HEALTH MATTERS

Health Consumers' Council (WA) Inc. Magazine

Autumn 2015

Clinical Senate Debate: Great Expectations

Planning for expected deaths in acute settings

Choosing Wisely... Bye bye

Medicare Co-payment, hello Medicine Wise

Patient Opinion Australia... Be Heard...

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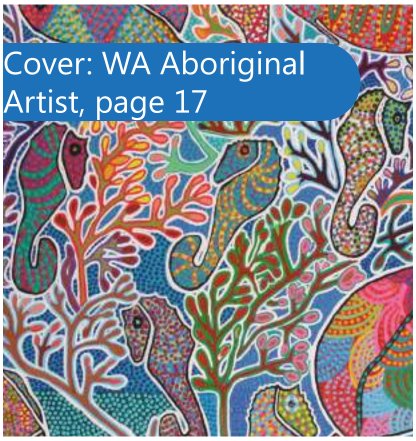

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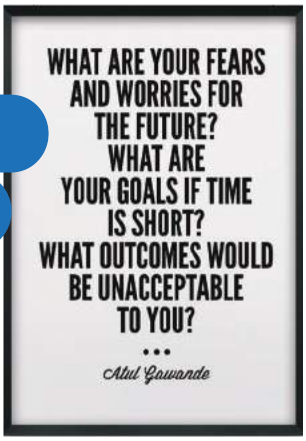

WHAT ARE YOUR FEARS AND WORRIES FOR THE FUTURE? WHAT ARE YOUR GOALS IF TIME IS SHORT? WHAT OUTCOMES WOULD BE UNACCEPTABLE TO YOU?

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Atul Gawande

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Features

Regulars

Cover: Painting by Brian Ocean Ward

Foreword

Welcome to our new look Health Matters. Gracing the front cover is an original artwork from Brian Ward, and his story is on page 17. This edition of Health Matters has feature articles on end of life care, inspired by the March Clinical Senate Debate. It also includes the new regular updates from each program, and news from across the state and country.

The first four months...

Since taking the reins of the Health Consumers' Council, I have enjoyed the support of the Board and Staff of HCC, all of whom have been so welcoming to me in the early months of my tenure.

A key focus has been our contract with WA Health which is currently being re-negotiated for a December sign-off. Like all not for profit organisations, HCC is being moved onto an outcomes based contracting framework. This has co-incided with a "mini-review" to reflect staff movements in the organisation.

Changes in the HCC Team.

Most readers will know Amy McGregor well. As the end of her maternity leave from the Operations Manager role approached, she decided she was not ready to leave her gorgeous little girl. We fondly farewell Amy and wish her all the best and thank her for the wonderful work she put into the HCC.

We have also farewelled Ann Jones who was on a fixed term contract as HCC Policy Research Officer. Ann's contributions to HCC are well-reflected in this edition of Health Matters and we warmly thank Ann.

We welcome Meegan Taylor as our new Operations Manager ; Meegan is an experienced Corporate Services Manager in both the not for profit and commercial sectors. Lucy Carter is now our Media and Communications Co-ordinator and will resume her wonderful front of house presence. Eileen McRory was temping on Reception for HCC and has found a permanent position elsewhere.

Our Consumer Representative Program has been reviewed in the light of contract development and have added a three day per week position to the newly named Consumer and Community Engagement Program. Stephanie Newell has joined the HCC and will work alongside Louise Ford to continue to develop this important program. Some of you may be familiar with Steph who among other things project managed the inaugural World Health Organisation Patients for Patient Safety three day Workshop in Perth in 2009.

New Strategic Plan

A key next step for the HCC is to review our 2012-15 Strategic Plan and create our 2015-18 Plan. This is a wonderful opportunity for the HCC to review and renew our vision, values and strategy.

We want to hear from you...

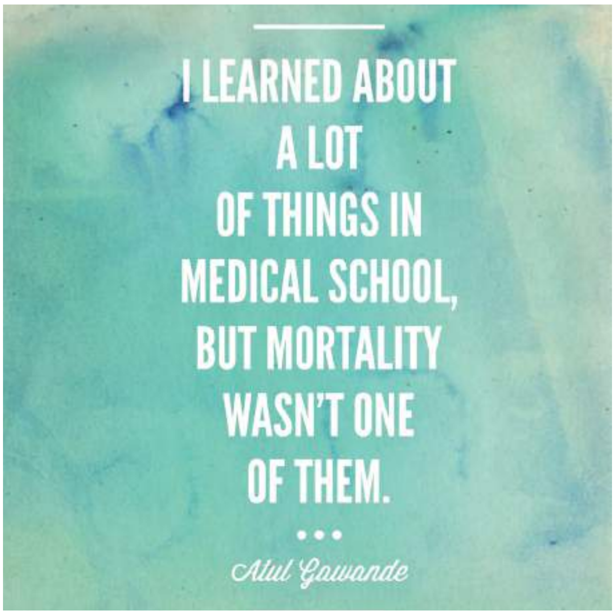
To support the strategic planning process, we have included on the back page of Health Matters a Member Survey and invite you to complete and return it to us, or jump online to answer the survey using this link: https://www.surveymonkey.com/s/HCCMember

Contact us on info@hconc.org.au if you need any assistance. We thank you in advance for your time.

Pip Brennan
Executive Director
Health Consumers' Council

Clinical Senate Debate: Great Expectations, Planning for expected deaths in acute settings

Pip Brennan Executive Director | HCC



There are some cases you never forget. During my time as a health complaints conciliator, I worked with a family struggling with the aftermath of a loved one's death. They had been fed a message of false hope and were still trying to obtain allied health interventions right until the end.

The family later sought help to untangle their dissatisfaction regarding his care. A quick review of his medical records revealed, contrary to messages of hope, the specialist had placed a "Do Not Resuscitate" order and this revealed that neither the patient or family had been informed.

The family only wanted to grant their loved one's dying wish; to die at home, surrounded by family, friends, and his dog. The family were unable to make informed choices to ensure that this happened because the difficult End of Life Care conversation never took place.

In 2013 a Stanford University School of Medicine carried out a study, "Do Unto Others: Doctors' Personal End-of-Life Resuscitation Preferences and Their Attitudes toward Advance Directives." It highlighted 88.3% of doctors that participated "predominantly wish to forego high-intensity treatments for themselves at the end-of-life". http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0098246

This study also showed little change in the attitude of physicians towards Advanced Health Directives.

Clinical Senate Debate

Pip Brennan Executive Director | HCC &
Dr Ann Jones Policy Research Officer | HCC

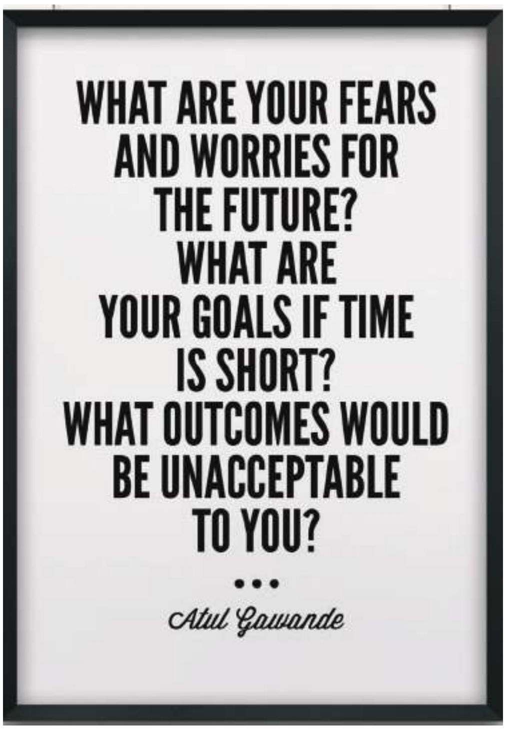
The March Clinical Senate Debate: Great Expectations, Planning for expected deaths in acute settings.

