



SERVICE DELIVERY DATA REPORT

HEALTH CONSUMER SUPPORT SERVICE

Reporting period:

Year: **2018**

July to December 2018

Organisation Name: Health Consumers' Council
Completed by: Pip Brennan
Contact Phone Number: 9221 3422

SECTION 1: SERVICE DELIVERY DATA OUTPUT MEASURES

1. CONTINUOUS SERVICE PROVISION FOR SERVICE ONE & TWO

- 1.1 The number of hours per week the service operated: 40
- 1.2 The number of weeks the service was operational during the reporting period: 26
- 1.3 If appropriate, description and explanation of any periods of time during the reporting period when the service was not available at 100% funded capacity:

Office closed 21/12/18 and reopened 7/1/19 for Christmas break.

Also closed for WA public holiday of 24th September – Queens Birthday public holiday

SERVICE ONE - HEALTH CONSUMER: INDIVIDUAL SUPPORT

2. DESCRIPTION OF SERVICE USERS

KEY ELEMENT 1 – Individual Support

Was this Key Element selected as part of the service model in your Service Agreement?

Yes No

If yes, you are required to submit data for all of the tables under 2.1 and 2.2.

2.1 The number and characteristics of **individuals** who received Individual Support.

a) Gender

Gender	Number
Female	148
Male	93
Unknown	1
TOTAL <i>(Total of all tables in 2.1 should be the same)</i>	242

b) Age

Age	Number
Under 20 years	20
20-29 years	18
30-39 years	48
40-49 years	46
50-59 years	45
60 years and over	57
Unknown	8
TOTAL <i>(Total of all tables in 2.1 should be the same)</i>	242

c) Ethnicity

Ethnicity	Number
Aboriginal/ Torres Strait Islander	7
Culturally and Linguistically Diverse Background <small>This includes those who self -identify that born overseas for countries other than Canada; Republic of Ireland; New Zealand; South Africa; United Kingdom; and USA.</small>	27
Other <small>This includes Australian born (<u>not</u> Aboriginal/Torres Strait Islander) and other main English speaking countries (Canada; Republic of Ireland; New Zealand; South Africa; United Kingdom; and USA)</small>	148
Unknown	60
TOTAL <i>(Total of all tables in 2.1 should be the same)</i>	242

2.2 The number of individuals who received Individual Support by health location/setting.
(Totals of all tables in 2.2 should be the same and equal that of 2.1)

a) Health Setting

Setting	Number
Public Health	135
Private Health	3
Public Mental Health	104
Private Mental Health	0
Unknown	0
TOTAL	242

b) Geographical Location

Location	Number
Perth Metropolitan Area	224
Rural, Regional and Remote Western Australia	18
Unknown	0
TOTAL	242

2.3 The number and type of presenting issues of individuals receiving Individual Support during the reporting period

(Individuals could present with more than one presenting issue – therefore the total will not equate to the total of tables in 2.1 and 2.2)

Type of Presenting Issue	Number
Health - Costs	17
Health - Rights	42
Health – Disputes Diagnosis/ Treatment	57
Health – Access	19
Health – Access to records	4
Health – Other	2
Mental Health - Costs	3
Mental Health - Rights	33
Mental Health – Disputes Diagnosis/ Treatment	45
Mental Health – Access	13
Mental Health – Access to records	4
Mental Health – Other	3
TOTAL	242

3. SERVICES PROVIDED

KEY ELEMENT 1 – Individual Support

Was this Key Element selected as part of the service model in your Service Agreement?

Yes

No

If yes, you are required to submit data for all of the tables under 3.1 and 3.2. Submit data in table 3.3 if relevant to your service model.

3.1 The number and type of Individual Support during the reporting period

Occasions of Service - Type of Individual Support	Number
Telephone Support	932
Home Visiting	0
Online Support – including email	525
Face to Face	366
Formal Referral/Active Linkages	38
TOTAL	1861

KEY ELEMENT 2 – Information and Linkages

Was this Key Element selected as part of the service model in your Service Agreement?

Yes

No

If yes, you are required to submit data for all of the tables under 3.4.

3.2 The number and type of information and linkages during the reporting period

Type of Information and Linkages	Number
Information provision	517
Active linkages for non-users of the service	93
TOTAL	610

KEY ELEMENT 3 – Community Education

Was this Key Element selected as part of the service model in your Service Agreement?

Yes

No

If yes, you are required to submit data for all of the tables under 3.5.

3.3 The number and type of community education activities provided by the service and the number of people that attended.

Type of Community Education Activities	Number Provided	Total No Attending
Workshops/Training		
Introduction to Consumer Representation 7/8	1	12
Advanced Consumer Representation 1/9	1	7
NMHS CAC Strategic Planning Session 14/12	1	45
Seminars/Presentations		
Consumer Rights Presentation – World Stoma Day	1	75
Community Activities (e.g. promotional stalls at fairs and festivals)		
Partnership Event with Derbarl Yerrigan Health Services, Yorgum, HCC & Wungening Aboriginal Corporation- Mental Health Week	1	50
NAIDOC stall at Champion Centre Armadale 10/7/18	1	128
Information Sessions		
My Health Record training session 12/9/18	1	5
Cultural Engagement		
Langford Aboriginal Association Community Conversation on My Health Record and obesity collaborative project	1	6
Other – please categorise		
RESILnZ Podcast 26/7	1	150
Heritage FM – radio show 5/9/18	5	500
TOTAL	14	978

KEY ELEMENT 4 – Interagency Collaboration

Was this Key Element selected as part of the service model in your Service Agreement?

Yes

No

3.4 The number and type of activities that work towards interagency collaboration.

Type of Activity Working Towards Interagency Collaboration and Strategic Planning	Number
Number of projects or partnerships worked on with other agencies	
Bayswater Futures – exploring deliberative democracy models 10/10	1
Derbarl Yerrigan Health Services & Wungening Aboriginal Corporation- Mental Health Week working group meetings	8
Langford Aboriginal Association 6/9/18, 27/9/18, 18/9/18, 11/10/18	4
Number of relevant interagency forums or networks participated with	
CaLD & Disability interagency meeting 4/12/18	1
Midland Women's Healthcare place afternoon tea 8/8/18	1
Marr Mooditj Training Centre 17/8/18	1
Ethnic Community Council of WA 15/8/18	1
Ishar multicultural Women's health centre 16/8/18	1
Fremantle Women's Health 23/8/18	1
Cross Cultural Intellect 30/8/18	1
Australian Digital Health 12/9/18	1
My health record AOD sector briefing 2/7/18	1
TOTAL	22

SERVICE TWO - HEALTH CONSUMER: SECTOR SUPPORT

KEY ELEMENT 3 – Community Education

Was this Key Element selected as part of the service model in your Service Agreement?

Yes X

No

If yes, you are required to submit data for all of the tables under 3.5.

3.5 The number and type of community education activities provided by the service and the number of people that attended.

Type of Community Education Activities	Number Provided	Total Number of People Attending
Workshops/Training		
Diversity Dialogues 16/10/18	1	6
Seminars/Presentations		
Policy Essentials Program Presentation – engaging with consumers 28/8	1	15
Midwest Health Service – presentation on HCC and the Patient Experience	1	12
Obesity Summit Presentation (here or at the end?) 17/10	1	200
Australian College of Nurse Practitioners WA Symposium presentation on the findings of the consumer engagement project done as part of the Obesity Collaborative	1	65
Emergency College of Medicine national conference – Panel Discussion 19/11	1	320
Silver Chain Executive Group presentation – consumer engagement	1	33
Intensive Care Network Workshop presentation on consumer engagement	1	38
WA Industrial Relations Commission presentation on mental health advocacy, mental health in the workplace	1	43
Presentation to the TRACS group 16/7/18	1	9
Community Activities (e.g. promotional stalls at fairs etc)		
Forums		
World Kindness Day Forum 13/11/18	1	102
Cultural Engagement		
Langford Aboriginal Association NAIDOC Breakfast	1	58
NAIDOC – therapy focus 13/7/18	1	8
Aboriginal Reference Group Meeting 15/8	1	7
St John of God Hospital Midland mediation meeting with staff and carer	1	13
Other		
TOTAL		929

KEY ELEMENT 4 – Interagency Collaboration

Was this Key Element selected as part of the service model in your Service Agreement?

Yes

No

If yes, you are required to submit data for all of the tables under 3.6.

3.6 The number and type of activities that work towards interagency collaboration.

Type of Activity Working Towards Interagency Collaboration and Strategic Planning	Number
Number of projects or partnerships worked on with other agencies	
Community Link Booth Project 3/7, 9/8, 29/8, 7/11, 19/12	5
Fiona Stanley Hospital Family Birth Centre Project WG meetings 11/7, 18/7, 25/7, 26/9, 3/10	5
World Kindness Day Working Group (HCC, WA Health Cultural Diversity Unit, WA Primary Health Alliance, Ishar et al) 4/7, 1/8, 15/8, 5/9, 26/9, 12/12	6
Council on the Aged WA – Mark Teale meeting 9/7, 13/9	2
Linkwest – meeting with Jane Chilcott 27/7, 3/8	2
Cockburn Integrated Health meeting 3/8, 13/9	2
Conflict of Interest – Cancer Care costs – Cancer Council, Cancer and Palliative Care Network, HCC 3/8, 17/8, 16/11	4
WA Primary Health Alliance Liaison meetings with CEO 23/8, 18/10	2
WA Primary Health Alliance – co-host of the Commissioning Framework consultation, 21/11	1
Fremantle Women’s Health Care Place meeting with HCC Cultural Diversity Coordinator	1
Health Equity Conference 2019 co-convened by WA Health’s Cultural Diversity Unit, Ethnic Disabilities Advocacy Council and HCC 28/9, 19/10, 7/11, 29/11	4
Royal Perth Hospital – Safety Week 3/9/18	1
Aboriginal Health Council of WA – Justice Project. 3/8, 22/11, 27/11, 22/10, 18/10, 10/10, 18/10, 22/10, 29/10, 10/12	10
People with Disabilities of WA. 12/9, 15/10, 16/10, 22/10, 29/10, 5/11, 12/11, 16/11, 19/11, 3/12, 10/12,	11
WAPHA – Alcohol & other Drugs Project	5
Health Engagement Network – Community of Practice. 28/9, 20/9, 6/7, 3/7, 12/7, 30/7	6
Dept of Health - Cultural Engagement Partnership Projects Meeting with Ruth L, Kelli and Pip 13/9/18	1
SCGH Partnership Project initial concept meeting. Shirley Jansen 4/9/18	1
Patient First – ATSI resources 13/9/18	1
Conflict of Interest – Cancer Services 3/8, 17/8	2
Number of relevant interagency forums or networks participated with	
Mental Health Advocacy and NDIS – Consumers of Mental Health, People with Disabilities and HCC 3/7/2018	1

