during your work hours can we meet outside of them? I only need an hour of your time. Sorry I sound desperate because I am. Regards Caz”

The relief I felt upon his immediate reply was overwhelming. Finally I was being heard, acknowledged and believed. He wrote back within 15 minutes.

“Caz I understand. Come overnight or tomorrow. I'll fit something in tomorrow. It is important. DH”

Little did I know from that moment in time, that this meeting with Derryn Hinch was going to change history. Within seven weeks, on the 22nd of November Hinch brought the mesh scandal to the Senate and stated that a Senate Inquiry was a must. A vote was passed in Parliament and in February this year Senator Hinch got the go ahead for a Senate Inquiry. What a man!

I spoke at the second public hearing which was held in Perth on the 25th August and it was the most cathartic release I have felt since I started this crusade 18 months ago.

My hope at the end of this Senate Inquiry is for the use of mesh to be suspended pending a thorough investigation including the process into how the products were approved for use, why the products were allowed to be marketed so aggressively by the manufacturers and why these devices were allowed to be implanted considering the injuries are so severe and life altering. Given the fact that full removal is near impossible, this alone should be reason to say “enough is enough”.

The Minister for Health has the responsibility to suspend these devices. The ball is now in his court.

You can listen to the full Perth Hearing on this link:

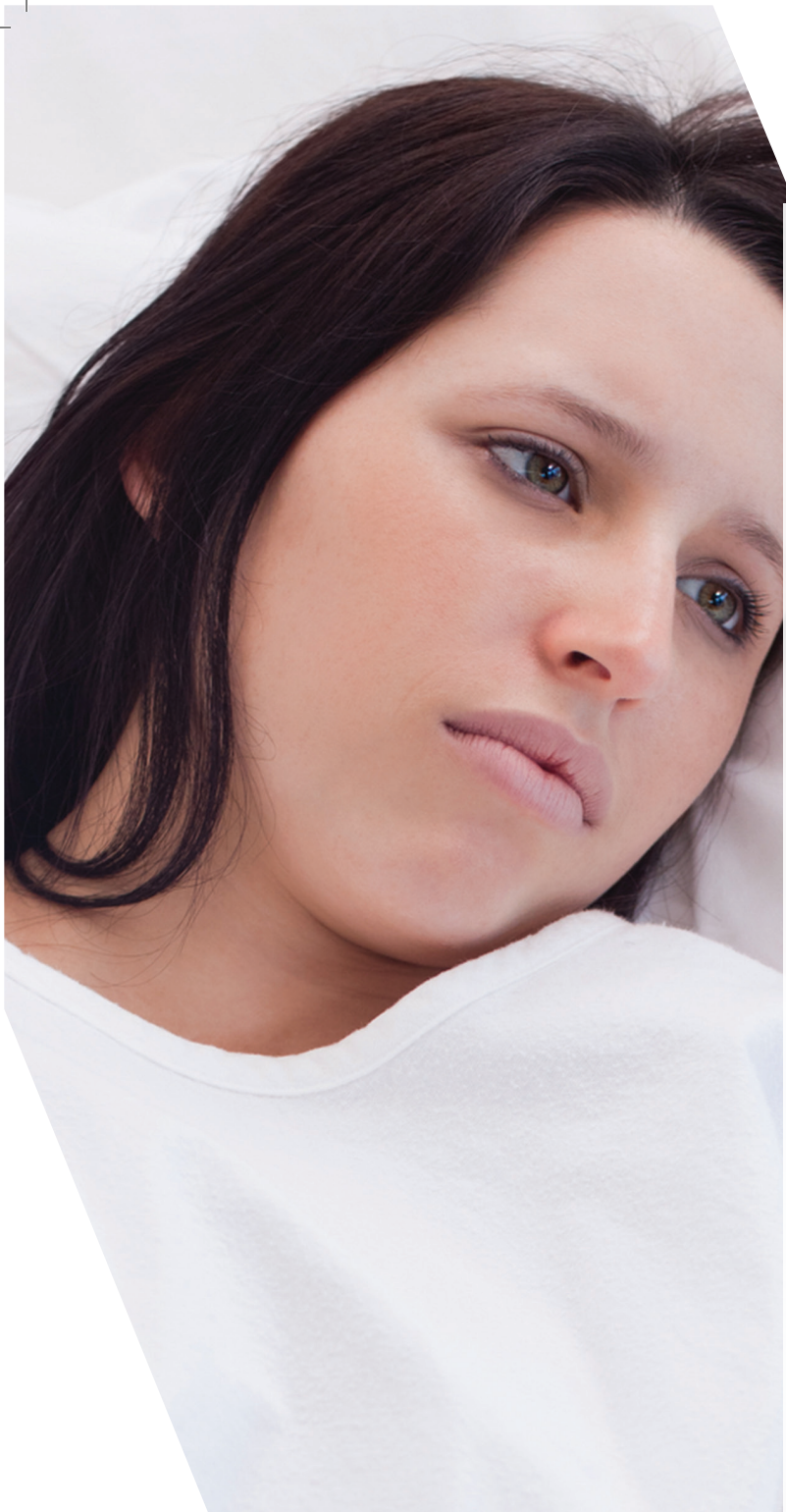
http://parlinfo.aph.gov.au/parlInfo/download/committees/commsen/23f63ceb-3e06-4bef-9e93-558e116dce87/toc_pdf/Community%20Affairs%20References%20;fileType=application%2Fpdf#search=%22committees/commsen/23f63ceb-3e06-4bef-9e93-558e116dce87/0000%22

Number of women in Australia who have had transvaginal mesh implants and related matters

Pip Brennan, Health Consumers' Council

You may have seen the significant amount of media coverage of this medical scandal which has unfolded over 2017.

Pelvic Mesh refers to polypropylene mesh implants to treat women treated for stress urinary incontinence or pelvic organ prolapse. Media coverage highlights the little known reality that when a pelvic mesh implant goes wrong, it can go badly wrong, with life-changing, permanent effects. This is of particular concern given that neither pelvic organ prolapse or stress urinary incontinence are life-threatening conditions. Complications can occur any time from straight



after surgery to years afterwards. The Therapeutic Goods Administration has recently updated the list of complications from the implants and these are listed on their website and HCC's webpage which is regularly updated. <http://www.hconc.org.au/services/policy-development/pelvic-mesh-consumer-update/>

In late 2016 I first met Caz Chisholm to discuss the appointment of a consumer representative on the Australian Commission of Safety and Quality in Healthcare's Reference group on the matter. I had heard about the issue through attending the semi-regular meetings of the Health Consumers' Councils across Australia. It is quite concerning to note that this came to our attention through a chance conversation between my Queensland counterpart and a mother at her daughter's school. My Queensland colleague elevated it to the relevant inter-jurisdictional committee and the ACSQHS convened the reference group.

There is only one complaint registered in our state's statutory health complaints body, despite hundreds of women having revision surgery after having mesh devices implanted. Over the months I have been involved in the project, it has gradually been revealed that WA is "ground zero" for the mesh scandal, with journalist Joanne McCarthy from Newcastle eventually uncovering the work done in the 1990s in WA by Dr Peter Petros (no longer a practising doctor) whose experiments formed the basis for the approval of mesh devices by the US's Food and Drug Administration, and later Australia's Therapeutic Goods Administration (TGA). AMA's Michael Gannon referred to the AMA's support of this work as "not their finest hour."

1800 Mesh Line - 1800 962 202

WA Health have created a 1800 number based at King Edward Memorial Hospital, answered from 8.30am to 4.00pm with a Message Bank for after hours or when the line is busy. The person answering the phone is not a doctor, nurse or midwife. The purpose of the 1800 Line is to gather information about women who have had mesh, whether or not they have had complications. Women will also be supported in obtaining their medical records and will be referred for medical follow up if required. HCC encourages you to ring if you have any concerns.