On February 18th the End-of-Life Consumer and Carer Consultation Forum was held at HCC. I encouraged my colleague Ann Jones to attend as at that time she was dealing with issues at the centre of the debate.

From among the attendees a consumer spokesperson is selected to address the Clinical Senate debate. Both Ann Jones and Helen Povey were selected to present. Ann's story about her experience galvanised the conversations on the day.

Clinical Presentations

The day started with Emergency Medicine specialist Professor Geoff Dobb "setting the scene". Professor Dobb illustrated a case study, describing the invasive treatments to the terminally ill patient as "water boarding". It was a powerful reflection on the experience of consumers, when the cure is worse than the complaint. The impact on Professor Dobb and his colleagues, signalled the urgency for a different approach. Identifing the need for clinicians to talk to patients, as raised in Atul Gawande's Reith Lecture series.



Gawande spoke about how vitally important it is for clinicians to talk to their patients; really talk to them, not just at them with statistics and options, but explore with them what their goals are. The questions that he recommended be discussed were;

"What is your understanding of where you are with your condition or your illness at this time?"
"What are your fears and worries for the future?"
"What are your goals if time is short?"
"What outcomes would be unacceptable to you?"

Goal of Care

Dr Barbara Hayes, Clinical Lead in Advance Care Planning at Northern Health, Melbourne, presented, 'Initiatives to promote shared-decision-making: ACP, GOPC, CPR decision- making'. It focused on Goals of Patient Care, (GOPC), a clinical framework for the limiting of medical treatment. This approach operates in two Australian health organisations, Royal Hobart Hospital and Northern Health, Melbourne. It replaces not-for-resuscitation orders. The aim of a GOPC is to identify patients who wish to decline medical treatments like resuscitation, or the administering of blood products.

IF YOU ARE NO LONGER ABLE TO MAKE A DECISION FOR YOURSELF, WHO WOULD YOU LIKE US TO TALK TO? HAVE YOU SPOKEN TO THIS PERSON?

In the process of developing a GOPC, there are two key questions to add to Gawande's list, to identify your substitute decision maker:

"If you are no longer able to make a decision for yourself, who would you like us to talk to?"
"Have you spoken to this person?"

A GOPC is compiled by the clinician and is used to assign patients to one of three phases of care; curative or restorative, to prolong life; palliative, the treatment aim, quality of life; and terminal, the goal, comfort during the dying process.

Assessment is undertaken as part of the admission process, shared with the patient or substitute decision maker i.e. the person you want to make decisions for you if you are no longer able to make them for yourself. While this can be articulated in an Advanced Health Directive (AHD), in practice many AHDs are not completed by consumers, and the lack of a central register means reliable communication and coordination of care is problematic.

A GOPC on the other hand is signed off by the clinician and added to the patient's file. It is better placed to ensure clinicians are able to follow the patient's wishes regarding treatment should a crisis situation occur.

To view the Clinical Senate powerpoint of the presentation, see www.clinicalsenate.health.wa.gov.au/debates/docs/B.Hayes.WA%20Clinical%20Senate.%20March%202015.pdf

For further information on Goals of Care, see www.mja.com.au/journal/2014/201/8/goals-care-clinical-framework-limitation-medical-treatment

What is the Clinical Senate?

The Clinical Senate is a forum established in 2003 where collective knowledge on clinical issues can be shared and provided to the Director General and State Health Executive Forum (SHEF). SHEF is a key body, promoting action within WA Health.

The debate involves presentations on the topic of the day, including a consumer presentation, a general discussion of the issues raised, ending with resolutions.

The resolutions from the Clinical Senate Debate are presented to the DG and SHEF for formal adoption and ultimately actioning.

The website notes; "Matters discussed will include the coordination and development of clinical planning clinical and resource decision making; other relevant clinical issues in health service delivery in Western Australia; and issues of key concern to the Director General".

For more information visit:
www.clinicalsenate.health.wa.gov.au/about/index.cfm

Consumers’ & Carers’ perspective: Communication at ‘end-of-life’ in hospital

Dr Ann Jones Policy Research Officer | HCC

I was asked to present at the recent Clinical Senate Debate from the carers perspective as my mother is receiving palliative care in hospital. I spoke about the journey from restorative care to palliative care. It was an emotional experience, however the issues I rasied formed the focus of the plenary debate. Hopefully this will change how institutions respond when patients are moved from a curative approach to palliative care only.

> *“Unfortunately no matter how hard we tried, the hospital system either could not, or did not, allow for us to be contacted regarding Mum’s ongoing treatment whilst she was in hospital. (Dr Ann Jones)”*

A key issue I rasied was a lack of understanding among hospital staff of Enduring Power of Guardianship (EPG). The drugs prescribed to my mother had the distressing effect of bringing on sudden dementia-type symptoms and luckily my sister and I held an EPG over my mother. Unfortunately no matter how hard we tried, the hospital system either could not, or did not, allow for us to be contacted regarding her ongoing treatment in hospital. We often relied on other patients to relay conversations medical staff had with Mum and what arrangements had been made.

This is totally unacceptable if there are legal documents in place to ensure the family must be involved in any decision-making processes. An EPG is there to ensure that guardians make any important treatment decisions, should the patient become incapable of making such decisions. Also to seek and receive information on the patient’s behalf. If a the patient has an EPG hospital staff need to ensure that the family is completely involved.

There was a the lack of general palliative care knowledge in the hospital setting. Each of the three doctors who spoke to us, gave different definitions of palliative care, and what treatments Mum would or would not receive. Clearly training is required so no conflicting information is given when patients and their families are being asked to make end-of-life decisions.

> *“Hospital staff need to ensure that the systems they have in place to keep patients and their families informed actually work.” (Dr Ann Jones)*

Communication has been an ongoing battle for the family since Mum’s treatment began in November 2014. The system is meant to work for us, not against us. In our case, we were fighting every step of the way to ensure Mum received adequate care and that we received the correct information when it was needed. Hospital staff need to ensure that the systems they have in place to keep patients and their families informed actually work.

> *“the Clinical Senate acknowledged that in acute health settings, clinicians and other staff were sometimes left wanting in relation to end-of-life discussions and treatment plans.” (Dr Ann Jones)*

It was pleasing that the Clinical Senate acknowledged that in acute health settings, clinicians and other staff were sometimes left wanting in relation to end-of-life discussions and treatment plans. Hopefully the recommendations to improve the policy and processes around this sensitive topic will be endorsed by SHEF.