Consumers Health Forum – HCCs across Australia 17/7, 16/8, 13/9, 20/9, , 15/10, 10/12 face to face meeting 10/9, attendance at CHF AGM 26/11	9
Family and Domestic Violence – exploring cooperative models convened by the Women’s Community Health Network and WACOSS 28/8	1
CEO Roundtable on Palliative Care 30/8, 7/9	2
Consumers of Mental Health WA – Consumer Participation meeting 1/8 & 31/8	2
Multicultural Diversity Café 29/8/18	1
Notre Dame University 10/9/18	1
Change the World 29/10/18	1
Social Inclusion Mirrabooka 18/10/18	1
Child & Adolescent Health Service workshop for parents, carers & young people 3/12/18	1
Local Government CaLD forum 4/12/18	1
Integrated Case Management – panel meeting 7/8/18, 16/8/18	2
WAPHA – country to city ITC service model development 13/8/18	1
People with Disabilities WA focus group 14/12/18	1
Lotterywest community investment framework 5/12/18	1
Partnership proposal meeting - South Metro TAFE 3/10/18	1
Dementia Australia networking meeting 7/8/18	1
Consumers of Mental Health WA. People with Disabilities WA & HCC – individual mental health advocacy 3/7/18	1
Family Birth Centre town hall planning meeting 25/7/18, 13/9/18	2
Chronic Pain Australia 28/8/18	1
Helping Minds 27/7/18	1
Chemo at Home 16/8/18, 13/9/18	2
National Law Consultation Forum for health practitioner regulation 15/10/18	1
Dementia Australia partnership introduction meeting 7/8/18	1
Gynaecological Advocacy and Information Network Meeting 3/10/18	1
WA Health Translation Network WAHTN – Discuss Consumer & Community Health Research Network (CCHRN) 6/11/18	1
Visit to The College for Educational and Clinical Art Therapy (CECAT) 13/9/18	1
WA Council of Social Services & HCC catch-up 28/9, 2/11, 20/12	3
Not For Profit Organisation Peaks Forum 14/8, 13/9, 8/11	3
TOTAL	49

3.7 Number of policy and information activities

3.7 The number and type of Policy Advice and Information activities – Needs Analysis (consultations).

Type of Policy Advice and Information Activities	Number of Activities	Number of Consumers Consulted
Family Birth Centre - Forum	1	31
Mesh Clinic Meeting Surveys	2	58
Exposure of Radiation consumer consultation 17/7/18	1	1
Cancer Care Costs Survey	1	41
Role of Type 2 Diabetes prevention and Management – for the Education and Health Standing Committee	1	748
TOTAL		879

3.8 Mechanism for Provision of Advice and Information

Mechanism for Provision of Advice and Information (through)	Number of Activities	Number of Instances
Consumer Representation* (HCC appointed) participation on Department committee or forum		
Health Networks Leadership Forum 16/8, 18/10	1	2
State Oral Health Advisory Council 17/8	1	1
Family and Domestic Violence Advisory Group meeting 28/8	1	1
Clinical Senate Executive Advisory Group, 9/8, 8/11, 23/11/18, 13/12 Aboriginal Forum 23/11	2	5
Women's Health Conference Meeting 11/9	1	1
Safety and Quality Senior Leadership Reform Group Meetings for 2018 - 8/8, 10/8, 12/12	1	3
Arts and Health Consortium Meetings 17/7, 9/10	1	2
Obesity Collaborative Expert Advisory Group 10/7, 6/8, 1/10	1	3
Sexual Health and Blood Bourne Virus 12/7, 15/10 Consumer engagement meetings 11/10	2	3
LGBTI Health Strategy Working Group	1	4
SCGH Consumer Advisory Council meeting 14/8/18, 9/10/18, 11/12/18, 7/12/18	2	5
SCGH Standard 2 Committee meeting 23/8/18	1	1
Aboriginal Health Research Translation Group 24/7/18	1	1
Consumer Advisory- participation on Department Committee or Forum – where HCC provides general support		
High Value Healthcare Forum 13/7	1	1
Medical Research Future Fund Priorities Consultation 6/8, 13/9	1	2
Renal expert advisory group (EAG) 15/11/18	1	1
Curtin University – Research Project on efficacy of Community Resource Centres 20/8	1	1
National HIV Strategy Consultation Forum 12/7, 3/9, Sexual Health and Blood-borne Virus Meeting (Co-Chair)	1	3
Digital Health Strategy 23/10, 14/11	1	2
Multicultural Policy Framework discussion 5/8/18	1	1
Consumer & Carer Reference Group 10/8/18	1	1
National Bowel Cancer Screening Program Resource Reference Group 4/9/18	1	1
National Clinical & Community Advisory Group Quarterly Meeting 24/9/18	1	1

Immunisation Forum planning meeting 25/7/18	2	2
Immunisation Forum workshop 6/8/18		
Health Networks Leadership Forum 13/9	1	1
Mental Health Research & Young People 3/10/18	1	1
The School of Medicine External Advisory Board Meeting 7/8/18, 2/10	1	2
Participation on (other) committees or forums whose purpose is aligned with the Department's strategic priorities		
Social Policy and Practice Research Consortium (UWA/ WACOSS/ Centre for Social Impact) 3/7, 13/9, 1/10	1	3
WACOSS - State Not for Profit Peaks Outcomes Framework 9/10/18	1	1
Dept of Finance - Delivering Community Services in Partnership Policy 16/10/18	1	1
Notre Dame School of Medicine Fremantle Expert Advisory Board 7/8, 2/10	1	2
WA Health Translation Network Board 27/8, 6/11, Forum 6/11. Consultation interview 7/12	3	4
Advanced Health Research Alliance Consumer and Community Involvement Steering Committee meeting 31/10, Forum 12/11 (Sydney)	2	2
Consultation – Advice meeting – P Wynn Owen Justice Health Project 4/7	1	1
WA Aged Care Liaison Group	1	1
Prison Health Governance Advisory Committee	1	3
Stillbirth Hearing – evidence to Committee 13/9, 10/8	1	2
Australian Commission on Safety and Quality in Health Services – Partnering with Consumers meeting 13/8, 13/9	1	2
National Registration of Practitioners Law Review 15/10	1	1
National Strategic Approach to Maternity Services 15/10	1	1
Attendance at the Gynaecological Health Forum 20/10	1	1
Reconciliation Action Plan Committee 31/10/18	1	1
Mental Health Assertive Patient Flow briefing at EMHS, with Kingsley Burton 6/12	1	1

Sustainable Health Review Panel meeting 22/8, 20/9, 8/10, 29/11 Panel page-turning session 16/11 Panel Follow up meeting Ryan Sengara 29/8, 27/9 Meredith Hammat 3/9, Susan Mylne 3/9 Australasian College of Health Service Management Sustainable Health Review Event 26/7 Art of the Possible 25/7 Workforce Training 27/7 Peel Roundtable 19/9 Consumer and Carer Reference Group 26/7, 20/8 Combined Clinical and Consumer and Carer Reference Group 22/8, 18/9 Thank you event 11/12	1	18
Palliative Care Network Forum Senate Inquiry recommendations -30/10 palliative care, 20/11 advance care planning	1	2
Formal or documented responses to policy issues aligned with the Department's strategic priorities		
My Health Record - Australian Digital Health Agency – Shauna Gaebler CoMHWa meeting 12/7, teleconference 17/7, meeting with WAPHA 12/9, 3/12, briefing with WAPHA 30/10 Attendance at special meeting regarding youth 3/10 Attendance at forum 28/11 (Sydney)	4	7
Meetings with (Department's) Minister, Ministerial staff and/or Department staff		
WA Minister for Health Advisor meeting 5/7	1	1
Briefing Meeting with the Health Minister's staff on the Noongar Boodja birthing on country project	1	1
Director General: Catch Up 4/10	1	
Office of the Chief Psychiatrist/ HCC Meeting 29/8, 20/11	1	2
NMHS Board - Catch up Pip Brennan and new Chair of Board, Jim McGinty 13/9	1	1
Meeting with AMA President 26/9	1	1
Meeting with Director of the Australian Health Practitioner Regulation Agency 27/9	1	1
Meeting with the Health and Disability Services Complaints Office 1/11	1	1
Meeting with Director of Department of Communities 1/11	1	1
TOTAL	65	115

3.9 Source and Number of Request for Policy Advice and Information

Source of Request for Policy Advice and Information	Number of Activities
Department of Health – Royal Street	
Womens and Newborns Health Networks Lead update meeting 4/10, 2/11	2
Patient Opinion Community of Practice 9/11	1
Renal Health Network Executive Advisory Group	1
Contracting and Purchasing Division – meeting Rebecca Hamilton	1
Clinical Leadership and Reform – meeting with Karen Bradley 11/12	1
Patient Safety Surveillance Unit meeting – 2019 priorities	1
Outpatient Reform Project	1
Bariatric Services Project	1
East Metropolitan Area Health Service	
North Metropolitan Area Health Service	
Meeting with new Chair of the NMHS Board 18/7	1
NMHS Board – People Engagement and Culture Board Committee Meeting 15/8, 10/12	4
Meeting with Theresa Marshall re CAC review 14/11 and 3/12	
North Metro Health Service Aboriginal Cultural Advisory Group meeting and NMHS peer review meeting 4/12/18	2
Pelvic Mesh Clinic 31/8	2
Prep meetings with WA Pelvic Mesh Support Group 16/8, 8/11	
Meeting with KEMH and Gynaecological Awareness Information Network 3/10	1
South Metro Area Health Service	
Training Centre for Subacute Care (TRACS WA) meeting 17/7	2
Aboriginal Liaison Meeting 17/8	1
SMART Sepsis Research project meeting – Susan Benson 5/11	1
Child and Adolescent Health Service	
Meeting regarding Complex Care Coordination after hours service 25/9, 22/10	2
Perth Childrens Hospital Consumer Advisory Committee 10/12/18	1
WA Country Health Service	
Stakeholder interview regarding the WACHS Strategic Plan 16/10	1
Meeting with WA Country Health Service 17/8/18	1
State Government (other agency)	
Supporting Communities Forum 17/9, 10/12	13
Data Sharing and Linkage Working Group 5/7, 2/8, 8/8, 29/8, 15/11	
Our Communities Report 1/8, 4/10, 5/11, 15/11, 20/12	
Outcomes Framework 9/10	
Prison Health Clinical Governance Advisory Committee 1/8, call with Eric Dillon, 16/11	2
Office of the Inspector of Custodial Services – 21/9/18 & 25/10/18	2
Funding and Contracting Services Liaison	1
Service (self-initiated)	
NMHS Roslyn Elmes, Executive Director, Mental Health, Public Health and Ambulatory Care Meetings 13/7, 5/9 meeting	2
TOTAL	48

COMMENTS ON SERVICE DELIVERY DATA OUTPUT MEASURES

SERVICE ONE

Advocacy Activities

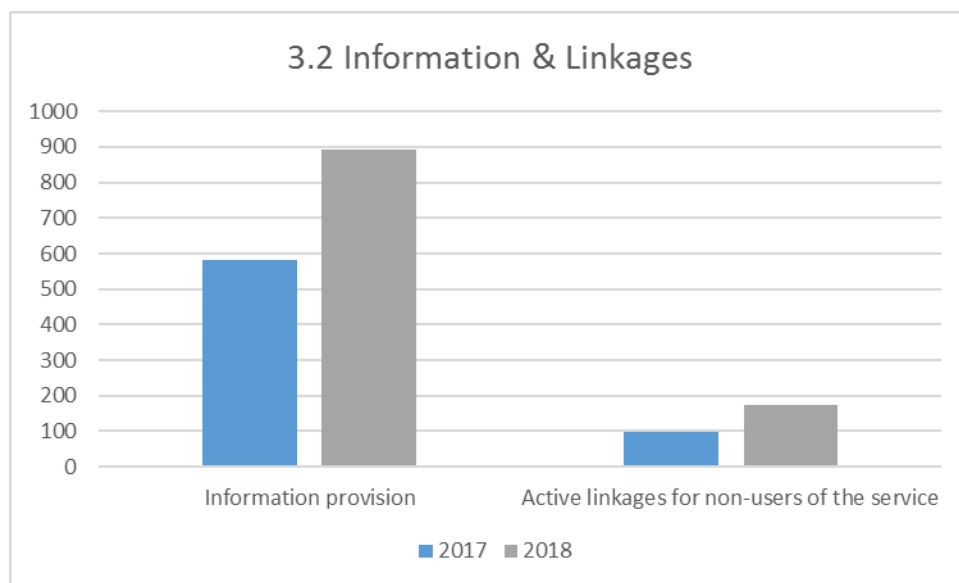
HCC provides a flexible individual advocacy service for West Australians seeking assistance with access to health service and/or redress processes. In this reporting period we have continued to refine and develop our advocacy processes. It is often the case that consumers approach HCC with unrealistic ideas of what might be achieved. In addition, we have noted that when consumers are contacted to be advised their current case is being closed, they can express concern.

