



HEALTH CONSUMERS'
COUNCIL
YOUR VOICE ON HEALTH

Annual Report 2014

The Health Consumers' Council (HCC) is an independent (not-for-profit) community based organisation, representing the consumers' voice in health policy, planning, research and service delivery.

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A copy is being provided to all members who attend the Annual General Meeting and copies are available to members upon request.

Board of Management

Nigel D'Cruz	Chairperson
Sally-Anne Scott	Deputy Chairperson
Cheryl Holland	Treasurer
Tony Addiscott	Secretary
Michelle Atkinson de-Garis	Member
Phillip Gleeson	Member
Tom Benson	Member
Elizabeth Kada	Member
Rasa Subramaniam	Member
Tricia Walters	Member

STAFF

Dr Martin Whitely	Acting Executive Director
Chrissy Ryan	Advocate
Carly Parry	Advocate
Maxine Drake	Advocate
Dr Ann Jones	Research Officer
Laura Elkin	Aboriginal Advocacy Manager
Leah Cooper	Aboriginal Advocacy Officer
Louise Ford	Consumer Participation Coordinator
Lucy Carter	Operations Manager
Eileen McRory	Administration Assistant

Thank you to the following staff who have worked at the Health Consumers' Council in the last year: Frank Prokop, Amy McGregor and Pieter De Marco.

Chairperson's Report

Nigel D'Cruz | Chairperson

After twelve months in the role of Chairperson, it is still with a great deal of humility and honour that I write this report. I want to acknowledge my fellow Board members for their extensive personal contribution of time, expertise, knowledge and high standard of professionalism. Their support has been invaluable. Having three Board members from regional Western Australia has ensured that both metropolitan and rural consumer needs are balanced. I would like to especially thank the Deputy Chair, Sally-Anne Scott for her unwavering support, without which I could not have performed my role.

Equally, the foundation of any successful organisation is the expertise, skills and professionalism of its staff. This annual report clearly displays the breadth and extent of programs, activities, submissions and engagements the staff of the Health Consumers' Council (HCC) have successfully delivered during the last twelve months. Their outstanding work ensures the voice of the consumer is heard by stakeholders across the ever growing and complex health industry in Western Australia.

The Annual Report highlights the sustained effort in meeting the demand for our advocacy services, notably in this year, the growth in mental health related issues. The Aboriginal Advocacy Program continues to be recognised as a leader in its field with requests for presentations on the program to be made locally in Western Australia and interstate. The injection of additional resources to this program will see it grow in the coming year.

Along with advocacy, the consumer representation program continues as one of the pillars of HCC service provision. I am proud to say that it was the opportunity to be actively involved and contribute to decision making as a consumer representative that originally attracted me to the HCC, and that interest and commitment remains today. The program continues to meet the growing demand for representatives across a diverse range of roles and committees. As in previous years, we would welcome more representatives from all demographics and across a multitude of industries to be the voice of the consumer in operational and strategic committees and forums.

The HCC continues to be actively engaged in influencing and responding to health policy development and direction. The wide range of subjects, such as Medicare Locals and the introduction of new mental health legislation in WA, has necessitated voicing our views on policy issues.

The HCC will continue to work collegiately with the State Government, the Health Department of WA, the Clinical Senate of WA, individual members, and member organisations to ensure the consumer perspective is balanced with the views of health care professionals, and that health systems promote positive consumer outcomes. To this end, we welcomed the Hon Dr Kim Hames, MLA, Minister for Health to a recent Board meeting to share his vision and advice on expanding consumer engagement, and how the HCC can contribute in an environment of a growing and ageing population and economic restraint. The insight he provided will aid our work going forward. We thank him for his time.

Mr Frank Prokop, Executive Director left us in July. I thank him for his efforts in leading the HCC and wish him well in his future endeavours. I would also like to acknowledge Phil Gleeson LLB, a long serving Board member who will be stepping down at the AGM. His support, expertise and legal acumen has been invaluable during his tenure on the Board.

On behalf of the Board, I thank the members and organisations that have supported the HCC this year. I look forward to your continued contribution in raising awareness of and advocating for health consumers' rights across Western Australia.