All the presentations and resolutions from the March debate is available on this web page: www.clinicalsenate.health.wa.gov.au/debates/mar15.cfm

Farewell & acknowledgement from HCC

This edition seems destined to linger on the difficult but vital conversations at the end of life. Ann's mother died on March 24th 2015 and her funeral was on April 2nd, the day the Clinical Senate posted all the documents from the Debate on their web page.

Bob Mansefield

In addition, we were given the sad news that Bob Masefield had passed away by our member Pat Booth.Given Bob's immense contribution to consumer representation, Michele Kosky was asked to provide a tribute to him.

> *It is with regret that we note the death of long time HCC member Bob Mansefield who died on February 24th 2015 after a long illness.*
>
> *Bob will be remembered by many HCC members as a man of great energy and commitment to health consumer rights and effective consumer participation. He was the Chairperson of Bentley Community Advisory Council for a number of years and an active member of the CAC Chairpersons Roundtable. Bob was enthusiastic, hearty with a great sense of humour and a willingness to ask the hard questions and go the extra mile. He will be greatly missed.*
>
> *Our deepest sympathy to his family.*
>
> *Michele Kosky*

Richard Hill

We would also like to acknowledge the passing of Richard Hill. Louise Ford the HCC Consumer and Community Engagement Manager has written a tribute to him.

> *At the end of March there was the unexpected, sad news of the death of Richard Hill, who was a very active community member in a range of contexts, including the health and disability sectors. Although Richard was not a member of the HCC we would like to mark his passing and pay respect to the significant contribution he made to promoting quality of life, employment and inclusion interests of people living with a disability.*
>
> *Sadly Richard passed away on Saturday 21st March after a brief illness. He has been an active member of the South Metropolitan Health Service CAC and also a proactive member of the City of Melville where he was Councillor for the Palmyra Melville Willagee Ward. Obviously passionate about the well-being of people with a disability Richard also enjoyed contact with the community in general and worked diligently to improve quality of life for all.*
>
> *The staff of the HCC send condolences to Richard's family and friends.*
>
> *Louise Ford.*

Operation offers hope for people with emphysema

Frank Smith | Guest Contributor

Hilary Monton is a remarkable woman who lives with emphysema, a type of chronic obstructive pulmonary disease (COPD).

"COPD comes on quite gradually. There are little things you can't do and they become more and more. Suddenly you realise you are an invalid, not able to participate in life. It is quite bleak," she said.

When her emphysema started to wear her down, and she couldn't do the things she loved to do, she decided to get a referral to lung specialist Dr Lucas Sanders.

Dr Sanders is one of the Lung Institute of WA's expert clinical researchers. He gave her some life changing advice – an innovative new surgery to remove parts of her damaged lung.

The surgical removal of the damaged parts of the lung aims to reduce the symptoms of emphysema making quality of life easier for an affected individual for a short duration of time (usually up to a few years). Between 20 and 30 percent of each lung is removed to get rid of damaged tissue. This therefore reduces the size of the lungs and enables the diaphragm to contract and relax more effectively which leads to improved breathing.

The operation was first performed in the US over 60 years ago but was discontinued due to its high risk.

Modern improvements have reduced the risk substantially, although it is still only performed on patients with very severe COPD. About 400 Australian patients have received the operation with 70 percent surviving three years or more.

Nowadays a six to ten week lung rehabilitation program is a huge part of the process. The patients are discharged once they are mobile, tolerating a regular diet and drainage tubes have been removed.

Following the operation Hilary is a proud supporter of the Lung Institute of WA and continues to have a positive outlook on life, volunteering in the community and feeling healthier than she has in years.

"Before surgery I was not even able to do basic housework. I couldn't even make the bed. I was quite disabled.

"Now I have amazing energy. I've gone back 10 years. I do things with energy and enjoyment. Its whole new life," she said.

Hilary describes herself as a 'social butterfly'. But like many people her age, smoking was part of that socialization.

"I started smoking in my 20s and I would have smoked under water.

"I lit up first thing in the morning and last thing at night. I had another cigarette if I woke during the night.

"I brought emphysema on myself. I did not listen to warnings."

But life is now much better.

"I feel like I've been given a new life," she said

The Lung Institute at the Sir Charles Gairdner Hospital, says COPD is a serious long term disease that affects the lungs and is the umbrella term for diseases such as emphysema and chronic bronchitis.

Around 14.5 percent of Australians 40 years old or over live with COPD, this figure increases to 29.5 percent in Australians aged 75 or over.

Smoking is the leading cause for COPD.

LungScreen Pilot
Lung Cancer Screening Study

Pip Brennan Executive Director | HCC

Unfortunately, lung cancer remains the number one cause of cancer death in Australia. Most lung cancer is found after it has spread outside the lung and therefore the overall survival rates are poor. The reduction of smoking rates in the community will reduce the number of lung cancer in the future, but smokers who have quit continue to be at increased risk of developing lung cancer.

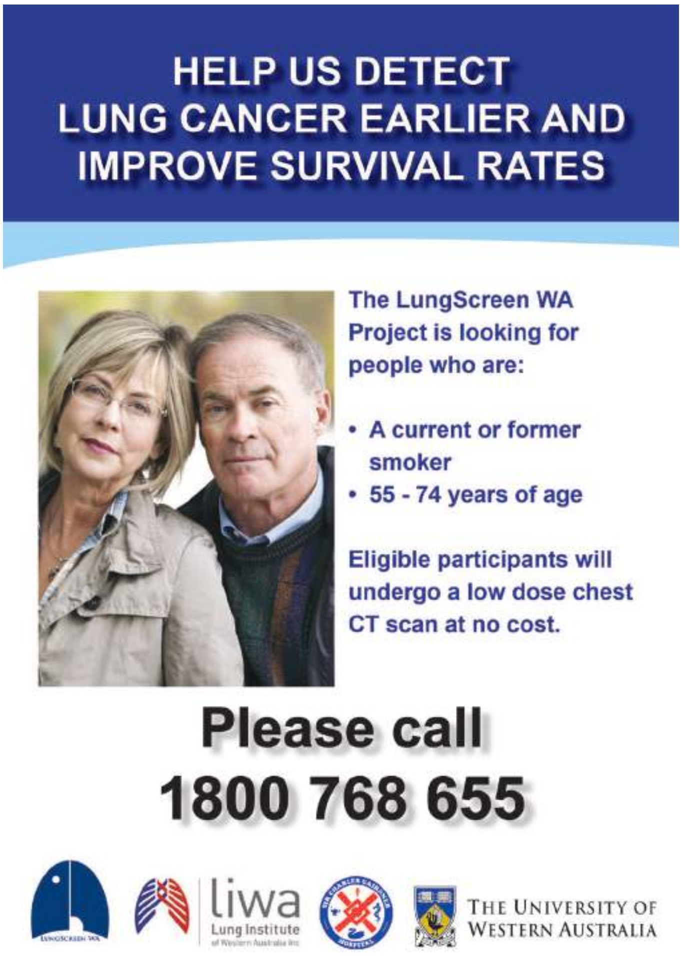
Previously, screening current and former smokers has not been recommended. In 2011, the results of a large scientific study in America showed that screening for lung cancer can save lives. The screening test is a low radiation dose CT chest scan. When compared to chest x rays, screening people who are at increased risk of developing lung cancer with CT scan reduced the number of lung cancer deaths by 20%.