To better manage expectations both about what can be achieved through our advocacy service, an intake form has been developed by staff to guide the initial conversation. This helps to ensure consumers have clarity about what we are setting out to do to support them through our advocacy service, and where it may come to a natural end. We utilise an interaction-based model of advocacy, rather than using a case management model. We aim to undertake all the strategies which assist in a resolution, and to finalise the matter either when there is a resolution, or when all useful avenues have been exhausted. However we always stress to consumers to contact us for other issues that may arise. Many consumers have chronic conditions and many interactions with the health system, and there are usually no limits to how often people can come back to us.

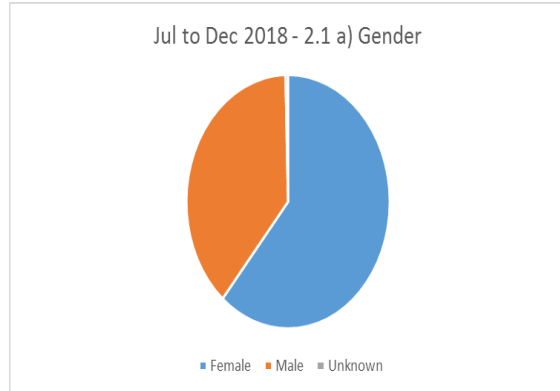
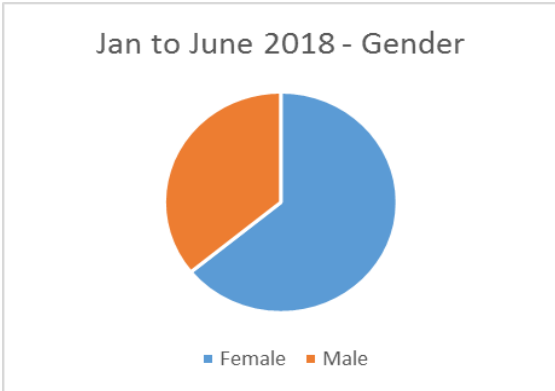
Advocacy is always complex work. Designing an advocacy interaction that addresses someone's circumstances, empowers them for future interactions but acknowledges that independent advocacy can transform the power balance and therefore the healthcare that people receive.

Advocacy Cases and Information and Linkages

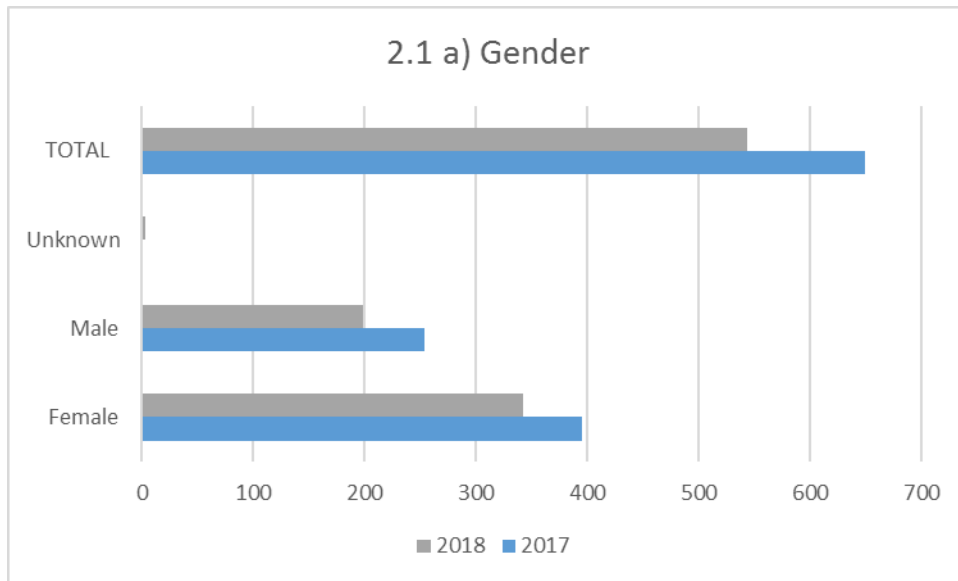
From July to December 2018, there were 242 individual advocacy cases, compared to 302 cases from January to June 2018. There were however 1066 information and linkage services provided for consumers through either our receptionists or the advocates, so that consumers' enquiries are being resolved without needing to be escalated to advocacy cases.



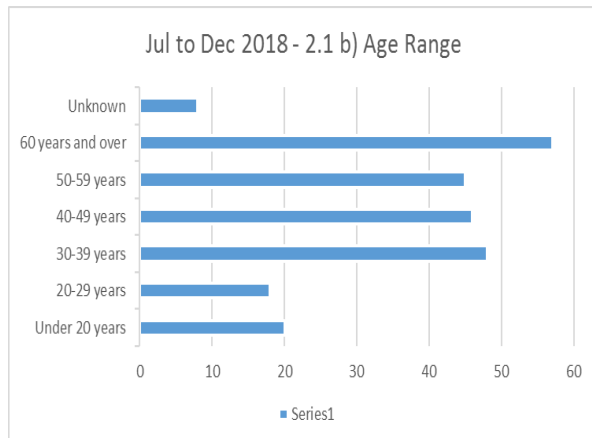
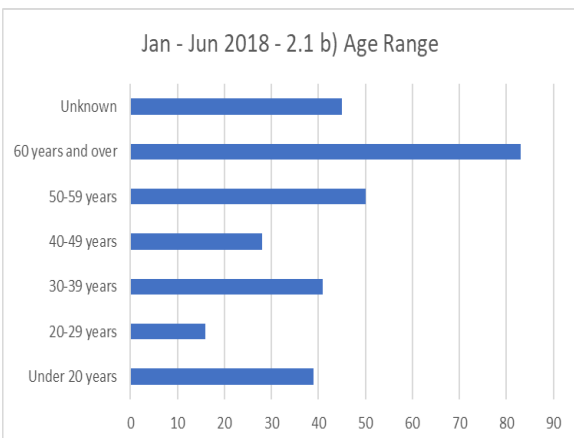
Advocacy Cases – Gender

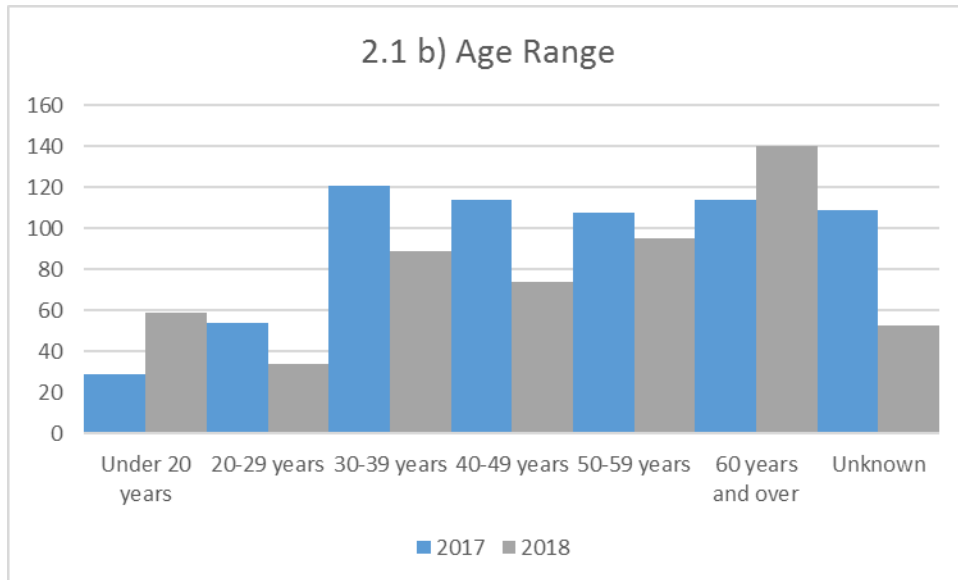


When looking at a comparison of the six months from January to June and then from July to December 2018, there is a similar proportion of females to males – and the graph below shows that over time, women are more likely to contact HCC.

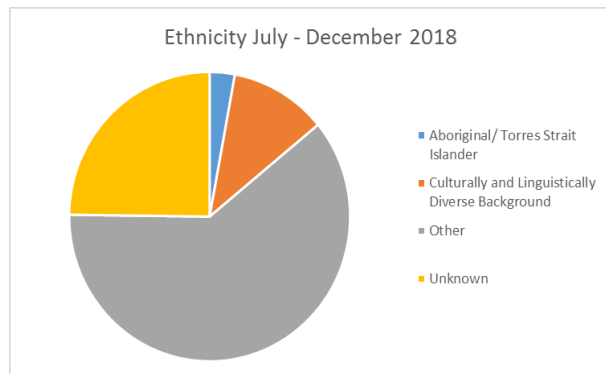
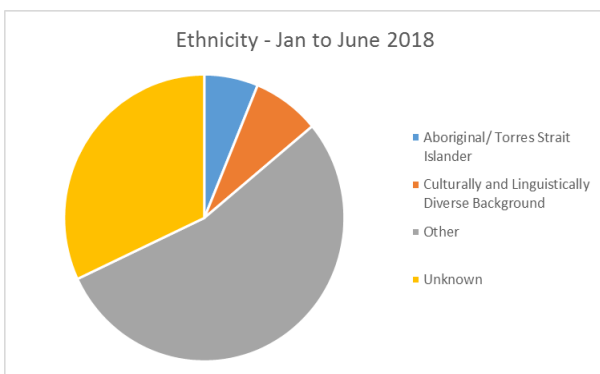


Advocacy Cases - Age Range



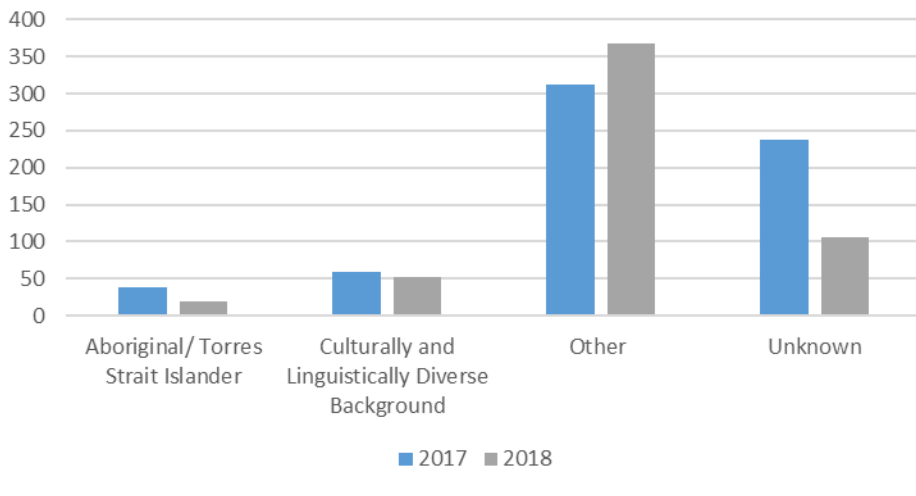


The graphs for this and the previous reporting period have also been supplemented with the age range across the last two calendar years. There has been a slight increase in consumers under 20 years of age in 2018, and an increase in people 60 years and over. However this needs to be balanced with a recognition that there are fewer consumers whose age is not known in the 2018 period, as compared to the 2017 period. As a continuous improvement process, the Advocacy Team have focused on ensuring that the age of consumers is captured wherever possible.