Acting Executive Director & Senior Advocate's Report

Dr Martin Whitely | Acting Executive Director



I joined the Health Consumers' Council as the Senior Advocate in December 2013. Following the resignation of Frank Prokop in early July 2014 I have been Acting Executive Director. On behalf of all the staff I thank Frank for the principled and passionate leadership he gave the HCC during his time leading our committed, capable team.

Thanks are also due to Chairperson Nigel D'Cruz and the Board for their significant commitment of time and expertise in an entirely voluntary capacity. It is the willingness of our board members and consumer representatives to give so generously of themselves that ensures the interest of consumers is the sole driver of HCC activities.

The financial contribution of the WA Health Department, who are ultimately funded by WA taxpayers, reinforces the obligation of the HCC to serve the interests of all health consumers (i.e. all West Australians).

I also need to thank our elected representatives. In particular the HCC continues to enjoy a very healthy working relationship with both the Minister for Health, the Hon Kim Hames, and his counterpart Roger Cook MLA the Shadow Minister. Both of these community leaders have an understanding of the complexities of health, and we are certain that we can continue our productive relationship with them. We have also had the opportunity to work constructively with the Minister for Mental Health, the Hon Helen Morton who has a long and productive history of involvement in the mental health sector.

Our core work - Individual Advocacy

Over the past year the Advocacy team has assisted well over 600 consumers with very diverse issues. The HCC is unique in that we are the only equivalent state service that provides such a comprehensive individual advocacy service. Our individual advocacy service grounds our work in reality and drives the systemic advocacy at the HCC.

There were several new additions to the HCC Advocacy Team and changes in roles during the past year. In December 2013 both Carly Parry (working three days a week) and I joined Chrissie Ryan as part of the individual advocacy team. Carly is a recent immigrant from the English Midlands where she worked as a domestic violence caseworker. Her appetite for hard work and her empathy for the often stressed and frustrated consumers she advocates for is a huge asset.

Chrissie continues to go beyond the call of duty particularly in supporting our most vulnerable consumers. Her detailed medical knowledge and extensive experience have helped to guide the advocacy team in dealing with some of our more challenging cases. Chrissie also deserves special mention for her efforts in holding the fort as the sole advocate for about six weeks in late 2013 before Carly and I joined the team.

To help fill the void in the Senior Advocate position two staff members have accepted three month part-time contracts (terminating in early November). Maxine Drake obviously needs no introduction and it is fantastic to have her 'institutional knowledge' available to all staff. Maxine, who also works part time as an 'Official Visitor', is now working two days a week

assisting our advocates and other staff as required. Our second temporary is also a very impressive individual. Dr Ann Jones, a former academic and electoral officer, is working three days a week primarily as a policy researcher. Ann is also helping the advocates with specific projects including co-ordinating the '5 Health Stories' project that the HCC is contracted to complete for the Consumer Health Forum.

During 2014 the advocacy team has been 'bedding down' our new case management system Lama. The system serves two purposes; it better enables advocates to monitor the details of individual cases and after the bugs are finally eliminated it will enable advocates to identify common threads in advocacy cases.

Approximately 30% of these cases relate to mental health issues, although mental health issues tend to be complex and our advocates spend approximately half their time attending to these issues. A worrying number of notionally 'voluntary' mental health patients have reported that they feel threatened that if they don't comply with the treating psychiatrists recommendation they will be made an involuntary patient. In recent meetings with both the Minister for Mental Health, the Hon Helen Morton and the Chief Psychiatrist, Nathan Gibson, I had the opportunity to raise concerns about this emerging problem.

Systemic Advocacy – the Mental Health Bill 2013 and Improved Pharmaceutical Regulation

One of the major systemic advocacy projects undertaken by the HCC team has been to lobby all Members of the WA Parliament to achieve improvements in the *Mental Health Bill 2013* that has been debated over the last six months. A detailed submission on this very complex piece of legislation (with over 500 clauses) was prepared by HCC and endorsed by seven other not-for-profit organisations in the mental health sector. These organisations include the Consumers of Mental Health WA (CoMHWA) with whom we are building a cooperative working relationship.