There are both potential and real harms from CT screening for lung cancer. The screening CT scan is not a perfect test. Up to half of the people who have a CT scan will show abnormalities named nodules. Very few nodules turn out to become lung cancer, but they can cause stress and anxiety when found. Expert care is needed to determine what is required for nodules that are detected. Most nodules require close observation with another CT scan to see if they change but some may need early tests such as biopsies.

Currently, CT scan screening for lung cancer in Australia is not recommended as we do not have the infrastructure available and information about the overall cost in the Australian setting.

The LungScreen WA Project is a pilot lung cancer screening trial being performed at Sir Charles Gairdner Hospital investigating the role and cost of lung cancer screening in Perth. The study, led by Dr Annette McWilliams and Dr Fraser Brims, is enrolling people aged 55-74 years old who are either current or former smokers. Participants will be offered a CT scan at no cost based on their individual lung cancer risk. The information gained will help with the planning of a future lung cancer screening program in Australia.

If you would like to participate, or have any further questions, please call LungScreen WA on 1800 768 655.



HELP US DETECT
LUNG CANCER EARLIER AND
IMPROVE SURVIVAL RATES

The LungScreen WA Project is looking for people who are:

- A current or former smoker
- 55 - 74 years of age

Eligible participants will undergo a low dose chest CT scan at no cost.

Please call
1800 768 655

Statewide News

Pip Brennan Executive Director | HCC

Image Source: https://sikaaustralia.files.wordpress.com/2014/02/p1010276.jpg

Fiona Stanley's Early Months

The opening of Fiona Stanley Hospital has been a huge logistical exercise, the like of which has not been seen for some time. In recent months there has been significant negative press associated with the hospital; in particular the use of contractor Serco to undertake activities such as sterilising instruments. Concerns have also been raised about clinical errors and patient safety, so in response to this, the Acting Director General of WA Health has commissioned an Independent Inquiry which is being undertaken as we finalise this issue. In addition, a Parliamentary Inquiry has also been convened. The HCC will watch these closely and provide further updates.

Bentley Hospital, Fremantle Hospital and Health Service

As part of the domino effect of Fiona Stanley Hospital opening, there have been changes in the services at both Bentley Hospital and Fremantle Hospital. Fremantle Hospital's Emergency Department has now closed, and the facility is being transformed into Western Australia's largest specialist hospital. Bentley has been part of the Royal Perth Group for some time now and has had a number of changes to its service. A question mark remains over whether maternity services will continue there, but at present the Minister for Health has decreed that there will be a wait and see approach until Fiona Stanley has been open 6 months.

WA has one provider to deliver the new Primary Health Networks

When the new Federal government came into power, they elected to abolish the Medicare Locals across Australia and created a Tender process for a significantly reduced number of what will be called Primary Health Networks. Essentially they build on the original iteration of Medicare Locals, GP Networks, to ensure a network of training, referrals and resources to GPs. With the advent of Medicare Locals, Allied Health professionals were also included as key primary care players.

Medicare Locals came in many shapes and sizes; and this caused difficulties in getting traction in improving co-ordination between hospitals and the Primary Care sector. From now on there are just three in the state of Australia; North Metropolitan, South Metropolitan and Country WA. One provider was awarded the tender for all three – the WA Primary Health Alliance. It will be interesting to see how this develops in the coming month. If you want to stay in touch, check their website www.wapha.org.au

Patient Opinion... Be heard

Pip Brennan Executive Director | HCC

PATIENT OPINION AUST
BE HEARD.

If you ever wanted to find just one website to provide your feedback, positive or negative, about a hospital or health service, you're in luck. Patient.Opinion.org.au has been developed along the same principles as patient opinion.org. from the UK and is based in Queensland.

Patient Opinion.org.au is designed to offer real-time feedback to health services that is open and transparent. I spoke to the CEO, Michael Greco. Here are answers to my questions:

What is Patient Opinion?
Patient Opinion is a not-for-profit organisation that exists to help improve health services by providing a platform to enable open and transparent dialogue between patients and health service providers.

It does this by providing a website where the public can publish their experiences of local health services. The website allows health service staff to interact with these patients and consumers to help improve care.

So is it always negative?
Absolutely not – it is more like a 50/50 split between positive and negative feedback.

How does it work?
1. Members of the public anonymously post a story (positive or negative) about a service on the website (Patient Opinion Australia retains their email address, but the service will not have access to it).

2. Patient Opinion moderates all stories to ensure they do not identify any single member of staff.

3. Health service staff at subscribed organisations are then alerted when a story is posted about their health service, ward or department.

4. The organisation can then publish a response to the story on the website.

5. The story teller is then alerted to the organisation's response and the dialogue can continue.

Sort of like a Trip Advisor for Hospitals?
Not at all. Patient Opinion is so much more. People visiting the website are able to search and review all patient/carer stories about healthcare services. Responses from relevant healthcare organisations are also public, as is the number of people in the healthcare organisation listening to patient stories.

The stories people tell on Patient Opinion don't just identify what might be done better, they often identify exactly how things should change. The human voice of the story can be a powerful motivator for change, too. Stories really can – and do – change the world.

In short, it transparently documents when a change occurs as a result of a story; it is a live "safety and quality" mechanism.

Can anyone enter a story?
Yes! On Patient Opinion, everything starts from the patient's story. So patients, service users and carers can say what is important to them about their experience, in their own way. Unlike surveys, people can start with what they want to say – not necessarily with what the service wants to ask them.

Why not just use a survey or run a consumer forum?
A survey is easier from a service perspective, but harder to access from a patient perspective. You have to be invited to participate. With Patient Opinion, the option to participate is open to everyone. Patient Opinion is easy for both services and patients, and more importantly, its outputs are transparent to the public

Why not just use something like Twitter or Facebook?
These social media platforms are easy for patients to use, but harder for services. Patient Opinion drives participation, improvements and change, not just social conversations.

What if a health service is not registered?
Patient Opinion.org.au notifies an organisation as a courtesy if the story about their health service is of a more critical nature.

The benefit for health services if they register is that they are given all notifications of positive and critical stories, and they are given these directly so they can quickly action responding to the story.

Patient Opinion understands that gathering stories is time consuming for busy health professionals. Knowing how to work effectively with patient takes some experience. Patient Opinion has over seven years of experience working with health organisations to help them get the most out of this type of patient feedback.

What about consumer organisations?
The Health Consumers' Council is a member and will be alerted if any Western Australian service is mentioned. There is no cost to this service.

Contact details
Patient Opinion Australia www.patientopinion.org.au Or see HCC's website.

T: 07 3354 4525 F: 07 3355 7047 E: info@patientopinion.org.au

Choosing wisely... Bye bye Medicare Co-payment, Hello MedicineWise

Pip Brennan Executive Director | HCC &
Dr Ann Jones Policy Research Officer | HCC

Choosing Wisely
Australia
An initiative of NPS MedicineWise

It would be difficult to pretend that the Health Consumers' Council is anything but delighted by the final demise of the Medicare co-payment.

Many people acknowledge that the Australian Government does need to reduce spending, but is it fair to target the most disadvantaged in society, including the elderly, unemployed, and chronically ill? And, it is not General Practice that is the cost driver in the Medicare Benefits Schedule in any case. In 2012/13 the Australian Government spent around $304 per person on general practice, and $1792 per person on public hospitals.