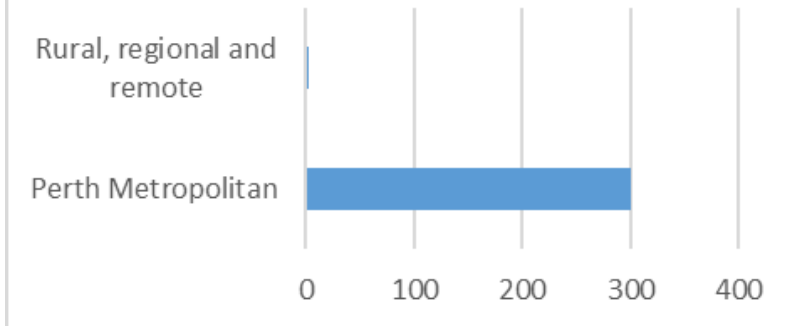
There has been a gradual decrease in Aboriginal and Torres Strait Islander consumers approaching HCC for advocacy. This is likely due to a shift internally for our Aboriginal staff member who moved from the Advocacy Team to the Engagement Team. Further work may be needed to ensure we are reaching this group effectively. In the same period, there has been a slight increase in the number of culturally and linguistically diverse consumers approaching HCC for advocacy assistance.

2.1 c) Ethnicity

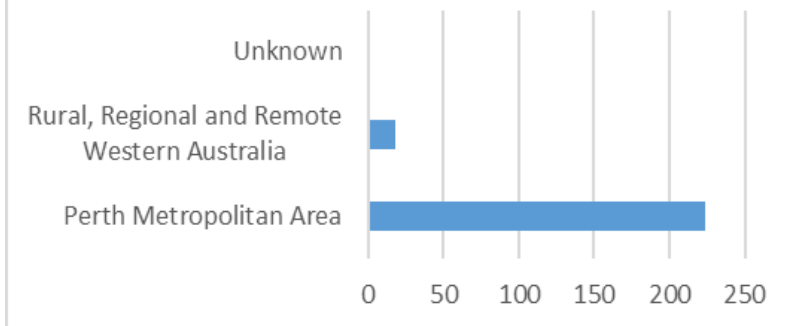


This reporting period has seen a slight increase in rural, regional and remote consumers contacting HCC.

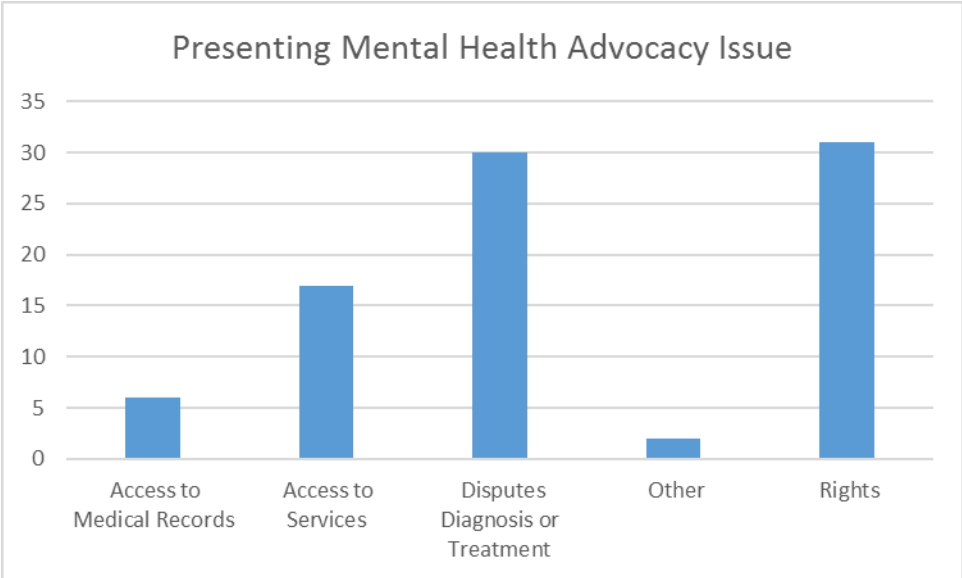
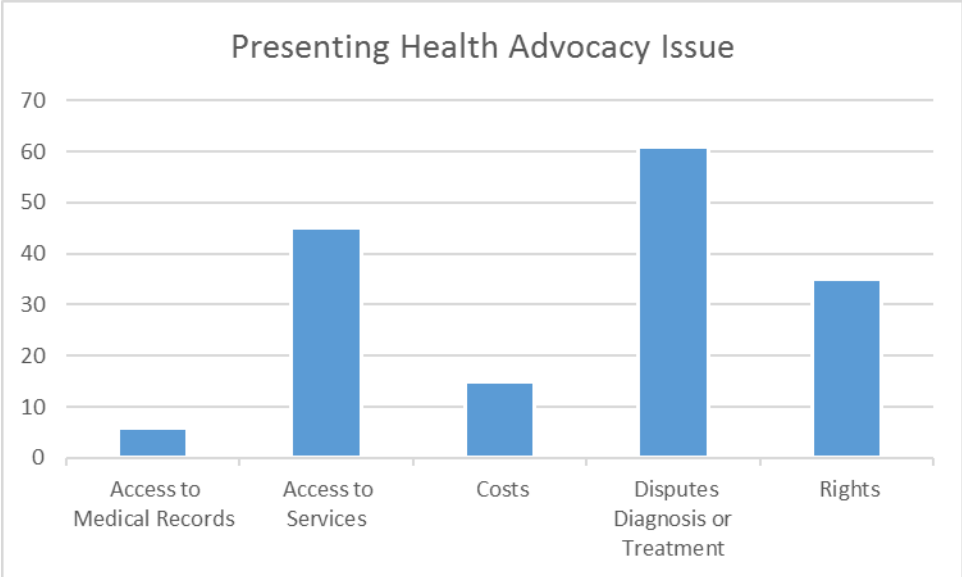
Geographical Location - Jan to Jun 2018



Geographical location - July - December 2018



Presenting issues are noted in the following graphs for both health and mental health advocacy cases. It is a long-observed trend that rights issues are more likely to be the key concern in mental health advocacy cases. There is a similar proportion in both types of cases for disputes in diagnosis and treatment.



Advocacy Activities - Case studies

Treatment after a complaint and the impact of advocacy

G lodged a formal complaint with AHPRA against a health professional. An investigation ensued, which resulted in the reprimanding of the practitioner by way of a lengthy suspension and fine.

G later felt victimised by his treating team who, despite the investigation's findings, said that he was delusional and had fabricated the complaint. G believes that the team made a referral for him to have a mental health assessment.

HCC's advocate attended the mental health assessment with G who presented very well, communicated clearly and demonstrated capacity and high functioning.

The assessing psychiatrist agreed that G appeared well but encouraged the use of medication, which he declined. The psychiatrist appeared to accept G's decision not to take medication but suggested they have one further meeting to 'check in.'

G reported that he had felt listened to and empowered during the assessment and attributed this to the advocate's presence.

The consumer did not request advocacy for the follow up appointment which they attended alone. G reported that this second meeting did not go well and described that the clinician acted very differently towards him, in that, they were not willing to listen and made suggestion they could detain him under the mental health act. G firmly believes he would have had a more positive experience had the advocate been present.

Decisions on treatment

J contacted HCC from his hospital bed concerned about a lack of discharge planning and feeling pressured to make decision regarding treatment. J has a progressive neurological condition, which can affect his organs and autonomic system. Further, J has another condition, which causes exaggerated startle symptoms and laryngeal dystonia where no air can pass through his body. J described a recent incident, when he was subject to a code Blue. J had identified an advanced health directive to the treating team, which stated his wishes. Despite this, the doctor had advised J needed to comply with the team's plan, and that non-compliance would result in the treating team terminating his care.

The HCC advocate contacted the service in a bid to convey J's views; J later reported a significant change in the demeanour of the team. J reported that his doctor had been to see him and expressed a desire to work together to find the best outcome.

Balancing care needs with family needs

Z contacted HCC as essential changes needed to occur around Z's mental and physical health medication due to the associated risks. Z was concerned about her doctor's plans to make these changes. The doctor advised that this would require intense monitoring, by way of a two-month hospital stay.

Z is parent to an infant child and described having experienced post-natal depression in the past. Not wanting to be away from her child, Z believed the hospital admission would be detrimental to their relationship. Z's initial attempts to negotiate with her doctor had failed given the treating teams insistence that the changes needed to take place in hospital. Z eventually accepted that she would have to be hospitalised but wanted to give her input around timing and planning as to avoid too much disruption to her family environment and routine.

HCC advocacy was powerful in this case, as it ensured Z's views and preferences did help inform a mutually agreed plan moving forward.

Health Rights Information for Consumers

New self-advocacy resources

HCC have uploaded one-page versions of the company EIDO Healthcare Australia's 42 procedure specific information sheets. HCC negotiated with EIDO to ensure we could have free one-page versions freely available for download for consumers. HCC can then alerting consumers to ask their clinician for a full, four-page version.

HCC have also developed an information sheet for consumers about Guardianship and Administration processes. The resource is a useful guide for consumers' who are subject to such applications. This sheet is easily digestible with both visual and written information around what Guardianship and Administration is, how best to prepare and what to expect at a hearing. This two page resource is included in the attachments to this report.

Collaboration

In October The Advocacy Manager met with the CEO of the Mental Health Law Centre (MHLC) for preliminary discussions regarding a successful grant application to fund a collaborative project (HCC & MHLC), which aims to produce 3 short videos. The videos will be aimed at mental health consumers' who are subject to Guardianship and Administration applications. During the meeting, discussion focused on the videos' content, which aims to be easily digestible for all viewers.

The videos will cover:

- What is Guardianship
- What is Administration
- What happens after an application for orders are made
- Timeframes
- What to expect from the hearing and who will be there
- How to prepare for a hearing
- What are plenary and limited appointments/orders
- The difference between an appeal and review
- How to apply for a review of an order
- How to apply for an appeal of an order

Planned focus group for advocacy clients

As part of HCC's contract review process, in the lead-up to the end of contract by December 2020, HCC's Engagement and Advocacy Managers are working together to develop consumer focus group(s) to further explore and co-design improvements with consumers on HCC's current advocacy service processes, such as:

- Advocacy case intake process
- Advocacy process manual
- Self-advocacy resources
- Advocacy service's evaluation/feedback process

We will be approaching advocacy clients in early 2019 to invite them to be part of this project to ensure we remain consumer-centred in how we deliver our services.