Caz, Derryn & Stella at the Senate Inquiry

Breast Cancer Network Australia

Di Treble, Breast Cancer Network Australia

When you, or someone you love, is diagnosed with breast cancer

A diagnosis of breast cancer comes as a shock. Unfortunately, breast cancer is very common – it is the most common cancer in Australian women.

The good news is that with early detection and improved treatment, survival rates in Australia are very high; more than 90 per cent of women diagnosed with early breast cancer are still alive five years later and most never have a recurrence of their breast cancer.

In the first days after a breast cancer diagnosis, everything can seem overwhelming. Along with

medical appointments and the impact on your family, you may have to learn what feels like a whole new language.

Breast Cancer Network Australia's (BCNA) resources can help. Containing up-to-date, evidence-based content, they are designed to help you understand your diagnosis and treatment, and make the decisions that are right for you.

All BCNA resources are provided free of charge to people affected by breast cancer.

BCNA's My Journey Kit: information for people diagnosed with early breast cancer



My Journey Kit provides a wealth of information, support and strategies to help you through what can be a very challenging time.

It includes an information guide, personal diary, resources for family and friends and a subscription to BCNA's free magazine, *The Beacon*.

The *My Journey Kit Information Guide* covers topics such as: responding to your diagnosis, choosing your treatment and care, living with breast cancer and life after treatment.

Presented in an easy-to-read format, the stories, tips and advice from others who have themselves experienced breast cancer, will help you realise you're not alone.

'I found it a great resource, which I returned to again and again to help me understand treatments, and particularly the new medical terminology, which was like a foreign language at first.' Teri

BCNA's Hope & Hurdles Pack

The information in Hope & Hurdles is designed to help you make informed decisions about your individual treatment, care and wellbeing.

Content includes treatments you might be recommended, managing side effects, practical and emotional supports that may be available, living well after your diagnosis, and specific information for young women, men diagnosed with metastatic breast cancer, and those whose first diagnosis is metastatic breast cancer.

In the Information Guide, people share their own experiences, lessons they have learnt, and practical strategies to help you focus on living well. The pack also includes information for partners, family and friends.

Also available with Hope & Hurdles are optional items, which you can choose according to your own individual needs, including:

- booklets with information on each of the four main metastases sites – bone, liver, lungs and brain
- booklets with information on treatment for the three main subtypes of breast cancer (HER2-positive, hormone positive and triple negative).

Hope & Hurdles includes a subscription to The Inside Story – BCNA's free magazine with articles and stories especially for those with metastatic breast cancer.

*'What a brilliant read!
Not only did I learn a few
more things about my cancer, but
my husband found it
very interesting also.*

*I think it hit the spot. Not too
overwhelming and covered
lots of medical questions that
I know I have had in the past.'*

Sonia



BCNA Members living with metastatic breast cancer

When your breast cancer has spread

Information for people with metastatic breast cancer

Hearing that your breast cancer has spread can be devastating, with the emotional, practical and medical needs that follow adding to what is already a very challenging diagnosis.

Every person's experience of metastatic breast cancer is different. Symptoms and treatment depend on the spread of the cancer and the part of the body affected. Treatment varies from person to person. Some people will have many symptoms, while others will have very few or none at all.



More Resources

BCNA's range of fact sheets and booklets cover key aspects of breast cancer research, treatment and care.

Topics include: bone health, exercise, health eating, sexual wellbeing, hormone therapy, menopause, breast cancer in men, breast cancer pathology, financial and practical assistance, fear of recurrence and more.

A complete list can be found on the BCNA website: bcna.org.au/resources.

Who is BCNA?

BCNA's vision is for a better cancer journey for all Australians affected by breast cancer.

We develop and produce high-quality information in a range of formats designed to help people diagnosed with breast cancer feel confident to participate in decision-making about their treatment and care.

Vale Christina Lyall

27 February 1946 - 6 August 2017

We are sad to announce the passing of long-time member Christina Lyall.

The Board and Staff send our condolences to family and friends.

Christina was a committed member of Health Issues Group (a former HCC consumer group), passionate about the rights and obligations of patients and often the calming voice in debates about mental health.



Injury Control Council is now Injury Matters!



Penny Carroll, Communications

The Injury Control Council of WA (ICCWA) has changed its name, and will now be known as Injury Matters.



They've always worked closely with health and injury prevention professionals, but even with a distinguished history over 25 years, their name was not well known within the wider Western Australian community, so they took the opportunity to refresh their name and brand to something that is modern, clear and approachable.

For those reasons Injury Matters was the name that they felt is right for the continuation of their journey.

Because injury does matter! For some people the impacts are life changing. They'd like the Western Australian community to know there is an organisation that is available to provide practical information and support. They'll be continuing their support of the Western Australian community in the area of injury, from prevention to recovery.

Injury Matters will be building on ICCWA's history of being a strong voice for injury prevention and supporting those recovering, and will be spreading the message that injuries are preventable louder and further than ever before.

Injury Matters will continue to coordinate its three flagship programs including Road Trauma Support WA, Stay On Your Feet®, and Know Injury.

For more information go to www.injurymatters.org.au.

Culture and Diversity

Louise Ford

Equitable Healthcare for Migrant and Refugee Women?

With the focus of this issue of Health Matters being women's health it seems pertinent to include an article regarding access to healthcare by women from migrant and refugee backgrounds.

Frequently we hear about equity in health care, but is it really equitable for all? I have many skills at my disposal; I speak, read and write English fluently, I have my own car, I have access to, and can use computers, I am employed and live in my own home. My education level has enabled me to process and utilise complex information. I have always had access to good food, clean drinking water and have been raised in societies deemed democratic.

What if I didn't have fluency in English? What if I didn't have computer skills? What if I had no idea I could question a healthcare provider? What if questioning someone I perceived has having authority was culturally inappropriate for me and I was just not able to bring myself to do that? What if culturally, it was completely off the scale to talk to a male practitioner about female sexual and reproductive health? Let's have a look at the potential impact of some of these things.

In a submission to the Royal Australian College of General Practitioners (RACGP) earlier this year, the Migrant and Women's Health Partnership (developed by the Migration Council Australia, ACT) stated that *"Migration and ethnicity-related factors are important social determinants of health. Migrants and refugees are frequently associated with impaired health and poor access to health services; there is evidence of inequalities in both the state of health and the accessibility of health services to these population*



cohorts. Further, migrants and refugees are more exposed to social disadvantage and exclusion. However, it is important to note that this is an average tendency, which does not apply to all individuals, and there is great diversity within the cohort."

(<http://culturaldiversityhealth.org.au/wp-content/uploads/2017/05/Submission-Development-of-RACGP-Standards-for-General-Practices-5th-Edition-Summary-Feb-2017->)

The submission raised several aspects of barriers to healthcare experienced by people, these included health literacy, health beliefs, help-seeking behaviour and language. In WA we have the WA Health Language Services Policy, recently reviewed and current until 2022.

(<http://www.health.wa.gov.au/circularsnew/pdfs/13359.pdf>)

This document clearly states that it is mandatory to use interpreter services in the public health sector. However, there is concern that this Policy is not always implemented as it needs to be. Included in the submission is the following:

"Limited English language proficiency in itself presents major obstacles to access. Patients with low English proficiency tend to have inadequate access to care and preventative services.

Particular situations at risk of harm resulting from failure of interpreter-use include: consent for procedures, instruction of hospital discharge medications, and inappropriate use of family members as interpreters. There is sufficient research that highlights an urgent need for proactive service policies and health staff education around the appropriate use of language services."

Whilst this is an article about women's health I think it important to mention the above, as these are aspects of service provision that are key to equitable healthcare access. In another document from the Migrant and Women's Health Partnership there are several striking paragraphs regarding the experience of women in healthcare.