The government needs to look at raising revenue in other areas rather than attempting to penalise the many health consumers whose health outcomes would be impacted by the imposition of a GP co-payment.

However the concern remains of the ongoing costs of our Medicare Benefit Schedule (MBS) and surely there must be other areas to trim? Absolutely, according to the Health Report's 2nd March 2015 episode. In the episode, Norman Swan interviews Associate Professor Adam Elshaug from the Menzies Centre for Health Policy at the University of Sydney. He is involved in the Australian version of Choosing Wisely, launched by NPS Medicinewise.

The Choosing Wisely campaign began in America and has been replicated successfully in Canada, The Netherlands, Germany and Italy.

There are around 5,700 items on the Medicare Benefits Schedule (MBS) many of which have been around since the 1980's without a strong evidence-base for their inclusion.

"... a paper in this morning's Medical Journal of Australia suggests a much more effective way of making the healthcare system sustainable than a GP co-payment. It's by reducing the use of low value tests and treatments which in many people do no good and sometimes do harm."

"... every item number within the MBS has a description of a patient characteristic for whom that test is appropriate, and it was realised that that descriptor was out of date, so it's been refined to better target the patient groups who we think these tests are actually valuable for."

An example discussed was the B12 and Folate testing which were included on the MBS as one item, but have since been split into two. The diagnostic veracity of the tests are considered questionable, as are the need for both tests to be done simultaneously.

... And the fee was reduced on each because of course when you split them apart they become two tests, so the fee should reduce."

Since splitting the tests, in "just three or four months in we can see now the numbers are looking like the Medicare program is saving $4 million per month, so almost $50 million per annum."
Who needs a price signal on GP visits?
For the full article, see www.mja.com.au/journal/2015/202/4/choosing-wisely-message-messenger-and-method

To listen to this episode of the Health Report, see www.nps.org.au/media-centre/media-releases/repository/choosing-wisely-australia-launching-in-2015

The @ChooseWiselyAu Twitter handle is now active if you are on Twitter to keep in touch with this initiative.

Report on actual GP expenditure

The recently released National Health Performance Authority report on GP visits and expenditure across the nation was succinctly reviewed by Steven Duckett and highlighted there are many more than two types of visitor to the GP, in fact there are six:

1. Very high attenders, who had 20 or more visits to a GP in 2012-13

2. Frequent attenders (12 to 19 visits)

3. Above-average attenders (six to 11 visits)

4. Occasional GP attenders (four to five visits)

5. Low GP attenders (one to three visits)

6.People who did not attend a GP at all in 2012-13. Duckett notes; "the very high attender group comprises just 3.8% of the population but consumed 17.7% of Medicare out-of-hospital expenditure."

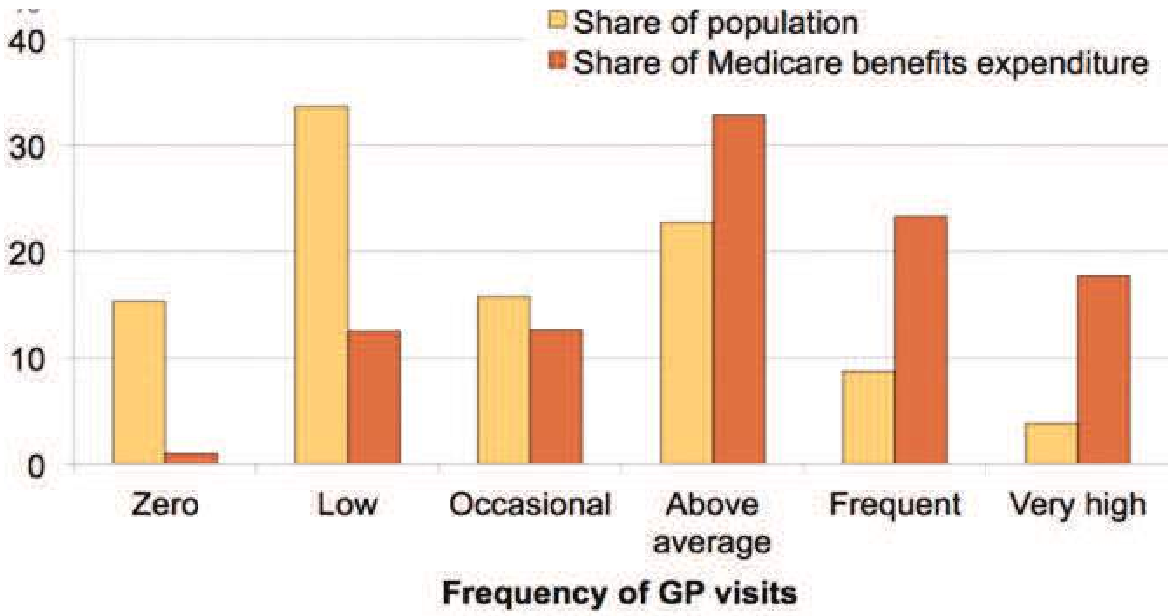
(See table below)

Duckett also writes; "People who see the GP most often tend to have more health problems than low-attenders and a greater level of disadvantage. But the original A$7 co-payment policy applied the same set of incentives to both groups. The A$5 rebate reduction was barely more nuanced.

> *"The next generation of health policies should respond to complexity and diversity, not pretend it doesn't exist."(Steven Duckett)*

The next generation of health policies should respond to complexity and diversity, not pretend it doesn't exist. Does the system work for all kinds of patients? Which patients are getting costly care that doesn't benefit them? By asking these questions, we can uncover how to improve the quality of care while also saving money. "

For the National Health Performance Authority report see here: www.myhealthycommunities.gov.au/our-reports#report-hc12
For the Steven Duckett Article see this link: http://theconversation.com/time-for-policy-rethink-as-frequent-gp-attenders-account-for-41-of-costs-38966



Dementia hits women hardest

Frank Smith | Guest Contributor

Alzheimer's Research UK recently issued a report, Women and Dementia: a Marginalised Majority, that clearly shows much of the burden of dementia is borne by women. And while the statistics are drawn from the UK population, Australia faces much the same problems.

In the UK dementia is the leading cause of death among women. In 2013 31,850 women died of dementia and many more were probably helped on their way by dementia. Dementia caused 12.3 percent of deaths amongst women, more than heart disease, stroke or cancers.

Nearly 850,000 people in the UK are living with dementia. Of these 39 percent are men and 61 percent women. After 65 the risk of dementia doubles every five years, so the longer you live the greater the chance of becoming demented.

Women live longer than men. Nearly three quarters of people in their nineties are women. Population data shows that an 85 year old woman has on average nearly seven years of life expectancy. People with dementia live on average five years after diagnosis. Even if dementia is not the direct cause of death it shortens a person's life. Unfortunately many are living out these extra years in chronic ill health.

> *...women in their 60s are almost twice as likely to develop Alzheimer's disease over the rest of their lives as they are to develop breast cancer.(Frank Smith)*

Older people fear dementia more than any other major life-threatening disease, including cancer, stroke, heart disease and diabetes. These concerns are well-grounded, women in their 60s are almost twice as likely to develop Alzheimer's disease over the rest of their lives as they are to develop breast cancer.