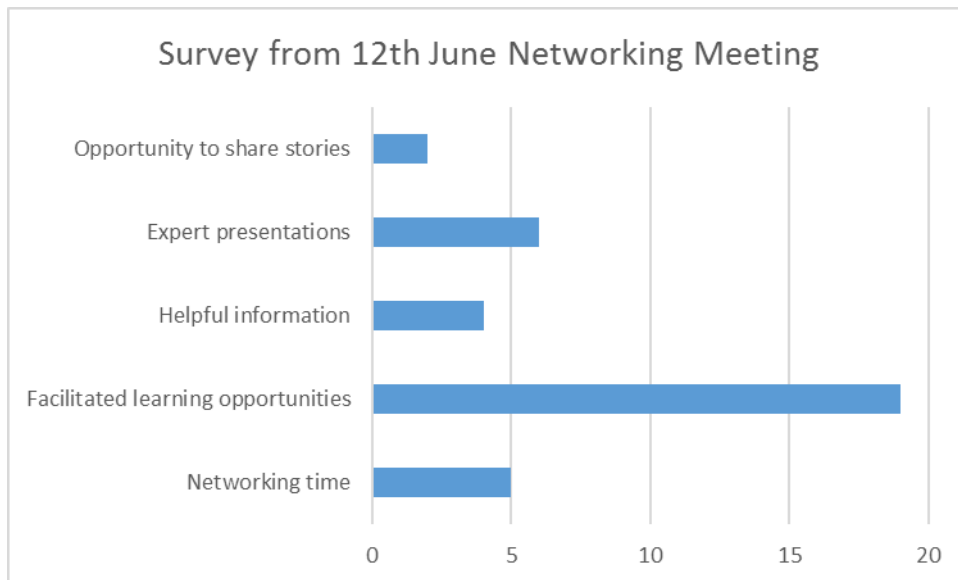
COMMENTS ON SERVICE DELIVERY DATA OUTPUT MEASURES

SERVICE TWO – SECTOR SUPPORT

Health Consumer Council Engagement Program

Consumer Representative Network

As noted in the last contract report, a fresh approach was taken to convening a Consumer Representative Network meeting with a more informal, flexible format. This event was held on 12th June 2018 and attendees who responded to the simple survey clearly indicated a preference to facilitated learning opportunities. A key feature of facilitated learning opportunities is that people can learn from the wisdom of the group rather than just the facilitator. This adult-learning-friendly approach acknowledges that attendees already have significant experience and knowledge to share.



In this contract period there has been a re-structure of the Engagement Team undertaken, with a new Engagement Manager taking up the role in September 2018, so we have not as yet landed on an identifiable, clear new format for Network meetings. The consumer engagement space is so dynamic and we have leveraged other initiatives, such as the Health Engagement Network, to continue to provide facilitated learning opportunities for consumers.

Health Engagement Network (Community of Practice)

Establishment and 2018 summary report

A project was established to explore the potential for a cross-system community of practice after discussions between the Health Consumers' Council, the WA Primary Health Alliance (WAPHA) and Aha! Consulting based on their observations and feedback from their work with health service staff and consumer/carer representatives across the health system in WA.

With funding from WAPHA, the Health Consumers' Council started a project (working with Aha! Consulting) to explore the level of interest for this community of practice amongst staff and consumer/carer representatives.

Phase 1 (Jan – July 2018) of the project consisted of:

- A steering group of staff from Health Consumers' Council, WA Primary Health Alliance and Aha! Consulting
- A survey of staff and consumer representatives across the WA health system in March 2018 which received over 130 responses expressing overwhelming support for the idea of a community of practice for consumer engagement.
- Two sense making workshops in April 2018 where staff and consumer/carer reps discussed what they'd like from a community and how it might work.
- Three working groups looking at:
 - Online platform for engagement
 - A launch event – held on 31 July
 - Other activities post-launch – including an event on diversity in consumer engagement on 20 September
- The survey results and notes from the planning workshops are attached.

The establishment of an active community of practice (CoP) for health service provider staff and consumer and carer representatives across the whole health system – WAPHA, WA Health and the community – has enabled members to share information and lessons learned and improve their practice in consumer engagement, drawing on and referencing all the frameworks that exist or are in development. The CoP includes face to face and online engagement activities, including different activities and initiatives to engage with staff and consumers.

Key deliverables

- A community of practice has been established – the Health Engagement Network (HEN).
- 97 people have expressed interested in the community of practice, or registered or attended a planning/working group meeting.
- 84 people had joined the online platform by 30 July 2018. As of 24 January 2019, there are 227 members registered with the online platform at www.healthengagementnetwork.org.au

Based on survey responses and feedback from workshop participants, there was strong interest in more face to face activities than had previously been anticipated at the pre-initiation phase of the project. This led to an increased requirement for participation by the project team in face to face meetings and working groups.Network activities

- A number of workshops took place to inform the development of the CoP activities:
 - 5 April – two workshops held (face to face and online)
 - 30 April – working group meeting
 - 7 June – working group meeting
- A group of Hosts and moderators has been established to support the progression of the CoP using the Mighty Networks platform. These come from across the health system including consumers.
- Three working groups have been supported all including staff and consumer reps:
 - Launch event – this group was coordinated by Tim Williams and met a number of times
 - Online platform and content – this group was coordinated by Clare Mullen and met a number of times. There are 7 members of the hosts/moderators sub-group on HEN

- Next events – this group met a number of times and planned the event on 20 September.
- A number of articles have been written and published online
 - History of network
 - Overview of frameworks
 - ORIGINS project at Telethon
 - Overview of NMHS MH Peer workforce model
 - Interview with Michael Greco from Patient Opinion
- A number of videos have been created and published
 - Introduction to the Health Engagement Network platform
 - Welcome video
 - Video panel discussion
 - Video of Simon Towler

Events

- 31 July Ignition Event – launch of Health Engagement Network. Over 100 registrations (68 attendees) from across health system and the community. Attendees had the opportunity network and hear from staff and consumers about their experience of consumer engagement.
- 20 July – Diversity in Consumer Engagement – hosted by the SCGH Nursing Education Team

Lessons learned

Some initial reflections from the project coordination perspective:

- There is strong support for a community of practice from a wide range of stakeholders and organisations
- People in the health workforce are time poor and many are unable to commit time to “coordination activities” of such a group – i.e. organising or attending meetings. However, many are very interested and keen to contribute when they can.
- There was strong interest in face to face activities. It may be worth allocating an increased resource allocation to face to face engagement activities in future projects.
- More time for a dedicated role to support the curation and facilitation of the network would assist it to grow and maximise its impact
- Steering committee members had widespread networks in the health system – this made it possible to communicate about the community of practice to a wide cross-section of the system.
- Inclusion about the Network’s plans and activities in the Health Networks newsletter enabled us to reach a wider still network.

Considerations for the future of this project

- This Network is still at a very early stage of its development – like a seedling. Feedback from people who coordinate other CoP in the health system suggest it could take a few years for such a network/community to become well-established. It is likely that this will require some ongoing support from HCC, WAPHA and perhaps others parts of the system.
- Consideration could be given to a structured approach to this nurturing – for example, contacting the members of the three working groups (launch, online and events) at least every two months and inviting them to meet and discuss next activities for the Network. An invitation to these meetings could also be extended to people on HEN online.

Funding

Seed funding for this project was received from the WA Primary Health Alliance.

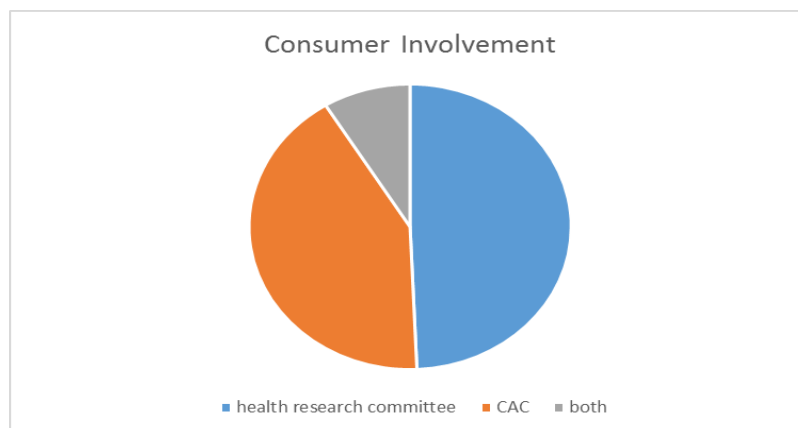
Consumer Involvement on Decision making committees

A partnership project between HCC and the WA Health Translation Network's Consumer and Community Health Research Network examined the issue "Why Do People Become Involved? Motivations for consumer and community involvement on decision making committees for health research and health services."

The purpose of the study was to provide a useful contribution to the limited information focusing on consumer and community involvement in the Australian context. It aimed to identify the key reasons for why people become involved in health research and services and what keeps them motivated. The results provide practical information for the recruitment and retention of consumers and community members on consumer representative committees, other involvement activities and for the ongoing improvement to these systems.

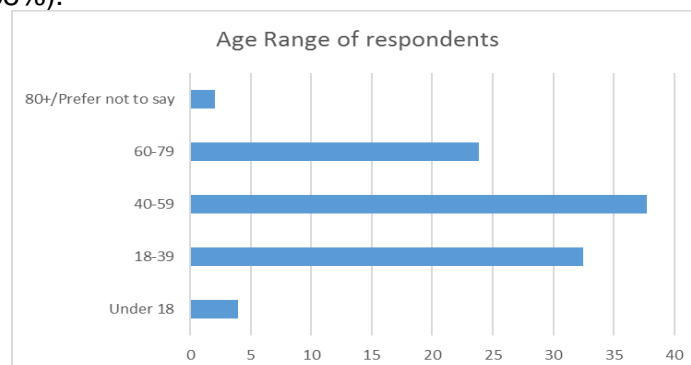
Sample population and committee membership

160 people participated in the online survey. Of the respondents, (49.32%) self-reported as members of a health research committee in a research organisation; (41.89%) as members of a consumer advisory committee in one of the tertiary hospitals; and (8.78%) reported membership to both groups. As at the close of 2018, preliminary discussions have been taking place with the WA Health Translation Network as to a possible partnership with HCC to undertake consumer involvement on an ongoing, and this may unfold over the next 2-3 years, because of the obvious overlaps and synergies.



Age group

The predominant age group for participants was between the ages of 40-59 years (37.75%). The second largest group was the 18-39 year age group with (32.45%), followed by the 60-79 year group with (23.84%). The smallest response groups were under 18s (3.97%) or those who were over 80 or preferred not to say (1.98%).



Gender and diversity

Survey participants were mainly female (81.57%). The majority (96.69%) did not identify as Aboriginal or Torres Strait Islander. A smaller cohort (3.31%) identified as Aboriginal or Torres Strait Islander or preferred not to say.