From a patient's rights perspective, the *Mental Health Bill 2013* is a significant improvement on the current legislation, the *Mental Health Act 1996*. For example the bill will allow patients, or carers, or mental health advocates, to request a review of any decision affecting a patient's rights. However, in Western Australia we are coming from a low base. Despite the improvements there remain significant problems. Particular attention needs to be paid to ensure that the criteria for making patients involuntary are not unintentionally broadened.

It must be remembered that people who are believed to be mentally unwell and in need of urgent involuntary detention and treatment have not committed a crime and that on many occasions throughout history the power to detain and treat those deemed to be 'mentally ill' has been abused in the guise of therapy or protecting the public. Despite the improvements in the Bill it is interesting to note that the maximum penalty for ill treatment or wilful neglect of a patient proposed in the bill is significantly less than the maximum penalties for causing unnecessary harm to an animal under the *Animal Welfare Act 2002*.

Although the majority of mental health practitioners are competent and responsible there are too many historical examples of mental health practitioners precipitating considerable harm, including avoidable deaths. And regrettably there is an unhappy local, national and international history of self-regulatory failure by some in the mental health professions.

At a recent meeting the Minister for Mental Health the Hon Helen Morton indicated that she had given thorough consideration to our submission and would be accepting some of our recommended amendments either in part or in full. The Minister stated other recommendations were unlikely to be adopted, although the Minister indicated that the

purpose of some of our recommended amendments could be achieved without adjusting the legislation.

In addition to our systemic advocacy on mental health the HCC has recently prepared a comprehensive discussion paper outlining potential reforms of Commonwealth Government pharmaceutical licensing and subsidisation processes. The HCC has had preliminary discussions with other agencies in regards to joint involvement in a campaign to promote reforms designed to increase disclosure to consumers of safety and efficacy data and reduce the cost to consumers and taxpayers of prescription medicines.

Two Emerging Issues – Pain Management and the transition to Primary Health Networks

The transition from Medicare Locals to Primary Health Networks is a significant emerging issue that requires monitoring. The details of the proposed changes will become available over the coming months. Concerns have been expressed about the possible loss of local planning input and the possible involvement of the for profit sector in determining the procurement of primary health care services.

Another emerging issue relates to pain management. Concerns about the potential for addiction and abuse of pain medications have led to a recent tightening of prescribing practices. Finding appropriate pain management relief has become an issue for some individuals with patients and doctors having to balance competing concerns; the need for effective pain relief, and the prevention of possible addiction and abuse.

Aboriginal Advocacy Program

Laura Elkin our Aboriginal Advocacy Manager, has shouldered responsibility for delivering the Aboriginal Advocacy Program throughout the year. Laura has done a great job. She is in heavy demand as a public speaker where she shares her insights into the challenge of closing the gap in terms of Aboriginal health outcomes. Her recent address at the conference organised by our national peak body, the Consumer Health Forum (CHF), was a standout performance in a forum that featured some very impressive and well credentialed speakers. Laura also took the lead role in preparing the HCC submission to the Legislative Council Inquiry into the Patient Assisted Transfer Scheme (available at <https://cpanel.blthosting.com.au/~hconcorq/couch/uploads/file/pats-inquiry-3.pdf>).

The HCC has recently recruited a second Aboriginal Advocate Leah Cooper. Leah is a Wongi woman originally from the Eastern Goldfields with an impressive CV working in government and community organisations. Leah has an obvious passion for improving Aboriginal health outcomes and Laura is very enthusiastic about working with her.

Consumer Representative Training

Louise Ford, our Consumer Participation Co-ordinator continues to provide excellent consumer representative training and run workshops in cultural competency. Her skills and knowledge were recognised when she was invited to address the African Women Summit (AWS). The AWS was a world forum on emancipation and advancement of the African girl child, held recently at the United Nations Headquarters in New York. Louise made a presentation on the experience of African women and girl refugees in adjusting to life in Australia.

The opportunities to expand our consumer representative training program are considerable. There is a growing recognition that engaging with consumers is central to the delivery of better health outcomes. The National Safety and Quality Health Service Standards – Standard Two (available at http://www.safetyandquality.gov.au/wpcontent/uploads/2012/10/Standard2_Oct_2012_WEB.pdf) was endorsed by all Australian Health

Ministers in 2011. This national standard requires health services to place greater emphasis on consumer feedback and input. As a result the demand for appropriately skilled consumer representatives is increasing rapidly. In addition the role of 'consumer representative' has become more onerous, creating the need for comprehensive training and support. The HCC is currently exploring opportunities with other training providers to develop a structured skill development pathway for health consumer representatives with the inclusion of a measurement tool to assess competency on completion.