Some fear the devastating symptoms of dementia, including memory loss, loss of the ability to communicate, mood and personality changes, and eventually declining health and death. Others fear becoming a burden to loved ones as the condition progresses because they have first-hand experience of the challenges of caring for someone with dementia.

It is mainly women that take on the role of caring for loved ones with dementia. In the UK nearly 70 percent of unpaid dementia carers are female. Women are nearly two and a half times more likely than men provide 24-hour care for people with dementia.

Sometimes women are hit with a double whammy, caring for their partner with dementia and then being hit with dementia themselves. Wives caring for their husbands with severe dementia reported receiving less support from friends and family than husbands caring for their wives in similar circumstances.

> *"More women are dying of dementia, more women are having to bear the burden of care and more women are leaving paid employment to care for their loved ones." (Hilary Evans)*

Hilary Evans, Director of External Affairs at Alzheimer's Research UK said: dementia has a devastating impact on all those whose lives it touches, but it's a 'triple whammy' for women. "More women are dying of dementia, more women are having to bear the burden of care and more women are leaving paid employment to care for their loved ones." "The experiences of these women underline the urgent need to tackle the diseases that cause this life-shattering condition."

"In recent decades we've seen increased investment in areas like cancer have a real impact, and we need to emulate that success for dementia. Only through research can we find ways to treat and prevent dementia, and transform the lives of the hundreds of thousands affected."

Health Consumers' Council Members Survey 2015

The Health Consumers' Council is developing our 2015-2020 Strategic Plan with the Board. We invite you as a valued HCC Member to inform this process by providing your feedback on the questions below. Your participation in the Survey will assist the Board in these deliberations.

1. I enjoy reading Health Matters:

☐ Strongly Agree
☐ Agree
☐ Neutral
☐ Disagree
☐ Strongly disagree

Comments:

2. I enjoy reading HCC's E-news:

☐ Strongly Agree
☐ Agree
☐ Neutral
☐ N/A I don't have an email
☐ Disagree
☐ Strongly disagree

Comments:

3. I follow HCC on:

☐ Twitter
☐ Facebook
☐ YouTube
☐ Linked In
☐ None of the above

Please turn over to complete survey

Your Involvement

4. Would you like to be more actively involved in the Health Consumers' Council?

- ☐ Yes
- ☐ No

Ways to be involved

5. How would you like to be more actively involved with the Health Consumers' Council? Tick all that apply.

- ☐ As part of a contact list to comment on policy and discussion papers or patient information
- ☐ As part of an online forum that explores areas of health care delivery
- ☐ As part of face to face forums that explore areas of health care delivery
- ☐ I would like to contribute articles to Health Matters
- ☐ I would like to develop skills to become a consumer representative
- ☐ I would like to build on my knowledge and skills as a consumer representative
- ☐ Other (Please specify, or add your comments here)

Further comments:

6. These are my suggestions that HCC should consider for strengthening current membership

7. These are my suggestions for expanding HCC membership

We know your time is very valuable and we appreciate your response to our survey to assist the Health Consumers' Council Strategic Planning process.

Best wishes,

Pip Brennan
Executive Director

Please tear out, scan and send to info@hconc.org.au or post to GPO Box C134, PERTH 6839. Or you can complete the survey online: www.surveymonkey.com/s/HCCMember

Advocacy Team Report

Dr Martin Whitely Senior Advocate | HCC

As part of our current contract negotiation process, the Advocacy Team surveyed fifteen clients who had utilised the HCC Individualised Advocacy service within six months.

Each client was contacted by a different advocate and each were asked the same questions:

1. What kind of health service were you having trouble with?
2. How did the complaint resolve?
    a. Referral to another service
    b. No change to the client's circumstances
    c. Improved service provision to the consumer
    d. Ongoing unresolved issue from the consumer's perspective
    e. Other (please specify)

6. Were you satisfied with the service our Advocacy Team provided?
7. Have you got any other comments or suggestions?

Issues being addressed

These included adverse events, wait list queries, carer and Guardianship matters.

Outcome of the Complaint

Improved service provision to the consumer (9)
No change to the client's circumstances (2)
Ongoing unresolved issue from the consumer's perspective (4)

Satisfaction with the service provided

All respondents were satisfied with the service provided.

Comments included:

Advocate was "lovely, I couldn't have attended appointments otherwise"

Consumer was reinstated on wait list with credit for time off the list and is now on priority wait list. Consumer noted he got "excellent service" from the HCC advocate who was "very, very helpful" and said "it is a great department and should be maintained". This was the second time he had used the service. He used it more than 5 years ago and it was the "same story".
A mental health consumer concerned she was being coerced into treatment she didn't want or need noted that the advocacy worked out very well and she considers it a "really necessary service".

A consumer who obtained his medical records noted the advocate was "extremely helpful 100% without her he wouldn't have been able to do it". The advocate dealt with his son's OCD in the way it needed to be dealt with. "It is a damn shame people don't know of your services".

The complaint was resolved through conciliation with HADSCO with the HCC advocate providing support. The consumer was very satisfied with the HCC advocate who went out of his way to help

A consumer noted that she found it hard to find HCC and couldn't initially find any agency to assist her. Once she engaged the HCC she found the advocate very helpful and the issue was resolved very quickly.

How to be a 'savvy' consumer when buying medications

Dr Ann Jones Policy and Research Officer | HCC

The cost of medications can have a serious impact on household budgets, and for this reason it pays to be a 'savvy' consumer when purchasing prescription medications. For many of us, as we age we tend to require more medications for age-related illnesses, for example drugs for arthritis, pain relief, blood pressure, and high cholesterol. The cost of these types of medications can impact greatly on people's disposable income, especially those on a fixed income, and for some health consumers the cost of medications can run into thousands of dollars per year. This can also apply to people dealing with a chronic health condition.

As health consumers we cannot escape the cost of prescription medications, but if we understand the pricing structures a little bit better, we can reduce the cost of our medications as much as possible. By asking questions of pharmacists, and shopping around, we can avoid paying extra costs such as those added by the manufacturer, and by the dispensing pharmacist.

One of the main ways however to reduce costs is to allow the pharmacist to dispense a generic brand in place of the premium brand, providing your doctor has not specifically indicated that this should not occur. Generic brands must be the bioequivalent of the premium brand, which means that they must have the same active ingredients and work just as quickly and effectively as the premium brand. The only time this could be a problem is if consumers have an allergy in which case they need to check with their doctor because sometimes the colours and fillers used are different to the premium brand, although this does not affect the quality of the medication. In Australia, a study by Deakin University found that only around 18% of health consumers substitute premium for generic brands, whereas in the US the percentage is 50%, and in Denmark 70%. It seems that Australian health consumers remain loyal to a brand, whereas perhaps we should start to focus instead on the active ingredient of the drug we are taking. The table below provides a brief glimpse into cost savings by purchasing generic brands:

Another way to reduce costs is to ask! A phone call or visit to pharmacies in your local area is an easy way to find out what they charge for medications, or if you have internet access, checkout online pharmacies as they are sometimes cheaper because they do not have the overheads of a bricks and mortar business. The pharmacist's profit margin can vary for different drugs and products, especially if they have purchased bulk orders of generic drugs direct from the manufacturer, or have a price-volume agreement which will impact on their profit margin. Pharmacists can also choose to charge an additional fee for safety net recording; a fee for Webster packing; a fee for dispensing a PBS prescription outside of normal hours; or a fee to non-concession card holders of up to $4.27 if a medication has a dispensed price for maximum quantity which is less than the general co-payment amount currently set $37.70, provided they don't exceed the co-payment. Not all pharmacists charge all or any of these fees, but many do, which helps to explain the different pricing of the same medications between pharmacies. The bottom line is that pharmacists are running a business and need to make a profit and it is up to us to be 'savvy' consumers and shop around for the best deal for our medications.