Comments included:

“Cultural and gender considerations were also noted in the context of receiving care. Refugee women repeatedly noted that they were more likely to feel comfortable around female doctors, particularly when disclosing women’s health related health issues. Some women expressed that they would sometimes not trust an answer given by a male GP. This was consistent regardless of how long the women had been in Australia. However, the gender of a health practitioner was considered significantly less of a factor when the situation did not involve a women’s health issue, or when there was an emergency and no choice but to see a male doctor.”

“Women expressed that health practitioners should be better aware of the health systems and medications used in other countries, in order to better support, and work more effectively with, women who are used to different health systems and medication regimes.”

“Health practitioners agreed that the hierarchy of the health care system in Australia is difficult for refugee women to navigate, and that practitioners should be aware of these complexities in relation to the cultural background of their patient.”

“Significant focus in the consultations was placed on the capacity of health practitioners to communicate effectively with women who lack English proficiency or health literacy, and to provide them with relevant information.

“Refugee women noted overall lack of literacy with regard to general sexual and reproductive health check-ups, as well as maintaining health post-pregnancy, and pointed out the challenges in communicating such information.

“It is very difficult to explain issues of female health, such as pelvic floor and exercises, to women who had never received any information on them before.”
– Refugee woman and community worker”

“Women often did not know of their rights as health care consumers. They also did not have the confidence to be active participants in their health care, for example, by enquiring about their treatment or care plan, requesting a chaperone or a female interpreter for a women’s health related consultation.”

Source: <http://culturaldiversityhealth.org.au/wp-content/uploads/2017/08/Consultation-report-on-strategies-to-promote-culturally-appropriate-care-and-consumer-health-literacy-May-2017.pdf>

In compiling this article I searched for suitable material from WA, unfortunately, according to Google, there is a large, vacant space where I would be delighted to see local research. There has been some work undertaken around ante and post-natal care and in the near future a new report will be released which includes experiences of healthcare.: Exploring Refugee Women’s Settlement Experiences in Australia Through Photovoice - Prof Jaya Dantas and Anita Lumbus

(<http://refugeeresearchblog.org/exploring-refugee-womens-settlement-experiences-in-australia-through-photovoice/>)

Louise Ford has convened the Refugee and Humanitarian Entrant Health Research Alliance (RAHERA). You can find out more about RAHERA on the website.

Also see the article on Ishar Multicultural Women’s Health Centre – a shining example of how to provide culturally inclusive care for refugee and migrant women.



“It is very difficult to explain issues of female health, such as pelvic floor and exercises, to women who had never received any information on them before.”

State News

Sustainable Health Review

You will hopefully be aware that a review into the sustainability of WA's health sector has been announced by the Minister for Health. All too often the services we receive are shaped by the funding structures, rather than community need (as highlighted in Alison Evans' article). We encourage you to have your say through either attending a forum or providing a Submission. All the details are on WA Health's website here:

<http://ww2.health.wa.gov.au/Improving-WA-Health/Sustainable-health-review>

This came hard on the heels of the Review of Safety and Quality of Health Services in Western Australia and is a unique opportunity to re-visit how we fund and deliver our services.

HCC has developed our own webpage for both projects to ensure the consumer perspective is considered, and to keep an eye on the implementation of any Recommendations.

<http://www.hconc.org.au/services/policy-development/sustainable-health-review-consumer-view/>

<http://www.hconc.org.au/services/policy-development/recommendation-implementation-watch-page/>

Patient Opinion Website now has all public hospitals in WA as subscribers

You may have already heard about the moderated platform, Patient Opinion. It can be found at www.patientopinion.org.au or you can phone them on 1300 662 996 to get them to record your feedback.

This website allows for patients and others to tell their story and remain anonymous. The service is identified and everyone gets to see the responses and any changes to the service that are undertaken.

It drives a quality conversation between individual and health service provider and is aimed at continuous improvement. 50% of the stories are positive, 45% are mixed with both positive and negative feedback and 5% are negative only. The Minister for Health,

the Director General and all the Health Service Provider Board members are watchers on Patient Opinion and the feedback is open and transparently addressed. HCC is proud to have been part of promoting this very important strategy.

Clinical Senate Debate

July's Debate discussed Safety and Quality and allowed for a consultation with clinicians on what were the top 20 safety and quality indicators that the new Boards needed to adopt.

The Recommendations for the Interpersonal Violence and Homelessness were presented together at the July Clinical Senate Debate. This reflects that it is a little more complex now to have Recommendations progressed now that there has been a devolution of responsibility to the new Area Health Services.

Interpersonal Violence

Endorsed Recommendations for the System Manager:

Recommendation 1: Introduce a consistent, system-wide response to interpersonal violence – possibly the Victorian model.

Recommendation 3: Identify a method to collect data on interpersonal violence presentations to hospitals and mental health services

Endorsed in principle

Recommendation 2: Implement a universal family and domestic violence screening tool across health services

Recommendations put forward for Health Service Boards for consideration:

1. Work in partnership with Aboriginal people within catchment area to develop and co-design domestic violence programs
2. Implement mandated domestic violence screening for high-risk patients
3. Allocate a position responsible for educating and training staff in interpersonal violence



‘Sustainable Health Review’ Public Forums

Port Hedland Clinical and Consumer Consult
Tuesday 10 October 9.30am – 12.00pm

Geraldton Public Forum
Thursday 12 October 1.00pm – 4.00pm

Kalgoorlie Public Forum
Monday 16 October 1.00pm – 4.00pm

Broome Public Forum
Thursday 19 October 1.00pm – 4.00pm

Mandurah Public Forum
Wednesday 25 October 6.30pm – 8.45pm

4. Develop an internal policy that enables:
 - Reporting of instances of interpersonal violence and records resulting stress on staff
 - Provides for ongoing training and education
 - Provides support for staff
 - Prioritises security response for staff and patient safety.
5. Develop pathway for managing interpersonal violence across the lifespan that gives clarity about tools and resources
 - Develop pathway for referral of individuals at risk of, or experiencing, interpersonal Violence

Homelessness

Endorsed Recommendations for the System Manager:

Recommendation 1 - Ask Minister for Health to consider establishing cross-jurisdictional Cabinet Committee to coordinate initiatives to reduce homelessness

Recommendation 2 - Introduce a standard definition of homelessness across the WA health system

Recommendation 4 - Add an alert to referrals identifying people who are – or are at risk of – being homeless