Operations and Administration

The HCC has been very fortunate to be served by two extremely capable 'Operations Managers' this year. Amy McGregor recently became a first time mum and is on maternity leave until May 2015. It is great credit to the competence of both Amy and her replacement Lucy Carter that there has been a seamless transition. The HCC continues to get outstanding service from our Operations Manager. Both Amy and Lucy have more than coped with an enormous and diverse workload that often requires an 'after hours' commitment.

Another recent addition to the team is our administrative assistant Eileen McRory. Eileen is the voice most consumers first encounter when they ring the HCC. She has made a great start both in providing support to our advocacy team and in helping Lucy with administration. Our one day a week bookkeeper Clare O'Neill also continues to provide excellent service.

Ongoing Viability of the HCC

A recent meeting with senior staff from the WA Health Department helped to clarify the process of securing ongoing funding. We have every reason to be optimistic that the future of the HCC is secure. Funding is currently 'contracted' until 30 June 2015. For the 2015/2016 Financial Year the WA Health Department is moving to a five year 'outcomes based' contract. The WA Health Department officials informed us that the process of negotiating this five year contract would begin in February and be completed by May 2015. We discussed the nature of the 'outcomes based' approach to funding and how the HCC can begin preparing for the process. The officials expressed ongoing support for the role performed by the HCC and confidence that the process would progress smoothly.

Their confidence in the future of the HCC is well placed.



Aboriginal Advocacy Report

Laura Elkin | Aboriginal Advocacy Manager

In 2014 we welcomed Leah Cooper to the program. Leah is a Wongi woman and proud mother of three daughters, who joins us with a wealth of experience in community development and advocacy.



Sorry Day sand art photo taken by Keith Bodman

We have continued to work with Aboriginal consumers around the state. To provide individual advocacy assistance to patients and their families and linked in with our advocates. We continue to work in partnership with health services around the state to address systemic issues. We have presented two workshops to 20 Aboriginal Health Worker students at Marr Mooditj College; to over 100 consumers and 20 staff members in the Wheatbelt; to over 200 students and 20 staff at Notre Dame University; to our Kullarri Consumer Group in Broome, to over 200 delegates at the Consumer Health Forum Conference, Australia National Workshop in Melbourne. Other highlights include the National Aboriginal Community Controlled Organisation National Conference; the Aboriginal Health Council of WA state conference; the Perth Family Matters forum and a Cultural Security workshop with North Metro Health Service run by Richard Walley.

We have joined a new working party focusing on the country patient journey with the Aboriginal Health Council of WA and worked with them and the Health & Disability Services Complaints Office (HaDSCO) in the design of new resources for Aboriginal consumers. We've also joined a new working party at Royal Perth Hospital focussing on the needs of homeless patients, which unfortunately can end up including some country Aboriginal consumers when they are accessing services in Perth. We continue to work strongly with the Telethon Institute for Kids, especially the Kulunga Research Network. We have continued to meet with different Medicare Locals and will soon be providing training to their consumers and staff. We've been working with the Better Aboriginal Heart Health in WA project, which is highlighting best practise cardiac care for Aboriginal patients and will be published soon. We've also been involved in the Missing Voices Project with Edith Cowan University which is researching communication difficulties for Aboriginal patients after stroke or traumatic brain injury.

We continue to sit on a number of existing advisory groups working in partnership to improve service delivery and outcomes for Aboriginal patients including: the Child and Adolescent Health Service Aboriginal Health Action & Advisory Group; the North Metro and

Sir Charles Gairdner Hospital Reconciliation Action Plan working parties; the WA Rural Health Outreach Advisory Group and the Wheatbelt Regional Aboriginal Health Planning Forum. We are still working closely with the Yagarrbulanjin Aboriginal Mental Health Carers Group and also the Kimberley Mental Health Consumer Carer Advisory Group.