Socio-economic status

The highest number of participants were employed for wages or salary or voluntarily (47.37%). Retirees formed the second biggest group (13.16%), closely followed by students (11.84%). Those engaged in home or care duties represented 11.18% of respondents, followed by those who were self-employed (7.89%), Other (5.92%) or Unemployed (2.63%).

Summary of involvement levels

Most consumers and community members reported being involved on their current committee for a period between one and two years (45.52%). A smaller group reported they had been involved for less than a year, had just started, or were just starting (24.62%). Some respondents described five to nine year lengths of involvement (10.45%) with a similar number for those reporting a three to four year commitment (9.70%). At the other end, a much smaller number of respondents described an overall contribution to their committee of ten years or more (2.24%). Those who commented on belonging to various committees described various combinations of these involvement lengths.

Consumers and community members were asked to describe a more general level of involvement, which included their current committee and any other involvement activities over a period of time. They reported commitment levels of anywhere from just starting, to one to two years, up to 32 years.

Consumers and community members who described five or more years of involvement showed varied understandings of involvement activities. Some included their experiences of being a patient or a consumer in these estimates 'I have been involved in a hospital setting as a parent for 13 and a half years. Involved in a research group for 6 months'. Others included definitions of voluntary activities in their assessment of involvement – 'Telethon Kids Institute – 2 years (reference group). Children's Leukaemia & Cancer Research Foundation – 7 years (fundraising, volunteer supporter and member).'

Long term members with 20 years' experience or more tended to include descriptions of working in the health industry and research participation into their length of commitment – 'My experience stems from a nursing background of 30 years plus experience as a 'consumer' patient in both private and public health services' and 'I have been involved in health research for the past 28 years, as an active participant. I became involved as a community member mid 2017'.

Perception of involvement roles and tasks

Consumers and community members described being on a range of committees with various purposes from 'Community Advisory Committee (CAC)', 'reference group member', 'community reference group member with TKI', 'youth advisory group', 'committee member', or 'Chair'.

Various roles and tasks were identified as part of their commitment to involvement. Broad conceptual understandings of their involvement role included – to bring the lived experience, represent a demographic group, represent the community and voice issues, to give advice or advocate; and to make a positive impact for future user experiences and the community.

What keeps people motivated to be involved

Several themes were identified for what motivates and keeps people motivated to be involved in health research and health services. These were ordered into four main categories:

- Core motivations: The initial and main motivations for becoming involved and continuing involvement. These held a continuous presence through all consumer and community member's responses
- Commitment considerations: Details regarded as important to making a commitment to be involved
- Maintaining motivation: Experiences that maintained motivation or could modify and potentially reduce involvement
- Supporting motivation: The structures that helped reduce barriers and supported the ongoing commitment to be involved

The full version of this paper is attached with this report.

Liaison with Community Advisory Councils (CACs)

As well as the inclusion of CACs on the above research project, and the June networking event described on page 22 of this report, HCC has been undertaking a number of initiatives to better support the CACs across the health system.

South Metropolitan Health Service – Family Birth Centre

In July 2017, HCC's Executive Director was first approached by South Metropolitan Health Service (SMHS) to provide consumer representation as they put together a business case for the Election Commitment of developing a Family Birth Centre. HCC argued for the inclusion of consumers who were of child-bearing age, but this was felt to be difficult due to the nature of the committee.

In order to ensure a strong consumer voice, HCC partnered with SMHS to develop a short consumer survey which was disseminated via the wards to women attending ante and post-natal appointments. This allowed for more than 300 women's voices to inform the development of the business case, and to put out a call for women who wanted to stay involved in the project. A Facebook Group was developed to keep women in touch with this and other key maternity consultations, such as the National Approach to Maternity Services (NSAMS – see below).

There was then a hiatus while this Business Case was being processed and the funding approved, and when the project was resumed, there was already a list of consumers who wanted to stay in touch and potentially get more involved, all ready to go.

To build on this momentum, a Town Hall forum was held to invite in consumers who had responded to the earlier survey, and who had joined HCC's Maternity Facebook Group. The consultation itself was held on 4th August 2018 at Fiona Stanley Hospital (FSH).

It is important to note that one third of attendees on the day were consumers. The rest were nursing/midwifery staff, doulas and others from the industry, some of whom hope to be future clients at the Birthing Centre when they birth their own children. Feedback in the attached full report has not been de-aggregated between these two cohorts and some of the midwifery staff could also be considered prospective consumers of the service.

The session followed on from two site tours of the proposed space for the family birthing centre. Its purpose was to identify the design principles which would guide the fit out of the new family birthing centre in terms of look, feel and functionality.

An EOI process was then utilised to appoint three consumer representatives to be part of the Consumer Reference Group to progress the recommendations from the FBC forum. The Chair of the FSH CAC and the Executive Director of HCC also joined this Committee, to ensure the consumer initiatives remained "joined up." It is very common for HCC to remind health service staff that there is a CAC for them to call on – they are often unaware of them and how to contact them.

Consumer Involvement outside CACs

HCC continues to expand its network to reach key groups ensure they have a seat at the table for key meetings, projects and decisions:

Community Link Booth (FSH)

In 2017, HCC partnered with ConnectGroups (the peak NGO for peer support groups) to facilitate a partnership with Fiona Stanley Hospital, HCC and ConnectGroups. The concept was to develop a booth where people could provide information about non-clinical supports to keep them well once out of hospital.

ConnectGroups received funding from LotteryWest for the booth, and is coordinating the booth

volunteers. FSH provide the floor space – adjacent to the main entrance and information desk, as well as internet and parking for volunteers. HCC ensured that the FSH CAC and Emergency Department CAC were across the development.

This is a new concept, and the booth is mentioned as an exemplar in the Sustainable Health Review report. The photo below is after its opening, the first week in January. How it works is that people can approach the booth and find out about what might be available for them in the community – Carers WA support for the partner of someone who has recently suffered a stroke and will have significant care needs, a Stroke Support group for the patient to attend. There are also links made to community pharmacies who can provide Webster pack, and so forth. The referrals are sent to ConnectGroups and all relevant information and links are sent out. There will be evaluation on how useful the referrals have been and potentially noting if they have had to return to hospital.

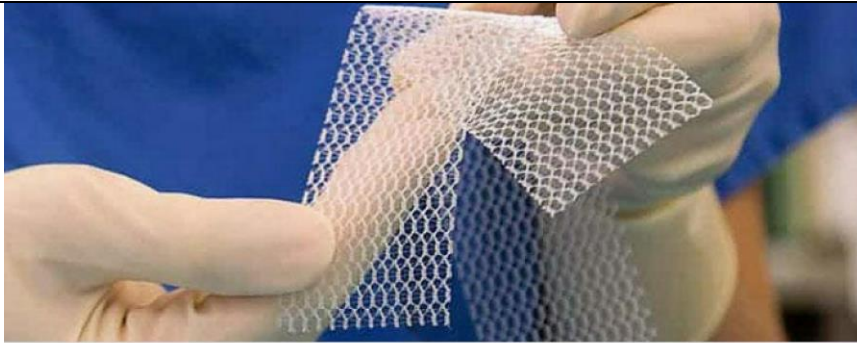


WA Pelvic Mesh Support Group (WAPMSG)

This peer support group has a self-managed online private Facebook group, and two key representatives from the group work with HCC to continue the co-design the Mesh Clinic and other services. HCC and WAPMSG collaborate to ensure there is up to date feedback about how the women are experiencing the clinic, but running a survey through the private group and then presenting the feedback at meetings. These surveys are

HCC has also supported WAPMSG to obtain a ConnectGroups grant to develop a website and obtain training to keep the website updated. The grant application was successful.

We are also working with health consumers councils across Australia to include WA women in the planning and outcomes for the Unfinished Business National Mesh Implant Forum to be held 5/4/19, which WA Health has provided \$10,000, in line with other state health departments.



Unfinished Business: National Mesh Implant Forum

by Health Issues Centre

\$10 - \$120



Tickets

Description

The National Mesh Implant Forum will be held in Melbourne on Friday April 5, 2019, to consider all aspects of Australia's mesh implant crisis. The event will bring together mesh injured consumers, carers, regulators, politicians, health officials and consumer advocates to collaborate to consider best practice treatment models and explore regulatory changes to the way medical devices such as mesh are approved and monitored. It is a unique opportunity for mesh-injured consumers to meet regulators and share their experiences of post-surgery complications and the effects of mesh implants and create real change.

Date And Time

Fri., 5 April 2019
9:00 am - 5:00 pm AEDT
[Add to Calendar](#)

Location

Citadines on Bourke Melbourne
135 Bourke Street
#131

Gynaecological Awareness Information Network (GAIN)

HCC was asked to attend a meeting with GAIN and KEMH in relation to a study day GAIN was organising. There was some controversy with one of the speakers who was attending, and HCC worked with GAIN and KEMH to tweak the subject of the session so that it leveraged the guest speaker without alienating the WAPMSG. HCC attended the Study Day in support of GAIN and maintained these key community links in a complex engagement environment.

PCH Complex Kids Group

HCC was asked to meet with convenors of a Facebook Group for complex children. There was concern about the cessation of a nursing help line for parents to support them to keep their children at home when for example something goes wrong with a PEG tube or similar. Parents of children with complex conditions tend to become very experienced in caring for their children, and keeping them out of hospital as much as they can. Many parents are fearful of attending Emergency Department as their children are often immune-compromised. HCC supported PCH Complex Kids in preparing for two meetings with PCH and assisting them to determine what they wanted to tackle as a group of parents. Very sadly, one of the mothers who attended the first meeting lost her child, who had a condition not compatible with life, who was receiving palliative care.

National Children's Digital Health Collaborative

The National Children's Digital Health Collaborative (NCDHC) was created on behalf of the Australian Digital Health Agency and includes representatives from across disciplines and all Jurisdictions. Its objectives are to co-design digital health solutions and ensure all Australian children regardless of location, socioeconomic status or cultural background have the same opportunity to be healthy, safe and thriving. HCC supported their Aboriginal Engagement Coordinator to apply and join the collaborative as a consumer representative and she currently sits on both the National Clinical and Community Advisory Group and the NT/WA Child Digital Health Checks Initiative. This has enabled the use of existing networks in order to share and disseminate the information from the NCDHC to important stakeholders within WA Health and the ACCHO sectors, to link the Agency staff to contacts within the WA health system and to ensure that the importance of considering WA and its children in any planning or consultations. This project is ongoing and dynamic, and we welcome the upcoming work around the child health checks within WA and NT.

Workshops

Consumer Representative Workshops

In this reporting period, we have repeated the refreshed format of the Introductory and Advanced Consumer Representative Workshops which were developed and delivered in the January to June 2018 period. As per the contract, we ran the Introduction and the Advanced Consumer Representative Training.

The workshops continue to provide a positive adult learning environment, with strong engagement from the attendees who attended the Introductory Workshops electing to attend the Advanced Workshop.

The Introductory workshop had 20 initial registrations, with 12 attending on the day, a 40% drop-out rate. The Advanced Workshop had 16 registrations and 7 attendees on the day, a 43% drop-out rate. As we don't charge for this workshop, we have the perennial problem of people registering and not attending. We have continued with the pre-survey of attendees to confirm attendance and check what their learning objectives were, which has at least allowed for a better idea of likely attendance on the day and builds commitment from attendees to come. We are considering charging a fee, and refunding it when people attend.