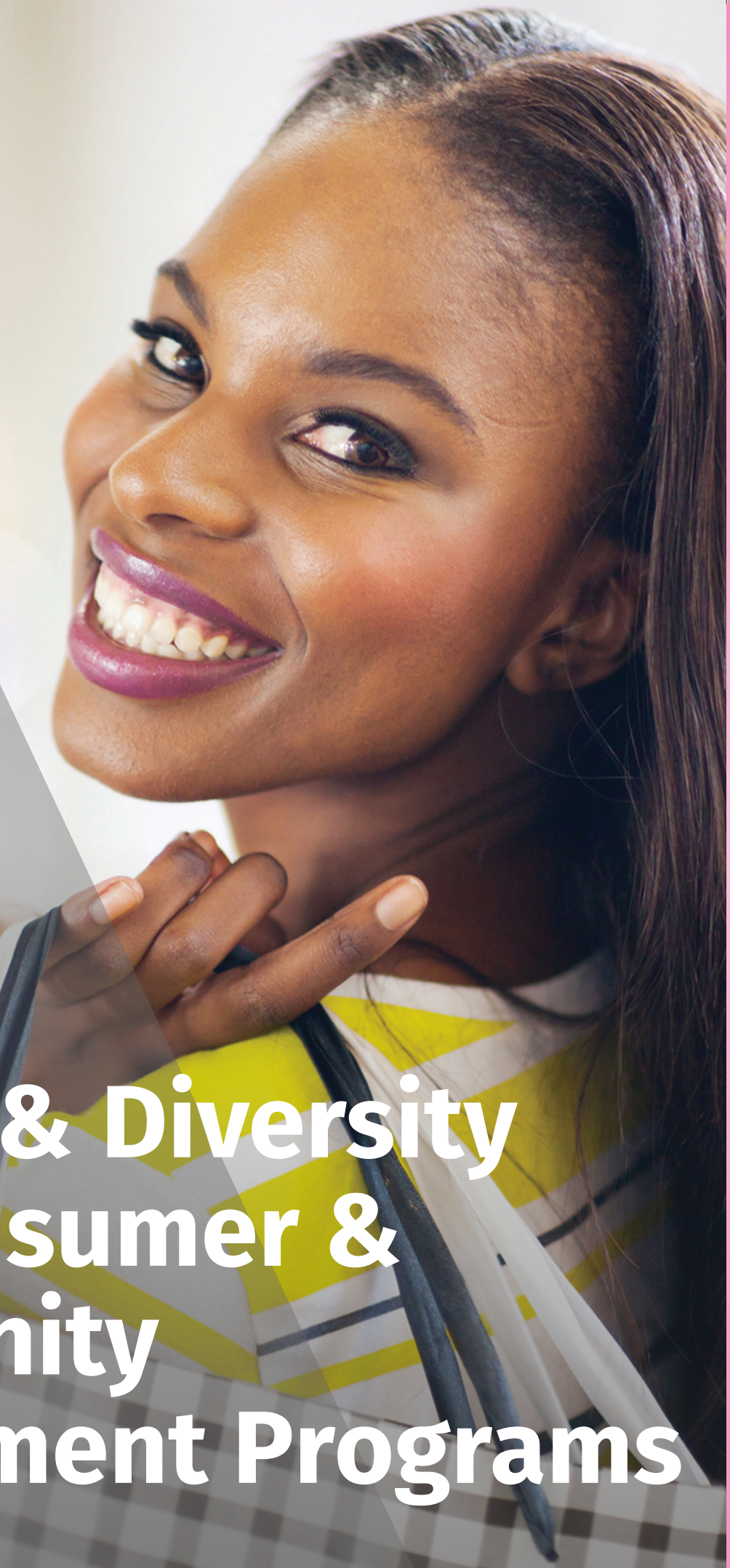
Endorsed in principle

Recommendation 3 - Gather and analyse data on homeless patients to inform the development of a WA Standard of Care

Recommendation 5 - Initiate a research project to determine the benefits of addressing the high cost of hospitalisation in homeless people through proactively sending specialist care into the community.

Recommendations put forward for Health Service Boards for consideration:

1. Invest in staff education that evaluates the social determinates of health and the linkages to homelessness
2. Introduce a ‘hub and spoke’ management process for homeless patients, with peripheral facilities having access to central expertise
3. Ensure Aboriginal Elders within catchment have input into service delivery and hospital culture.



Culture & Diversity and Consumer & Community Engagement Programs

Since May, HCC has been managing the ongoing change inherent in any organisation, and working on the ongoing quality improvement of our programs. We have decided to split our offerings between Diversity and Culture, and Consumer and Community Engagement Programs. They are now on separate pages on our website.

Consumer and Community Engagement Program

Work has been progressing on a review of HCC's Consumer and Community Engagement Program working with a Reference Group of consumers and other stakeholders, including WA Health. Some of you may be aware that when HCC developed the Consumer Payment Policy back in 2002, this was adopted by WA Health to guide how they pay consumers in hospital's Consumer Advisory Councils and any representational role. This policy still guides WA Health and while it has been updated over the years it was overdue for a review. Many things have changed in recent years, and the Mental Health Commission had done a significant piece of work in developing a consumer and family participation policy. HCC has been using from this as a template to update our consumer payment policy.

We have also taken the opportunity to look at what how we link health services and consumer representatives, and recognise that it is a very different world than it once was, with most consumers having a direct relationship with the health service that appoints them, rather than being recruited through HCC. Our role is more strategic, in working with health services to advise them on how to engage with consumers, and stretching the concept beyond the "one person on a committee" model.

The training we provide is also being reviewed, as is the Consumer Representative Network, and the Consumer Advisory Council Roundtable. We anticipate having all the Review work completed by November 2017, and having a new Co-ordinator in place to replace Stephanie Newell. Kate Bullow has been moonlighting on this for HCC as well as working on the Informing New Models of Primary Care (see overleaf), and has done an amazing job at keeping the project moving forward. Please email kate.bullow@hconc.org.au if you have any comments or questions.

<http://www.hconc.org.au/services/consumer-involvement-program/>

Diversity and Culture Service

Louise Ford has developed all the programs and offerings HCC provides to support a more culturally inclusive health system. HCC felt that this program had grown in size and scale to the point where it needed to be recognised as a separate service. One of the programs offered through the Diversity and Culture Service is the Refugee and Humanitarian Entrant Health Research Alliance, which brings together key academics and not for profit organisations to address the paucity of research in this area. Other services include Diversity Dialogues, Let's Talk Culture, and Supporting Diversity in Healthcare workshops. Please email louise.ford@hconc.org.au if you have any questions.

<http://www.hconc.org.au/diversity-culture/>

WA Primary Health Alliance Programs

The WA Primary Health Alliance (WAPHA, pronounced WAFFA) is a not for profit organisation which oversees our state's three Primary Health Networks. These replaced the Medicare Locals, which in turn replaced the GP Networks. However Primary Health Networks have a different, expanded role from either of these predecessors – WAPHA doesn't provide services, they fund services, and most importantly, co-ordinate what services are funded where. They are what is known as a "collective impact" structure, in that they can help bring organisations together to create better, more joined-up services.

In 2017, The Health Consumers' Council was pleased to be given the opportunity to work with the WA Primary Health Alliance to undertake consumer engagement projects in our primary care sector, in other words, everything that is not hospital care. There are three projects we are doing with WAPHA outlined on page 16.

Informing New Models of Primary Care

Informing New Models of Primary Care is a six-month collaborative project between the WA Primary Health Network (WAPHA), Health Consumers' Council, and Curtin University.

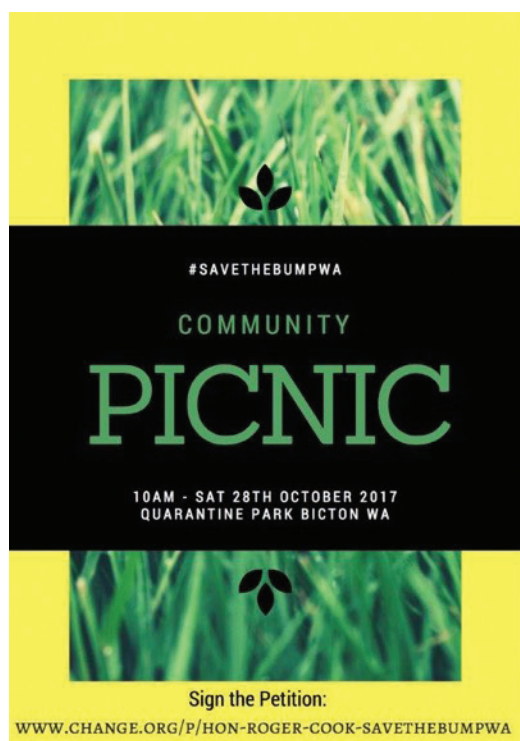
Prior to this project being established, WAPHA and Curtin undertook consultations with general practice staff to inform how care can best be provided to people to keep them well and out of hospital as much as possible. This Informing New Models of Primary Care project is the second stage, and HCC is working with WAPHA and Curtin but this time focusing on the experience of people who access GP services. A series of focus groups have been undertaken in Perth with people who have multiple chronic health conditions with management under a Care Plan. Findings of these discussions will be reported to WAPHA and shared with the community, and a community forum will be held 1st December 2017 to further the conversation on the developing models of care. If you have any enquiries or would like to find out more about upcoming focus groups, email kate.bullock@hconc.org.au