We had been waiting for news as the COAG Closing the Gap funding cycle came to an end in June. Whilst there is still some uncertainty about all the National Partnership Agreements for Closing the Gap in Aboriginal & Torres Strait Islander life expectancy and disparity by 2030, we welcome news that the State Government has committed to funding the majority of those programs for the next 12 months. These programs have been funding a significant number of Aboriginal Liaison and Outreach workers across the state as well as many other health programs for the previous five years. There is also uncertainty around future funding for all Social and Emotional Well-Being programs.

Long term planning needs commitments to long term funding and if we really want to ensure we end the disparities by 2030 we need to continue to work in partnership with Aboriginal consumers and health services and continue the leadership and commitments made through the Close the Gap pledge. There are already encouraging signs that we are beginning to make a difference, especially in maternal and child health.



Consumer Participation Program

Louise Ford | Consumer Participation Coordinator

As the Annual Report goes to print we are waiting for new information brochures to be printed for the Program. These informative and attractive brochures have been reviewed and re-vamped in collaboration with HCC Operations Manager Lucy Carter and are both pleasing to the eye and easy to read. They tie in well with the new HCC logo and the re-vamped website. They are visually appealing and, in the case of the latter, informative.

Consumer Representation

During the 2013-2014 financial year as the Consumer Participation Coordinator I have run several workshops, presentations and forums and assisted with the facilitation of others. These have included:

- Four Consumer Representative Skill Development Workshops with a total of 43 attendees
- A forum regarding women's health – 'The social determinants of health, and gender equity principles' – guest speakers were Sue Lee, Community Development Program Manager, Women's Health and Family Services and Kathy Blitz-Cokis, Women and Newborn Health Service, Women's Health Policy and Projects Unit. The focus of the forum was the empowerment of female health consumers - March 2014
- A workshop engaging with consumers to discuss 'the next level' of skill development for consumer representatives – January 2014
- A roundtable - Consumer Representation in 2014 and Beyond – to discuss the way forward with consumer representatives – January 2014
- Presentation to ConnectGroups regarding consumer representation and engagement – May 2014
- Co-facilitating two workshops for HCC member and non-member organisations - February and March 2014
- An information session regarding Ehealth and Telehealth

Further opportunities for consumer engagement and input have been provided via:

- Consumer Consultation Workshop - End-of-Life Care in Acute Hospitals
- Coordinated Veterans' Care Program Workshop at Murdoch Hospital Focus group - School of Nursing and Midwifery at Curtin University
- National Clinicians Forum - The WA Cancer & Palliative Care Network
- Oxford Day Surgery and Dermatology information session regarding consumers
- Family and Domestic Violence Advisory Group - WA Health
- Medicines Australia Code of Conduct Consumer Workshop
- Improving the Management of Cognitive Impairment using the National Safety and Quality Health Service (NSQHS) Standards - The Australian Commission on Safety and Quality in Health Care
- Consumer Focus Group - Australian Commission on Safety and Quality in Health Care

The above sessions and opportunities were promoted via the HCC eNews and personal email as well as in hard copy to those without email access.

Currently there are sixty five placed consumer representatives participating on one hundred and nineteen boards/committees/CACs and advisory groups/councils. It is noted that many requests the HCC now receives for consumer representatives are for high level placements requiring high skill sets accordingly. The HCC is looking into this and exploring strategies to accommodate all who are interested in providing a consumer perspective.

The following departments/organisations requested a consumer representative in the last financial year.

- Dept. of Health – Epidemiology Branch - The Patient Evaluation of Health Services (PEHS) Program
- North Metro Health Service and Medicare Locals - Executive Partnership Group
- Australian Medicare Local Alliance - Clinical Engagement & Cross Sector Collaboration Project Advisory Committee
- Wounds West - Clinical Governance Committee
- Dept. of Health – Epidemiology Branch - WA Chronic Conditions Self-Management Reference Group
- Curtin University - School of Nursing & Midwifery Advisory Board
- Dept. of Health - BreastScreenWA
- Bethesda Hospital - Safety & Quality Committee
- Dept. of Health - Drug & Alcohol Office
- Dept. of Health - Health Strategy and Networks Strategic System, Policy & Planning
- St John of God Hospital – Midland - Community Advisory Council
- Dept. of Health - Women's & Newborn Health - WA Women's Health Strategy - Senior Officer's Group (SOG)
- Dept. of Health – Health Strategy and Networks - Falls Prevention Health Network Executive Advisory Group
- Dept. of Health - WA Clinical Deterioration Statewide Executive Steering Committee

One EOI did not receive any response/s, one placement remains pending whilst another was withdrawn by the provider after a change of circumstance.