This article was inspired by consumer Rebecca Coglan who contacted the HCC to discuss the issue and request an article.

Brand with surcharge	**Savings if a generic is chosen**	**No. of different brands with no surcharge**	**Active ingredient**	**Form and strength**	**Used for**
Lipx 10	$3.33	21	Simvastation	Tablet 10mg	High cholesterol
Tramal SR	$4.50	8	Tramadol	Tablet 100mg slow release	Pain relief
Feldene-D	$2.95	1	Piroxicam	Tablet 20mg	Anti-flammatory/ anti-rheumatic
Capoten	$6.92	3	Captopril	Tablet 25mg	High blood pressure

Table 1 – Brands of medicines listed on the PBS that have increased their brand premium on 1 August 2012. Accessed at www.pbs.gov.au/info/news/2012/08/brand-premium-increases-1-august-2012

Perth Aboriginal Youth Forum: AHCWA & YMCA

Natasha Nannup | Aboriginal Health Council of WA (AHCWA)

On Monday the 23rd February 2015, AHCWA and YMCA came together to deliver a youth forum. The purpose of the youth forum was to communicate and discuss, with youths what they thought the major issues affecting the youth of today include.

Hayley Thompson, our Aboriginal Youth Coordinator played an instrumental role in coordinating the event, beginning with an outline of the Forum and overview of expected outcomes gained from the information gathered during the forum.

The participants were broken down into four smaller groups, with at least one adult volunteer from YMCA, who supervised the discussions. Each group wrote down all of the issues they thought affected youth in today's society.

Each group were then asked to choose an issue to workshop. Each group had to explain their chosen issue and why they felt it impacted on them as youth.

The final task was to explain ways in which they, as young adults could implement positive ways to overcome these issues.

There were some really great comments made by the participants with the forum having a very positive outcome. Hayley is now looking forward to coordinating and facilitating similar youth forums in the metro area soon.

AHCWA provided e-Readers as prizes for three of the participants, who showed enthusiasm, leadership and great effort whilst participating in the forum.

WA Aboriginal Artist

Brian Ocean Ward's Story

Brian was born in Perth in 1979. He grew up in Broome and after finishing school, got his pearl diving ticket and worked for a number of skippers in the Kimberley. He was very popular around town and known as an honest worker and fun bloke. He was a provider for his family.

In 2004 he became a merchant seaman working out of Perth, travelling all over the world. In May 2006 Brian was assaulted and left for dead. He spent two weeks in a coma and was left with a frontal lobe injury. Doctors originally gave no hope for Brian and told the family to say their goodbyes.

A month after the doctors turned off Brian's machine in the ICU, they were calling him 'a walking miracle' as they didn't expect him to survive. He spent a year in hospital and another year in rehabilitation. He has been back in Broome for two years.

Brian was a member of MUA, who supported Brian and the family through this tragic time.

The effects of the brain injury are still with Brian and have affected his life in so many ways. Unable to work and live an independent life, he has now found his life's work and it speaks from his heart.

Brian has had no formal art training and paints images from his love of the ocean and his Grandmother's country.

Aboriginal Advocacy Service

Laura Elkin Aboriginal Advocacy Manager | HCC

Close the Gap, not Communities

It was reported in the last Health Matters that there is widespread concern about the proposed closure of remote Aboriginal communities as announced by Colin Barnett in November 2014, following the Federal government's decision to cease funding remote Aboriginal communities. The social media campaign #SOSBlakAustralia page started in Wangkatjunka in the Kimberley and has galvanised protests not just in in WA and across the nation, but also internationally.

On Friday 1st May and the days that followed thousands of people rallied in Perth, Broome, Warmun, Beagle Bay, Fitzroy Crossing, Halls Creek, Geraldton, Kalgoorlie, Melbourne, Canberra, Sydney, Darwin, Brisbane, Adelaide, Alice Springs, Wollongong, Central Queensland, Berlin, Hong Kong, London, Wellington, Los Angeles, New Zealand and more. The Kimberley Land Council has written to the United Nations permanent forum on Indigenous issues who supported their submission condemning the proposed closures.

Following a history of removing our people off their land with no consultation, at the time of writing, there has been no consultation what so ever with the relevant communities, and ongoing uncertainty and community distress remains high. The Hon Terry Redman and the Hon Helen Morton have recently been appointed by the Premier to undertake a consultation process over the next few months, so it will be important to see how effective and thorough this consultation process will be.

This is against a background of uncertainty regarding funding for both federal and state Aboriginal health services and programs. Western Australia has been reviewing its state services, but the review was not released publicly and a business case has gone to Treasury. Programs that were previously funded under COAG Closing the Gap funding are only funded until June 30, though all WA Aboriginal health programs were reviewed.

In addition there is no clarity about the outcome of the federal tender for services known as the Indigenous Advancement Strategy. Some of the funding has been announced, but as they collapsed over 150 programs into 5 areas it is difficult to be clear about how much has been defunded. Many of our social and emotional support programs to address intergenerational trauma and dispossession are earmarked to lose funding, as our many of our youth centres across the nation, plus many more essential support services. In the absence of any concrete information, including any criteria the reviews and cuts are based on, many services are losing heart and good staff as the uncertainty drags on. The Suicide Standby Program, which is a multi-agency approach to support families bereaved by suicide, and to prevent further tragedies has suffered large funding cuts, this is not because we are seeing a reduction of suicides among our people, we still experience higher rates than other Australians. HCC has been working out in the community hearing from consumers and services throughout this difficult phase; however even we are not assured of continued funding for our Aboriginal Advocacy Program, at the time of writing.

It can sometimes seem that nothing has been learned about the importance of partnering with Aboriginal communities. Once again critical decisions about the future of so many of our communities and services are being made allegedly "for our own good" without us.

Survival Day 2015

Leah Cooper Aboriginal Advocacy Officer | HCC

Leah Cooper and Laura Elkin at the HCC stall on Survival day

While most Australians celebrate Australia Day as the commemoration of the day Australia was founded, many Aboriginal people celebrate their history by calling it "Survival Day". This year, "Survival Day" celebrations were held at Stirling Gardens in Perth, attended by many people, mainly from the Aboriginal Community. Our Aboriginal Advocacy Program had an information stall alongside other community organisations also providing information stalls and a valuable opportunity to promote and network with community and organisation partners. We received 50-60 visitors. Many of the visitors were not aware that the HCC existed but were very favourable in their responses when informed about all of our services and programs.

The day reflected the riches of the Aboriginal Community's culture which included music, dance, food and spiritual connection. The proceedings of course began with a Welcome to Country ceremony: and a flag raising ceremony including the Aboriginal, Torres Strait Islander and Australian flags.