Country Primary Health Network Project

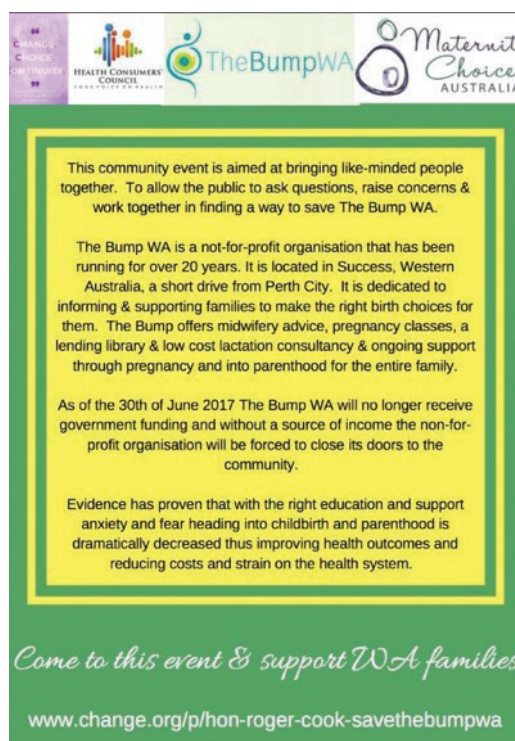
The purpose of this project is to increase the number of Primary Health Network (PHN) health consumer activities in Country Western Australia. This is to support people to have a voice in what the healthcare looks like in their town. In particular, the project is looking to give youth, pastoralists (farmers) and Aboriginal people a voice in healthcare service planning. So far, projects have been undertaken in the Great Southern area, the Kimberley, Midwest and Pilbara. The project will be completed by December 2017 and will provide a strong foundation for ongoing engagement with people in country areas.

Alcohol and Other Drugs Project

In 2015, the Health Consumers' Council began a project aimed at building on the recommendations from the November 2014 Forum, Improving Consumer Involvement in the Alcohol and Other Drug Sector. Two of these Recommendations were addressed; to develop a common set of principles for engagement, and best practice engagement strategies for the sector. In 2017 WAPHA funded the ongoing work of this group, whose focus is now to develop training to support consumers to be involved at all levels of the system, ensuring the voice of the Alcohol and Other Drug service user is heard. If you have any enquiries about this project, please contact pip.brennan@hconc.org.au.



A poster for a community picnic. The top and bottom sections feature a green field of grass with a small black leaf icon. The central section has a black background with white and green text. The text reads: "#SAVETHEBUMPWA", "COMMUNITY PICNIC", "10AM - SAT 28TH OCTOBER 2017", "QUARANTINE PARK BICTON WA", "Sign the Petition:", and "WWW.CHANGE.ORG/P/HON-ROGER-COOK-SAVETHEBUMPWA".



A flyer for a community event. At the top, there are logos for "CHANGE CHOICE COMMUNITY", "HEALTH CONSUMERS' COUNCIL", "The Bump WA", and "Maternity Choices AUSTRALIA". The main text is enclosed in a green border and reads: "This community event is aimed at bringing like-minded people together. To allow the public to ask questions, raise concerns & work together in finding a way to save The Bump WA.", "The Bump WA is a not-for-profit organisation that has been running for over 20 years. It is located in Success, Western Australia, a short drive from Perth City. It is dedicated to informing & supporting families to make the right birth choices for them. The Bump offers midwifery advice, pregnancy classes, a lending library & low cost lactation consultancy & ongoing support through pregnancy and into parenthood for the entire family.", "As of the 30th of June 2017 The Bump WA will no longer receive government funding and without a source of income the non-for-profit organisation will be forced to close its doors to the community.", "Evidence has proven that with the right education and support anxiety and fear heading into childbirth and parenthood is dramatically decreased thus improving health outcomes and reducing costs and strain on the health system.", At the bottom, it says "Come to this event & support WA families" and "www.change.org/p/hon-roger-cook-savethebumpwa".

The Pressing Issues in Women's Health

Alison Evans – Women's Community Health Network WA, Interviewed by Lucy Palermo

Women's Community Health Network WA

Alison is the Executive Officer at the Women's Community Health Network WA, the peak body for not-for-profit women's health and community services across Western Australia. They engage in a health equity approach and work to promote better physical, mental, sexual and reproductive health outcomes among women and girls who experience the most significant disadvantage.

Thank you, Alison for agreeing to be interviewed for the Women's Health Issue. I would like to start with what do you think are the most pressing issues in Women's Health?

Family, domestic and sexual violence; poverty; and gender inequity are not readily associated with poor physical, mental, sexual and reproductive health outcomes. However, their impact on women's health is significant and can be long-lasting. These are largely gendered experiences in that they are predominantly experienced by women. It is very difficult to organise sustainable services for women around this complexity because funding arrangements are not geared to do that. Yet women-specific, integrated models of care that are tailored around women's needs, experiences and circumstances work well for women in that women are more able to sustain quality outcomes post service engagement. Thus, I would argue that family, domestic and sexual violence; gender inequity and poverty are the most pressing issues to be addressed if we are to improve health outcomes for women. Poverty impacts on men too, of course, but the societal factors involved are often quite gender specific. For example, a significant proportion of people living in poverty are sole parents and most sole parents are women.

It is important to understand that family, domestic and sexual violence, gender inequity and poverty

are risk factors and social determinants of other serious health concerns such as Non-Communicable Diseases and many NCDs are linked to common risk factors of tobacco use, harmful use of alcohol, unhealthy diet, physical inactivity and low health literacy. All risk factors are highest among the most disadvantaged groups in Australian society. Chronic disease in adulthood is associated with risk exposures across the life course. Risk factors are considered to be modifiable and from a gender equity perspective, there is good evidence that gender-specific prevention and health promotion programs improve outcomes for women. Interventions need to be developed for women separately from men, along with efforts to understand the challenges of lifestyle modification for disadvantaged women.

Why are they the most pressing issues in Women's Health?

Family, domestic and sexual violence; gender inequity and poverty are pressing issues for women's health because they depend on social and cultural change, which depends on political will and the investment of resources. This means that we can't just look to women and the women's health sector if we are to improve women's health in a meaningful and sustainable way. In my role, I consider this a pressing matter because it is critical that government and the community understand that this is where change lies.

Socio-economic position and material circumstances lead to the unequal distribution of health and well-being. The determinants of social position include education, occupation, income, gender and ethnicity. The fundamental structures of society determine the conditions that result in good health, ill health or disease, and in which people grow, live, work and age.



It is the differential exposure to, and experience of, those conditions of living (such as education, employment and secure/adequate housing) that create health inequities. Gender norms and roles create inequitable power relations between men and women that affect women's vulnerability and exposure to health risks, their health-seeking behaviour and eventual health outcomes (WHO 2010). In addition, there are systemic upstream barriers that influence health-behaviours including insecure housing, sexual discrimination and poverty.

Who would you describe is at most risk in the community?

Priority population groups in the women's health sector are: Aboriginal women; women with low socio-economic status; women with barriers to accessing health and support services such as those living in remote and rural areas; from non-English speaking backgrounds, including refugee and migrant women; with a disability; and experiencing one or more priority issues.

The women coming through our women's health, sexual assault and unplanned pregnancy services often fall within more than one of these priority areas. These are the women most at risk in the community. What I would like to emphasise is that women who experience co-occurring issues (for example are Aboriginal, living with violence and poverty) are not at risk, due to a lack within themselves, but due to external factors such as, racism, discrimination, men's violence, poor service infrastructure, poor pay and conditions. Compounding factors can severely diminish a woman's resources or her capacity for good health. Women's capacity for survival and to make the best of things is incredible, but it is personally taxing and it is unfair. Women who are more vulnerable to poor health behaviours due to factors not of her making or choosing – such as family, domestic and sexual violence - require a more equitable allocation of resources than women and men with higher levels of advantage.