Comment from the introductory session:

I feel having the opportunity to speak with others, sharing ideas was helpful. I feel our CAC needs to change and be more open to our engagement before I am able to work more effectively in my CAC role.

It is interesting that often experienced consumer representatives who may have been in a CAC for a while attend this workshop. There appears to be an opportunity to better leverage our time and reach more people by conducting training with CACs where we focus on their strategies and how they are working together. We could potentially create an online resource for people who are absolutely new to consumer representation to meet that market, and build skills and interest in the community to connect with bodies such as a CAC to start on the road to being a consumer representative.

North Metropolitan Health Service (NMHS) – CACs, CAGs, ACAG

During this reporting period, we have responded to the need of NMHS's new Board and its People, Engagement and Culture Committee to support their CACs and other consumer bodies across NMHS, albeit without the inclusion of Joondalup Health Campus. This stretched our capacity but we wanted to respond to NMHS' need.

We were asked to facilitate a half day workshop in December 2018, with consumer/carer/community committees and groups across the Health Service to collectively develop a shared vision for consumer engagement activities to explore ideas and develop plans for future activities.

35 people attended this planning session from across NMHS, including from:

- Osborne Park Community Advisory Council (CAC)
- North Metropolitan Health Service Mental Health CAC
- Sir Charles Gairdner Hospital CAC
- Women's and Newborns' Health Service CAC
- Aboriginal Cultural Advisory Group

Workshop aims

- To develop a shared understanding of what is working well in community advisory committees currently across NMHS
- To explore together what committee and group members and staff would like to achieve through consumer engagement activities in 2019 and beyond
- To discuss what is required to achieve these goals

During the session, attendees requested that more time be allocated to enable a fuller discussion of the issues being raised. It was agreed that NMHS would organise another session in early 2019 for the group to meet again and continue the discussion. A fuller draft report from this event is included as an appendix. While this work is still being finalised, this draft report is included as it contains key feedback and insights which are driving HCC's current re-evaluation of our services.

Cultural Diversity Program

Diversity Dialogues

On 16th October a Diversity Dialogue was held on the subject "Difficult conversations: Delivering health information for people from Culturally and Linguistically Diverse Backgrounds"

There were 22 attendees, a mix of health service providers and community members. The event was a collaboration between HCC, WA Health's Cultural Diversity Unit, and Ishar Multicultural Services.

HCC's Diversity Dialogue format includes having a panel of community members and service providers, and an audience of health service providers who can hear diverse perspectives on the topic, and then work together to develop recommendations for more culturally inclusive practice.

- People who struggle with the English language are not intellectually poor, but they may struggle in understanding and expressing themselves. Interpreters will be very helpful.
- Earning trust is a gateway for more meaningful conversations with a client or your audience.
- Diversity in the workplace can help provide better views in communicating with people from different cultures.
- Most people from CALD background prefer to listen or watch rather than read.
- Health service providers coming from CALD background does not necessarily mean they are culturally competent in providing care to a person from another CALD background. Organisations still need to provide appropriate orientation and training.
- Always use straightforward and simple information in print materials.
- Its good practice to consult communities in developing print materials and pre-test them.
- Time can be a challenge in the consultation process, but it is worth doing.

Recommendations from this forum were:

- Establish trust when communicating face to face with people from CALD background
- Always use simple language
- Avoid putting too much information in a health material
- Picture and illustrations are helpful both for face to face communication and print material

The full report including evaluation is part of the attachments to this report.

World Kindness Day

World Kindness Day was part of the suite of Patient Experience events which the Health Consumers' Council has been holding since 2016. In April 2018, we ran a Gathering of Kindness/ Patient Experience Week event, in partnership with Child and Adolescent Health Service. Dr Catherine Crock from the Hush Foundation, and co-founder of the Gathering of Kindness attended via video-conference. Lucy Mayes, author of *Beyond the Stethoscope*, Doctors' stories of reclaiming hope, heart and healing in medicine gave a keynote presentation. Patient Opinion's Michael Greco, and World Kindness Day's Australian Ambassador Michael Lloyd Wright joined Lucy Mayes to convene a through provoking panel discussion on what could we do to create a kinder health system.

We decided we would hold an event on November 13th, World Kindness Day, to build on this theme later in 2018. This was another partnership with WA Health's Cultural Diversity Unit, and Ishar Multicultural Services as well as the WA Primary Health Alliance, who part-funded the event. Other partners included the Youth Affairs Council of WA's Multicultural Youth Advisory Network and Ethnic Communities Council of WA.

The event created a space for a shared discussion on what kindness means, discussed barriers and highlighted new perspectives for how to overcome these barriers.

Our Spring edition of *Health Matters* focused on culturally and linguistically diverse communities, and the Summer edition had a summary of the World Kindness Day event. Extracts from the two magazines are attached along with the report and evaluation from the day.

Aboriginal Engagement



“Kindness, Connection, Community – see the Whole Person”

Patient Experience Week 2019 will be held on April 30 2019 and will focus on Aboriginal health. The theme for the event will be “Kindness, Connection, Community–See The Whole Person.” Planning for this event occurred during this reporting period, with key input from HCC's Aboriginal Reference Group, and our Aboriginal Engagement Coordinator has been doing significant networking with key Aboriginal Elder and Reference Groups throughout Perth to progress this event's organisation.

On 13th December 2018 HCC convened a meeting with key health staff responsible for patient liaison/ patient experience to discuss what Patient Experience events they may convene on their campuses which HCC can promote. This has been the vision since 2016 - to mirror movements such as Mental Health Week to encourage the whole sector to focus on this area, rather than just HCC holding events.

We also held a Reference Group meeting with Aboriginal Health Liaison and other key organisations such as the Aboriginal Health Council of WA to include them in our 30th April event.

NAIDOC Week – Because of Her, We Can



In previous years, HCC has run their own NAIDOC event, but we believe we have better leverage by joining other, larger events. In 2018 we attended the Armadale NAIDOC event at the Champion Centre and joined stall holders to provide information about our services to the community. The theme was a particularly positive and generative one “because of her, we can.” HCC had made postcards which people could write their messages of appreciation to the women in their lives, and go in to the draw for a pamper package for her. The postcards were so effective we plan to re-purpose them for the April 2019 Patient Experience Week event.

Mental Health Week Partnership Event

HCC partnered with Derbarl Yerrigan Health Services, Yorgum and Wungening Aboriginal Corporation to run a collaborative event for Mental Health Week.



While the partners did not receive a WA Association of Mental Health grant to run the event, we agreed to share the expenses to ensure the event could run. Holding the event in Wellington Park allowed for a gathering of both community members and staff from the key NGOs. A drumming circle and healthy food choices were provided. One of the key attractions was the “Smoothie bike” where

attendees could have a smoothie if they cycled long enough to generate enough power for the blender. There is agreement among the partners to do something similar next year.

Justice Health Project

HCC was approached by George Newhouse from the National Justice Project (<https://justice.org.au/>) to design some training for community members and community service workers, in Aboriginal health advocacy. The purpose of the training would be to give basic Advocacy skills training, Health system navigation knowledge, Health Rights knowledge, information on recognising racism that exists in our health system and therefore helping workers and community be able to assist their clients and community to access better healthcare. The training would cover complaints processes, when to refer, self-care and other important topics.

HCC has partnered with the Aboriginal Health Council of WA (AHCWA) to develop and deliver the training, and it is envisaged that the training should be able to be delivered throughout Australia, wherever the need is.

The project is still in the early stage, with a Reference Group being formed, and MOU finalised and with funding from the National Justice project, it will continue to progress in 2019.

Consumer input into research project

HCC's Aboriginal Reference Group has provided support for a FSH researcher to help shape their research paper on "The frequency and rationale of identifying a patient's ethnographical background during clinical handover and/or in the hospital medical record of a tertiary hospital." An extract from the soon to be published paper notes:

"This is the first study to formally document the frequency of ethnographical identification during medical handover and in the hospital medical records. After adjusting for socio-economic and medical factors, Aboriginal patients were significantly more likely to be identified than patients from all other ethnic-national backgrounds.

The implications In an era of increasing cultural awareness, our results highlight the disparity and inconsistency in identifying Aboriginal patients. Further research and community consultation are required to understand the reasons and implications for this practice...

Conclusions: Patient ethnographical identification is inconsistent and seldom rationalised. After adjusting for socio-economic and medical factors, Aboriginal patients were significantly more likely to be identified than patients from all other ethnic-national backgrounds."

HCC is continuing to work with the researcher as the paper goes to print, to guide how the results may be disseminated and acted upon.

The Integrated Case Management Program (ICMP)

The ICMP aims to reduce the risk of HIV transmission by people who place others at risk of infection through applying an integrated care approach and, where necessary, implementing public health interventions. HCC's Aboriginal Engagement Coordinator participates on the Advisory Panel by invitation and reviews clients under consideration for a public health order, participates in decisions on whether a client needs to be changed to a new level of management and refers the case to the Chief Health Officer if appropriate. HCC input to this process allows for a consumer perspective to be added to the conversation, an approach that the program finds valuable.

Submission to Department of Premier and Cabinet on the proposed Aboriginal Advocacy Agency

This was done during the reporting period, and is attached for reference.

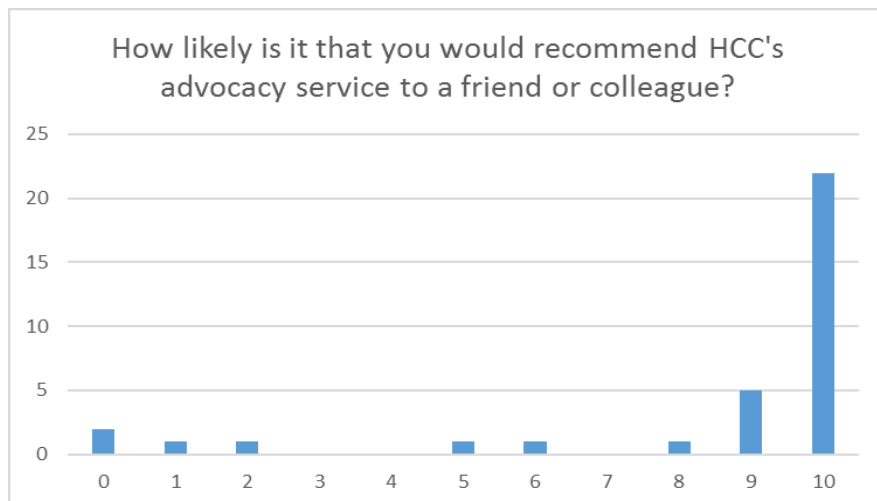
SECTION 2: OUTCOME PROGRESS REPORT QUALITATIVE FEEDBACK ON OUTCOME MEASURES

SERVICE ONE - HEALTH CONSUMER: INDIVIDUAL SUPPORT

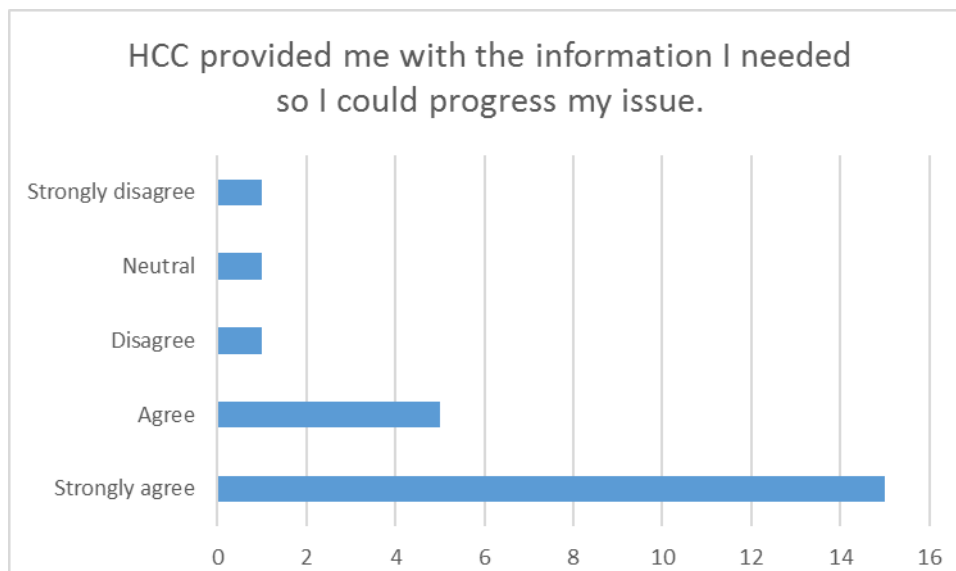
4 Health consumers are supported to effectively manage their own experience whilst utilising the Western Australian health care system.