Consumer Representative Reports

In line with the requirements of a consumer representative, a request for consumer representative reports was sent to consumer reps on the 4th of June 2014 with a closing date of the 4th of July. A total of six people provided reports which equates to a 9.23% response rate. The HCC thanks those who responded for their effort, accountability and commitment.

According to the reports received, concerns include:

- Funding cuts/issues – implications for health consumers
- Tokenism
- Meetings few and far between
- Activity Based Funding
- Lack of consumer representative inclusion in meetings
- Amount of documents to be reviewed
- Delays in receiving material to be reviewed
- Detailed medical information that is not 'translated' for representatives

Other information has been provided in the Reports however it is not appropriate to disclose this for reasons of confidentiality and anonymity.

Consumer Representative Recruitment

Potential consumer representatives have been recruited through the workshops, advertising on the HCC website, e-News and through our networks. This has led to engagement with a diverse cohort, which is essential to refreshing the program and ensuring that it remains relevant.

There is a need to recruit potential representatives from a range of age, socio-economic, family structure, health service experiences and minority/disadvantaged groups to ensure we provide a voice that is truly representative and reflective of WA's population.

A community participation and development approach to gaining consumer input has the potential to support greater diversity in consumer representation and lend itself to community forums as a means of accessing consumer perspectives and experiences.

Consumer Representative Network Meetings (CRNM)

These meetings are held bi-monthly with attendance fluctuating. It has been pleasing to welcome some new members and to see the return of some more experienced ones. Towards the end of 2013 a small group of consumer representatives who are regular attendees developed new Terms of Reference for the meetings. These provide a sound framework for members and clearly articulate responsibilities, guidelines, the role of the group and that of the HCC.

The meetings are facilitated by members and include opportunities for networking, information sessions and guest speakers. Facilitating meetings provides an opportunity for members to develop skills and confidence, all useful in their consumer representative roles.

HCC Consumer Advisory Council (CAC) Chairs' Meetings

Meetings are held bi-monthly including two meetings per annum for all CAC members with the remainder being for Chairs only. Members value the opportunity to share their experiences and to learn from each other at the meetings. The past twelve months have seen changes in the group with new Chairs attending and other Chairs standing down from their positions. Currently members are being encouraged to update their Terms of Reference. The majority of members report that the organisations they are part of are supportive and inclusive of their CAC.

Other Activities

Other areas that have been engaged in include:

- Co-delivery of WA Health's Cultural Competency Training by request of the Senior Policy Officer, Cultural Diversity Unit, Dept. of Health – Fee for Service (2)
- Health Consumer Rights and Responsibilities for CaLD – presented at a Parent's Night – Balga Senior High School by request; ditto for students attending the Central Institute of Technology in Northbridge
- Eight Fee for Service Cultural Competency workshops have been facilitated for staff at Peel Health Campus (1), Holyoake (2), Royal Perth Hospital (4), Bentley Armadale Medicare Local (BAML) (1)
- Two Fee for Service Cultural Competency workshops for individuals on site (HCC)
- A presentation regarding the importance of including fathers in the maternity process was made to fellow members of WARHAC (WA Refugee Health Advisory Committee). This was in regard to health consumers from new and emerging communities being unfamiliar with the health system in WA and vice versa.

In order to build networks, improve the spread of information and to educate health care providers as the Coordinator I initiated Diversity Dialogues. This is becoming an increasingly popular forum and has proven a sound base with which to develop partnerships, for example Alzheimer's Australia WA. The initiative has a community development approach and engages CaLD community members to share cultural information and perspectives with providers. Research has shown this is critical to effective health care, adherence to medical advice and to recovery.

To facilitate this we have run three Diversity Dialogues forums, attended by a total of 74 people on the following topics:

- The use of interpreters in health care provision
- Men's Health
- Dementia

All in all it has been a very busy year!



Men's Health Form Speakers, Assaad Salame & Nelson Muhirwa





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

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