Have you read the Conversation series on gender medicine (<https://theconversation.com/au/topics/gender-medicine-39178>)? The articles raise some interesting differences between women and men regarding bone growth, heart attacks, medication, pain and immune systems. Have you come across any instances where women were not being treated with their gender in mind?

Yes, I have read these articles and it is good to see that they are being widely circulated (many people have sent me the link!). The articles highlight that a focus

on gender is crucial in understanding the pathways to illness and poor health and the tailored responses required to ensure quality outcomes for women. In the case of non-communicable diseases among women, for example, there has been little emphasis and even less action, on the differences that women experience in these diseases. This has meant that women with non-communicable diseases have not received the level of support and services needed to ensure the best possible outcomes or that necessary research and education into gender differences has been funded. The lack of research into gender differences and the consequent lack of education for health providers and the population generally, potentially promotes poorer outcomes for women and increases gender inequities.

In 2015 the Australian Women's Health Network (AWHN) published a paper that highlighted, amongst other things, the low rate of women in research trials and the low levels of reporting of sex-disaggregated findings. These indicate that treatment recommendations are more generalisable for males than females and the research benefits are therefore greater for men. In turn, this accords a lower status in research to women's health.

AWHN recommended that the National Health and Medical Research Council issue a guideline for the equal inclusion of women and the evaluation of gender differences in clinical trials. It is good to see that they have now introduced guidelines that require applicants to address gender equity among research participants.

I understand the Women's Community Health Network WA recently held an online survey seeking information to assist improving the health and support services community women's health centres provide. I understand the survey was very successful with more than 300 responses.

It is probably a little early to ask, but did you find any of the responses surprising?

The survey has only just closed. However, I have been getting updates from my colleague at Women's Health and Newborn Services who is just as impatient as me to know the results! Oddly, I think we were a little surprised to find the extent to which the results are confirming what national research has been showing: too many women are currently experiencing or have experienced family, domestic and sexual violence and this is having an impact on their mental health and alcohol and other drug use. Respondents are also telling us that poor body image, poor pay and conditions, insecure and unaffordable housing, and

a lack of safe, accessible and appropriate support services are making it difficult to be healthy, well and connected to their communities.

would like to mention that the Women's Community Health Network has also been running focus groups with adolescent girls and young women. This was prompted by the research showing that 30% of young women are experiencing mental health issues. What is emerging as a big issue for young women living in particularly disadvantaged areas is the impact of boys and young men's exposure to online pornography. Many of the girls and young women felt very uncomfortable about how disrespectful, degrading and violent a lot of the content is. They feel a lot of peer and social pressure to conform to this depiction of sexuality which can often be unsafe, physically painful, not fully consensual and bereft of mutual pleasure and equal negotiation. This seems to confirm the necessity for a serious approach to sexual and respectful relationships education. It is clearly a matter that must address boys and men's behaviour and attitudes towards girls and young women. But until these attitudes change, girls and young women will need the supports to enable them to safely negotiate this space and access activities and opportunities that are known to protect them against these social pressures and harmful social norms.

What is the next step, how will you implement change? Do you plan on using a collaborative process to develop improvements to community women's health centres, if so how can people get involved?

I think any next step must be well planned, based on best available evidence, and co-designed with women most impacted by external/social problems such as family, domestic and sexual violence and poverty.

We know that gender is a powerful social determinant of health and so we must continue working with others to make inroads into the root causes of the social ills affecting women. However, because there is not nearly enough invested in prevention we need high quality services and supports that are accessible to a diversity of, particularly disadvantaged, women, staffed by professionals with expertise and the best knowledge available in working with women and children affected by family, domestic and sexual violence and constrained by their social and economic circumstances and/or cultural barriers. With the right supports to navigate difficult barriers women can manage their own health and their own lives. Currently, women's health, sexual assault and unplanned pregnancy services

receive a tiny fraction of health funding. This is not good enough; nor is it good enough to fail to fund the implementation of the WA Women's Health Strategy given that family, domestic and sexual violence are recognised world-wide as serious public health issues.

We always welcome people in the community supporting our advocacy work and particularly value the participation of women that have or are experiencing our priority health issues in the planning of our services.

Would you like to add anything?

I would like to end by re-stating that promoting good physical, mental, sexual and reproductive health amongst women is a social responsibility because underpinning poor health are social ills such as family, domestic and sexual violence. But social and cultural change requires resources and it takes time. In the meantime, women must not be left without the supports and services that they require to live safe, well and economically secure.



Ishar Multicultural Women's Health Centre

By Ishar Multicultural Women's Centre

Celebrating 25 years of commitment to Women's health.

This year Ishar Multicultural Women's Health Centre (Ishar) celebrates its 25th anniversary. The journey began on 10th August 1992, and the priority remains enhancing women's wellbeing. This commitment is reflected in Ishar's mission "to provide inclusive, holistic and culturally sensitive services for women and their families promoting healthy communities".

Over the last 25 years, Ishar has worked extensively with newly arrived humanitarian refugee and migrant women from culturally and linguistically diverse (CaLD) backgrounds. The integrated range of information provision and services enhancing physical and mental wellbeing, encouraging social connections and the development of life skills, empowers women and assists their settlement in Australia. This is demonstrated by some of the testimonies collected from women who have attended the centre.

"Coming to Ishar is like my second home. It (Ishar) gives me the chance to make new friends. I come often and enjoy getting information on different topics that help in my life."

"The support we received though Ishar is amazing and we hope this continues."

"You (Ishar) have been very understanding and outstanding in your care of people with special needs."

Ishar grounds its service delivery ethos in the Social Model of Health. The "medical" condition of the women seeking support is not separated from their "real life" interconnections, and their individual, social, economic, racial, cultural, age and gender related circumstances. Ishar is committed to providing gender specific and culturally appropriate holistic health services, encouraging women to make informed decisions, care for their emotional and physical health, and access services which are matched to their individual needs.

Ishar's success is largely due to a number of key factors:

1. Strategic Integration of Services

The services provided by Ishar respond to clients' interests and needs. Clients often access more than one service and internal referrals are common.

2. Creation of a safe and trustful space where women feel respected and welcome

Women value the space to discuss women's business not only from a clinical perspective, but every physical, social and emotional aspect needed for migrant women to feel empowered in Australian society.

3. Services are available for vulnerable and isolated groups (refugees, newly arrived migrants and victims of domestic violence)

People newly arrived in Australia from multicultural backgrounds face significant barriers when attempting to settle and access services. In addition, prior experiences in their country of origin leading to their refugee status may have caused significant hardship, trauma and mental illness. Ishar has a history and reputation for working with empathy and cultural sensitivity to serve these groups.

4. Good use of partnerships and networking

Ishar is an active party in sharing expertise and providing inputs that benefit the development of coordinated services and the creation of policies supportive of the needs of humanitarian refugee and migrant entrants. Its extensive partnerships promote the coordination of resources and the optimization of each partner's value creating a vast network of government services, not for profit organizations, other service providers and educational and research institutions.

Core Services

Health Services

Through its Health Service Agreement with the WA Department of Health, Ishar provides a wide range of ancillary services including counselling, antenatal care, health promotion and education. Ishar also has a female general practitioner who provides bulk billed health care services. These services go beyond clinical practice and provide a safe space in which women's issues can be shared in confidence.