Headlining the talented entertainment line-up was Geoffrey Gurrumul Yinapingu. Gurrumul as he is commonly known was born in Galiwin'ku (Elcho Island), off the coast of Arnhem Land, Northern Australia about 580 kilometres from Darwin. He is from the Gumatj clan of the Yolngu people and his mother is from the Galpu nation. He was born blind, has never learnt Braille and does not use any visual supports such as a guide dog or white cane. Gurrumul speaks only a few words of English, and is said to be acutely shy. He has performed for HRH The Queen of England, US President Barack Obama, Crown Prince Frederik and Princess Mary of Denmark, in addition to being one of only two Australian performers at the Queen's Diamond Jubilee Concert at Buckingham Palace, confirming this multi ARIA award-winning musician's place as an international star, capable of transcending cultural boundaries.

One of the acts on Survival day

Other acts included Yabu Band,an Aboriginal Australian rock, roots band formed in the mid-1990s in Kalgoorlie. The word "yabu" is Wongatha – a western desert tribal language – for 'rock' or 'gold'. Core members are brothers Delson (vocals) and Boyd Stokes (guitar); and Jade Masters (drums). Other entertainment included more Aboriginal singers, groups and dancers.

The day was a scorcher so the free water was very welcome, as was the free sausage sizzle. The Elders were given their own marquee to enjoy cups of tea, coffee and cakes, stay out of the sun and heat enjoy a yarn while watching the celebrations.

Consumer & Community Engagement

Louise Ford Consumer & Community Engagement Manager | HCC

Image Source: http://starconsultancy.com/services/training/management-leadership-training/

"Our children have dramatically different life chances depending on where they were born. In Japan or Sweden they can expect to live more than 80 years; in Brazil, 72 years; India, 63 years; and in one of several African countries, fewer than 50 years. And within countries, the differences in life chances are dramatic and are seen worldwide. The poorest of the poor have high levels of illness and premature mortality. But poor health is not confined to those worst off. In countries at all levels of income, health and illness follow a social gradient: the lower the socioeconomic position, the worse the health.

It does not have to be this way and it is not right that it should be like this. Where systematic differences in health are judged to be avoidable by reasonable action they are, quite simply, unfair. It is this that we label health inequity. Putting right these inequities – the huge and remediable differences in health between and within countries – is a matter of social justice. Reducing health inequities is, for the Commission on Social Determinants of Health (hereafter, the Commission), an ethical imperative. Social injustice is killing people on a grand scale."

I thought it pertinent to use words taken from the WHO's Commission on Social Determinants of Health Final Report | Executive Summary 2008 (Introduction) to begin my article for this issue of Health Matters. After all, is this not what the HCC is all about, working to reduce health inequities and injustices via empowering consumers and informing practitioners and policy makers? Yet so often those least able to speak up for themselves are the ones who are constantly overlooked in health care provision and, indeed, by many other agencies and individuals. Hence the need for truly representative consumer comment and engagement.

You may be aware that the HCC is about to commence a new funding contract with the Health Department. This has provided an opportunity to evaluate what has been known as the Consumer Participation Program and to explore ways of adding to and developing it so that it functions effectively in 2015 and beyond.

Bearing in mind the notions of social justice and the social determinants of health, some current thoughts are to engage with a more diverse age range including young families and youth, to provide on-line opportunities for comment, to hold forums that can inform both consumers and health care providers, to video conference events (when possible) so those in rural WA can access and engage in information sharing, to utilise on-line surveys and to hold workshops and/or forums at varying times of day to accommodate people with work/family/study commitments. There is also potential to partner with other agencies and provide information re rights and responsibilities in health care to their clients who may otherwise remain unaware of those and therefore not have equity in their access to health care and other support networks.

As informed and empowered consumers we can make a difference to the quality of health care provision and help to reduce social inequities and injustices by remembering that we represent all health consumers...that is our power and our strength.

Consumer & Community Engagement survey: About change

In response to and in preparation for a new funding round that includes re-modelling the Consumer Participation Program, a survey was designed to provide consumers with an opportunity to provide input into the changes.

The survey was generated (via Survey Monkey) to sixty two consumer representatives, CAC and CCAC members on Friday 13th February, 2015, fourteen responses (22.5%) were received by the closing date, 26th February, 2015.

Survey questions covered a range of areas including requesting ideas for forums, feedback methods and ways in which training could be provided. The notion of on-line surveys was supported by eleven of the fourteen respondents.

Several suggestions were made regarding forum topics, some of these reflected a desire for more information on health related topics such as sugar content in diet which is not part of the HCC's mandate but rather something that Diabetes WA (for example) would cover. I thought it timely therefore to highlight the HCC's mandate here: "The Health Consumers' Council of WA (HCC) is an independent voice, advocating for patients in Western Australia. It offers a unique perspective on health policy and service delivery matters." (Source: The HCC"s website - http://www.hconc.org.au/aboutus/whoweare.php)

As result of the survey the HCC will be trialling and/or implementing several things, these will include:

After hours workshops

A mentorship program; this will include training potential mentors

Web-based surveys

Forums including web-based forums

Having on-line forums and surveys will mean that consumers in rural WA will have greater ability to participate and provide feedback. The HCC is also aiming to run its workshops via video-conferencing which again provides opportunities to those living away from the metropolitan area. The use of electronic media is also of benefit for those who have decreased mobility for whatever reason and who would like to provide a perspective or comment and/or participate in on-line discussions or forums. A further benefit will be that those who are unable to attend physically due to work, study or family commitments will be able to participate.

The Consumer Participation Program will be re-named the Consumer and Community Engagement Program to reflect the re-modelling previously mentioned and the wider scope and inclusion of the Program.

This is an exciting time for this particular aspect of the HCC's service provision and I am looking forward to implementing the changes.

The Global Health Media Project

"In a remote corner of South Sudan — where I was running a medical program with Médecins Sans Frontières/Doctors Without Borders in 2008 — I was called to a difficult birth in the middle of the night. When I arrived our doctor and midwife were trying to resuscitate the baby. I quickly realized that they didn't know how and I intervened. We started giving the baby breaths and he soon started breathing on his own.

This experience affected me deeply. I thought of all the health workers across the world who face the anguish of a newborn not breathing and don't know how to help. It's an infrequently needed but life-saving skill—a skill every birth attendant needs to know."

And so began the story of Deborah Van Dyke, NP, MPH — President and Founder of the Global Health Media Project. (http://globalhealthmedia.org)

Deborah Van Dyke and patient

The reasons I have included this Project in Health Matters are:

To demonstrate the care and compassion that many health care providers have and their desire to improve things for their patients

To provide this link as a resource to any of you who are working with people from new and emerging communities so you can gain some insight into what some health care facilities and methods may have been like in their past experience – the videos provide some great learning re conditions and facilities (http://globalhealthmedia.org/videos/)

To provide the above for those of you who are consumer representatives and CAC members to assist you in developing your knowledge of what health care experiences and facilities may have been like for people who access 'your' hospital or area of health interest

To demonstrate how cost- effective and accessible on-line resources can be for both health workers and consumers and how widely they can be accessed

I hope you enjoy browsing the site and find it as interesting and heart-warming as I did.

HEALTH CONSUMERS' COUNCIL
YOUR VOICE ON HEALTH

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