Carers Support Program

Carer Support Services and Programs are focused specifically on men and women from CaLD backgrounds, caring for an adult with mental health issues or another chronic health conditions. The support is based on client need and may include individual support, group activities and information sessions delivered by diverse service providers. An integral part of the case management includes carer respite and group outings, while individuals are referred to internal and external service providers for additional support as required.

Settlement Grants Program

The Settlement Grants Program provides orientation and settlement services for women and their families who arrived in Australia on humanitarian visas and have lived in Australia for less than 5 years. The individual and group case work provided at Ishar is a comprehensive and client-centred advisory, information and referral service. The aim is to empower clients with the skills and confidence for active community involvement.

Family Support Program

The Family Support Program provides information and assistance to newly arrived mothers from CaLD backgrounds. The key service activities include: parenting, family relationship and personal skills development, welfare information, information on access to and engagement with support services, and pre-employment training.

Ishar's effort and contribution in providing "inclusive, holistic and culturally sensitive services for women and their families, promoting healthy communities" has empowered thousands of women and improved the lives of numerous families. In recognition of their contribution Ishar was inducted into the WA Women's Hall of Fame in 2012 and has received numerous service awards since inception.

For more information about Ishar's services:

Email: info@Ishar.org.au

Phone: 08 9345 5335

www.ishar.org.au



Ishar staff on International Women's Day 2017

Events

Volunteers Wanted for Focus Group Research on Chronic Health Conditions

Bunbury, 13 October 2017 1.00pm - 3.00pm

Albany, 27 October 2017 10.30am - 12.30pm

Let's Talk Culture Seminar Series

WHEN: Thursday 26 October 2017

TIME: 10:00 am - 12:00 pm

WHERE: The Billabong Room, Herb Graham Recreation Centre, 38 Ashbury Cres, Mirrabooka

Fremantle Women's Health & Wellbeing Day

WHEN: Tuesday 10 October 2017

TIME: 10:00am - 1:00pm

WHERE: Fremantle Town Hall, 8 William Street Fremantle WA

Orientation to the Health Consumers' Council

16 November 2017

Advanced Consumer Representative Workshop

WHEN: Tuesday 14 November 2017

TIME: 10.00am - 1.00pm

Peeking into the Future - Snapshot - Making Consumer Engagement Frameworks Come To Life

WHEN: 24th November

TIME: 2.00pm - 4.00pm

WHERE: The Platform, 256 Adelaide Tce, Perth

COST: \$50

In September 2017, the Executive Director met with Patient Opinion UK and Membership Engagement Services. These two innovative organisations are partnering on how best to bring patient feedback to where it can best create change - to the hospital or care facility where the event occurred, as soon as possible. HCC has also met with Dr Avi of Energesse in Australia several times. Energesse partnered with Member Engagement Services to bring this new technology to the Eastern states of Australia.

Come and hear Dr Avi outline the 6E Framework developed by Energesse as a step-by-step guide to holistically improve the patient experience and consumer engagement in an integrated manner. The 6E briefing session will share insights into evidence-based learning and best practices from the USA, UK, Australia and Asia. This follows a formal workshop for health department staff and other interested stakeholders to understand the possibilities beyond current patient improvement initiatives.

This is not a funded event and therefore, HCC has to charge to bring Dr Avi over. Price includes afternoon tea.

The event is being held at The Platform which is a collective and event space for not-for-profits, social enterprises and industry groups. The aim is to build a community of purpose-driven individuals using their unique gifts to collectively affect change in our world.

Street parking is limited but there are regular buses up St George's Tce.

Expressions of Interest

The Health Consumers' Council is currently seeking full board members and subsidiary officers to join its Board.

For a non-profit organisation, it's been said that effective board service starts with the right match – the right match between an individual with the talent and commitment to make a difference and an organisation that is in need of that individual's unique blend of skills and attributes.

Have you ever considered being a volunteer member of a non-profit board?

If you're interested, please complete the EOI found at <http://www.hconc.org.au/get-involved/expressions-of-interest/> and email to: info@hconc.org.au by 31/10/17.

1. **A Full Board Member** is a person who has been appointed and/or elected to the Board of HCC, He or she is the equivalent of a Company Director in the for-profit sector and, with other members of the board, has a fiduciary and statutory duty to govern the Association within the law and in the best interests of all stakeholders. Full board members

may in exceptional circumstances, be exposed to one or more personal liabilities arising from the conduct of the Association and its business. Board members are elected by the general membership at the Annual General Meeting of the Association. The next AGM is 8 November 2017.

2. **A Subsidiary Officer** is someone who is appointed by the full board to bring special skills and experience to the board meetings to assist the members to govern the Association appropriately. Subsidiary Officers have no statutory duties and are not exposed to the possibility of any personal liabilities other than any which may arise from failure to do his or her common law duty to serve the Association in a professional and reliable manner.

Health Matters asked HCC Board members what prompted them to join the Board:

"I feel strongly that people need to know they can question their doctors and health professionals about their recommended care and make personal and informed decisions. I joined the Board to support the HCC's work to educate people regarding their health care rights." *Cheryl Holland*

Annual General Meeting

Wednesday, 8 November 2017

You may recall in the last issue of Health Matters, HCC held an Extraordinary General Meeting (EGM) on 22 March 2017 to adopt new Rules to replace our Constitution, to ensure we are compliant with the new state Incorporations Act 2015. One of the outcomes of this change of Rules is that we are able to hold our AGM slightly later in the year, so the date of the AGM will be 8 November 2017.

This year's AGM will be held at 21 Moore Street, which has disabled access and provides work experience opportunities for APSI's hospitality students. We held our EGM there and the food was delicious.

The event for this AGM will be a panel discussion and Q&A regarding the Sustainable Health Review.

Check our website at <http://www.hconc.org.au/agm-2017/> for further information or call 9221 3422, or email info@hconc.org.au



Upcoming changes to Australia's National Cervical Screening Program

What is HPV?

HPV is a very common virus that affects both men and women, with most people being infected with at least one type of HPV at some point in their life. While HPV infections are normally cleared naturally by the immune system, sometimes they cause cervical cells to become abnormal. The body is usually able to rid itself of HPV and the abnormal cells, but in some cases this doesn't happen and the abnormal cells develop into cervical cancer. The time from HPV infection to cervical cancer is usually 10-15 years.

There are many types of HPV; however, only certain types may lead to cancer. HPV types 16 and 18 cause about 70% of all cervical cancers.

The HPV vaccine protects against HPV types 16 and 18 but does not protect against all types of HPV that can cause cervical cancer, so HPV vaccinated women still require regular cervical screening.

From 1 December 2017, women in Australia will have access to a new primary screening test that will help further reduce the impact of cervical cancer. The Pap smear, which has been the primary tool used to screen for cervical abnormalities for decades, is being replaced by a more effective Cervical Screening Test. This is bringing about big changes to the way cervical screening is delivered across the country.

What the Program will look like

Based on an intensive review of evidence, the following changes to the National Cervical Screening Program (NCSP) will be implemented on 1 December 2017:

- A five-yearly Cervical Screening Test will replace the two-yearly Pap smear. The Cervical Screening Test looks for the presence of human papillomavirus (HPV) and, if found, a reflex liquid based cytology test (like the Pap smear) is performed on the same sample to check for abnormal cervical cells
- The screening age range will become 25-74 years
- A self-collection option will be available for a select group of women 30 years of age or over, who have either never-screened or are overdue for cervical screening by two years or longer

What the changes mean for women

The procedure for collecting a Cervical Screening Test is the same as a Pap smear - a health care provider will take a small sample of cells from the woman's cervix and send this sample to a laboratory for testing. However, since the Cervical Screening Test is more accurate than the Pap smear, women with negative (or 'normal') findings will only need to screen every five years. This will reduce the number of routine cervical screening tests over a woman's lifetime from 26 to around 9 or 10. These changes are expected to reduce cervical cancer cases and deaths by up to 30%.

Increasing the screening start age to 25 years

The commencement age for cervical screening will increase from 18 to 25 years. This is for several reasons:

- Cervical cancer in young women is rare (in both HPV vaccinated and unvaccinated women)
- Despite screening women younger than 25 years of age for over 20 years there has been no change to the rates of cervical cancer or deaths from cervical cancer in this age group
- Investigating and treating common cervical abnormalities in young women that would usually

resolve by themselves can increase the risk of pregnancy complications later in life

- Studies have shown that delaying screening until the age of 25 is safe (and has been safely implemented in other countries)

It is important to remember that women with symptoms, such as unusual bleeding or spotting, can have a Cervical Screening Test at any age.

Transitioning women to the renewed program

Most women will be due for their first Cervical Screening Test two years after their last negative Pap smear. Women who are undergoing follow-up and/or treatment should transition to the renewed program as outlined in the Guidelines for the Management of Screen Detected Abnormalities, Screening in Specific Populations and Investigation of Abnormal Vaginal Bleeding (2016 Guidelines). These guidelines are available on the Cancer Council Australia Guidelines Wiki platform.

And in the meantime?

Until 1 December 2017, all women are encouraged to have their Pap smear when they are due; cervical screening should not be delayed. Cervical screening using the HPV test is not recommended before this date because the infrastructure and supporting quality and safety activities will not be in place. Medicare Benefits Schedule (MBS) items for the new screening pathway will be available from 1 December 2017; MBS items for the Pap smear will no longer be available after this date.

Further information

- Overview of the Renewal (NCSP)
- Future changes to cervical screening (NCSP)
- Changes to cervical screening (WA Cervical Cancer Prevention Program)
- Subscribe to the Partner Reference Group (PRG) e-newsletter
- Subscribe to the WA Community Cervix Announcement newsletter



BreastScreen WA informs women about their breast density

Dr Eric Khong – Liaison GP and Sonya Schultz – Program Officer BreastScreen WA

Recently there has been increased public awareness and media discussion regarding breast density.

What is Breast Density?

Women's breasts are made up of different types of tissue including fatty tissue, glandular tissue and connective tissue. Women with low breast density have more fatty tissue compared to glandular tissue while women with high breast density have more glandular tissue compared to fatty tissue.

Breast density describes how breasts look on a mammogram. It does not describe how breasts feel on examination by a woman or their doctor.

Dense breasts are common and normal, occurring in approximately one third of women over 50 years. For many women breast density decreases as they get older.

For example, only about 25 percent of women aged 60 and older have dense breasts. Breast density varies from woman to woman. Factors including age, body mass index (BMI), having children, going through menopause and being on hormone replacement therapy (HRT) can influence the density of a woman's breast tissue.

Why is breast density important?

Research shows that higher breast density is associated with an increased risk of breast cancer. It is important to remember that the risk of developing breast cancer is influenced by a range of other factors including:

- increasing age (the biggest risk factor)
- having a strong family history of breast cancer
- ovarian cancer
- being overweight

- drinking alcohol
- taking HRT and
- other lifestyle factors.

On a mammogram, fatty tissue appears black and non-fatty tissue appears white or 'dense'. Breast density has the potential to hide breast cancers that also appear white on the mammogram image. Therefore, screening mammograms are a less sensitive test for breast cancer in women with dense breasts.

Screening mammograms and breast density

BreastScreen WA may notify women and their GPs when a mammogram shows marked increased breast density. Women are advised in writing to consult their GP to discuss the significance of their breast density, to have a clinical examination and receive further advice about their breast cancer risk.

What you can do if you have dense breasts

- Women aged 50-74 years with no breast symptoms are recommended to have a free screening mammogram with BreastScreen WA every 2 years. It is still the best screening test for the early detection of breast cancer.
- Be "Breast Aware"; get to know your breasts and what is normal for you. Look in the mirror at your breasts and feel your breasts from time to time. If you notice any unusual changes in your breasts even if your last mammogram was normal, please see your GP promptly.
- See your GP for regular breast examinations

Should women with dense breasts have additional tests?

Currently there is no evidence that additional tests are routinely advised for all women with dense breasts. Some women, who may be at higher risk of breast cancer due to additional risk factors, may benefit from extra tests (e.g. breast ultrasound) after discussion with their GP.

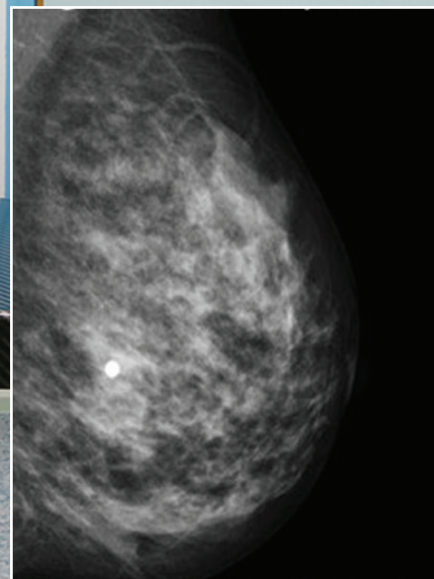
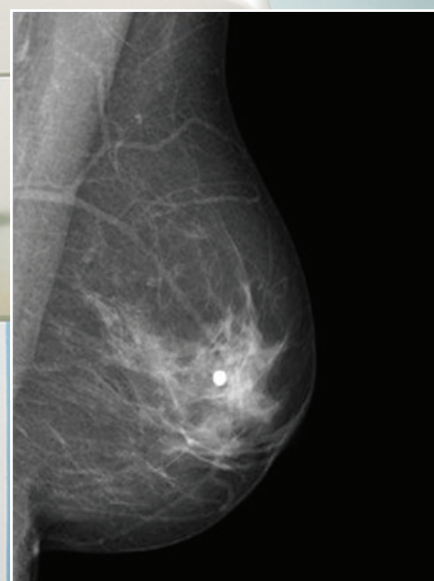
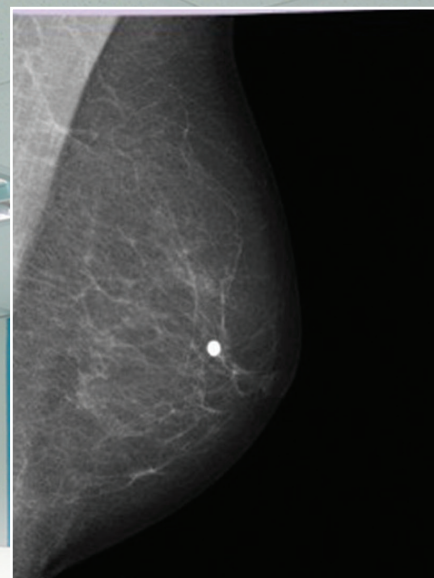
How can I keep informed?

BreastScreen assists Western Australian women in maintaining their breast health, it has been providing free screening mammograms for eligible women in WA since 1989 and provided its 2 millionth screen in August 2017. BreastScreen WA uses innovative approaches such as online booking, extended clinic opening hours, text message appointment reminders and Facebook to ensure easier access for busy women and continued awareness about the importance of regular breast screening.

For more information visit the BreastScreen WA website at www.breastscreen.health.wa.gov.au

The greater the breast density, the more white areas on the mammogram, and the less obvious the dot.

Editor's Note: WA is currently the only state which routinely informs women if they have dense breast tissue to ensure further follow up. HCC applauds WA for leading the way.





**HEALTH CONSUMERS'
COUNCIL**
YOUR VOICE ON HEALTH

Health Consumers' Council

GPO Box C134, Perth WA 6839
Phone (08) 9221 3422, Fax (08) 9221 5435
Country Freecall 1800 620 780
Email info@hconc.org.au
Web www.hconc.org.au

Opening hours

Monday - Friday 9.00am - 4.30pm
Closed Public Holidays