4.1 The extent to which health consumers were supported to effectively manage their own experience whilst utilising the Western Australian health care system.

HCC undertakes outcomes evaluation on our advocacy service in a two-part process. When simpler cases are closed, a link to a survey is sent to advocacy clients via email. Postal options can also be provided. While uptake to this survey is low, feedback from this reporting period is included below. There was strong positive feedback from advocacy clients using the friends and family question:



Overwhelmingly, people strongly agreed or agreed with this statement below:



Positive comments included:

- Couldn't have done this on my own.
- Kerrie was very professional
- Perfect
- really felt, heard and supported - it was wonderful
- Strongly Agree. Chrissy Ryan has been very helpful to Barrie & Pamela Addis. She has been there for us.
- Very encouraging outcome. Had spoken to my lawyer approx 2 yrs ago. Told nothing could be done about this matter. He did photocopy what I presented him with the letter from Joondalup Hospital.
- Very Helpful

Often HCC is not able to provide what consumers are seeking, and we try to advise people what may or may not be possible with our current system.

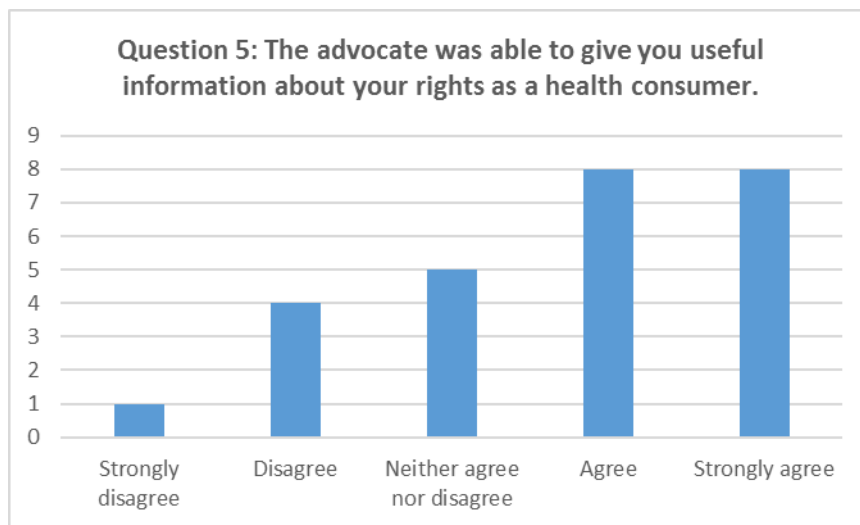
5 Health consumers are supported to participate, engage and partner with the Western Australian health care system as a result of their involvement with the service.

5.1 The extent to which health consumers are supported to participate, engage and partner with the Western Australian health care system as a result of their involvement with the service.

Outcomes Evaluation

For complex cases requiring significant time, an interview is undertaken with someone other than the advocate. We have been using medical students and volunteers to undertake these calls. This survey also includes indications of how well people understand their health care rights to better navigate the system. The data from this reporting period appears below, and reflects that most consumers either agree or strongly agree that their knowledge of health rights has increased through the advocacy intervention.

As noted, the full outcomes evaluation report for the advocacy service is included in the attachments.

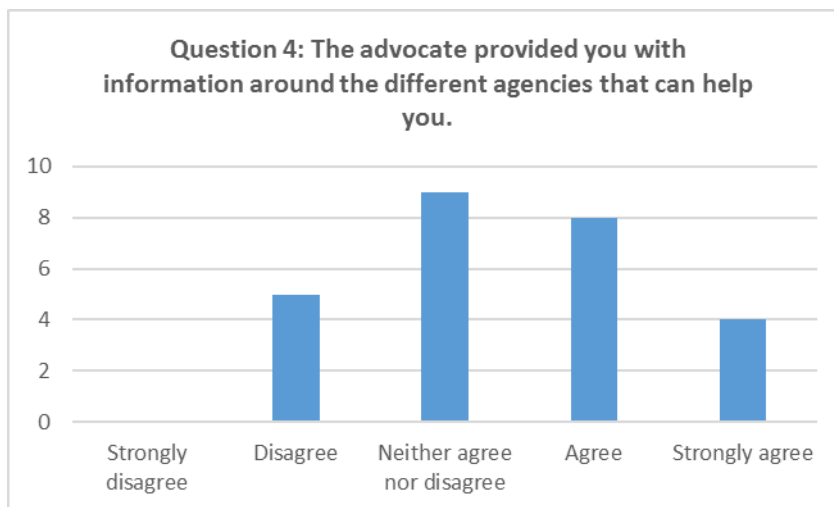


6 Health consumers are appropriately referred, when required, to other agencies in order to meet their needs.

In this reporting period, as we placed a stronger focus on triaging calls when they first come in, rather than immediately escalating them to advocacy cases, 517 people were provided with information to meet their needs in navigating the health and human service sectors. This compares with 375 consumers in the previous six months.

93 consumers were referred to other agencies to assist them, a similar amount to the 81 consumers in the last reporting period. This reflects that the focus on triaging calls when they first come in allows for consumers to get the information they require without necessarily needing a referral elsewhere.

For those advocacy cases which are more complex, consumers are asked if they were provided with information about the different agencies to support them. While some agreed and others strongly agreed, there is a large proportion of neither agree nor disagree. This may reflect that many consumers do not require referral agencies.



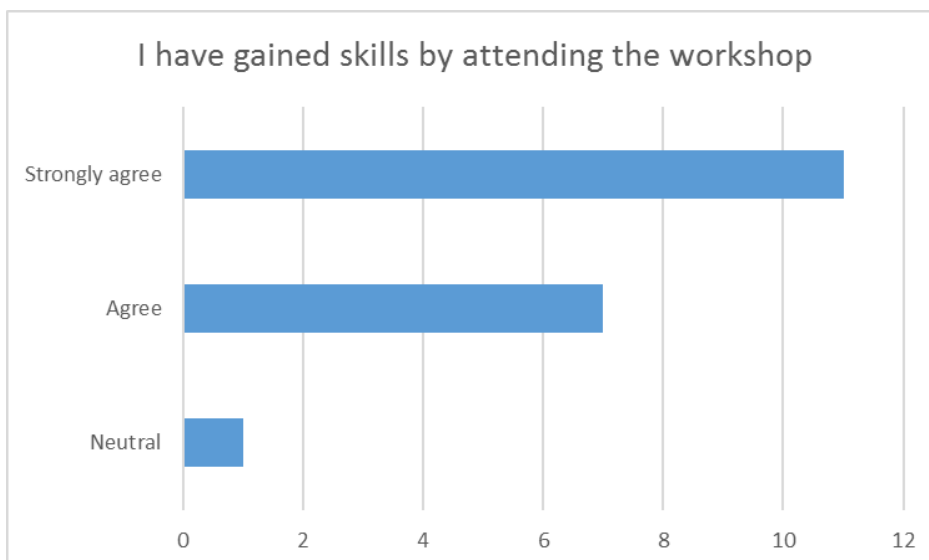
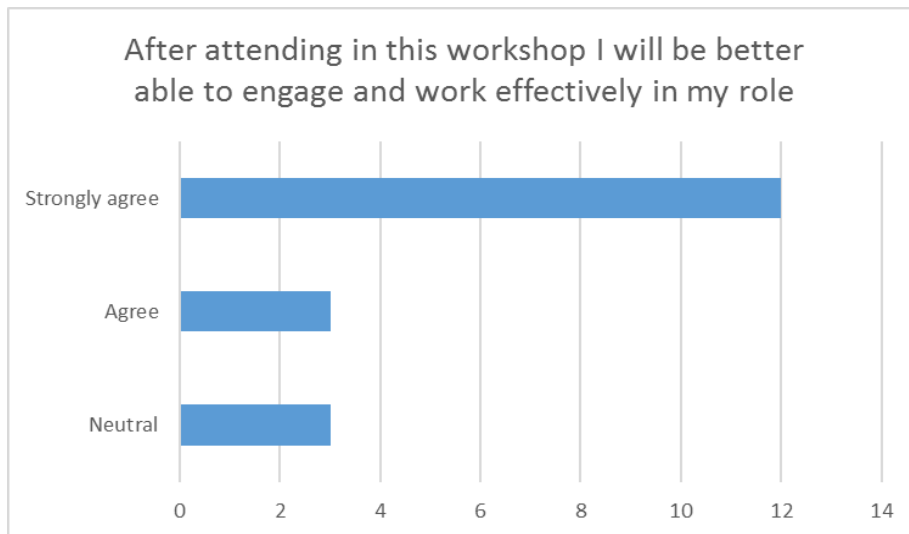
SERVICE TWO - HEALTH CONSUMER: SECTOR SUPPORT

7 Health consumers have the opportunity to be supported and linked to health consumer networks and partnerships in the Western Australian health system

7.1 The extent to which health consumers have the opportunity to be supported and linked to health consumer networks and partnerships in the Western Australian health system.

As noted in the earlier part of this report, HCC is still refining how best to support health consumers with networks with the health system, and continuing to innovate through the Health Engagement Network. HCC has not, for example, checked in with the WA Pelvic Mesh Support Group about how they feel supported and linked to networks and partnerships, as this is a relatively new way of us working with consumers and consumer groups.

Consumer representative workshop attendees in this reporting period have generally agreed or strongly agreed that they will be better able to engage and work effectively in their CAC and consumer representative roles because of their attendance at the workshop. They have also agreed that they have gained skills by attending the workshops.



8 The Department of Health and Area Health Services are assisted to facilitate and promote active engagement with health consumers in the planning, delivery and review of health services.

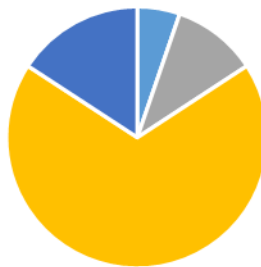
8.1 The extent to which the Department of Health and Area Health Services are assisted to facilitate and promote active engagement with health consumers in the planning, delivery and review of health services.

Consumer Engagement

The work with North Metropolitan Health Services to bring their consumer groups together has been a big piece of work within this reporting period.

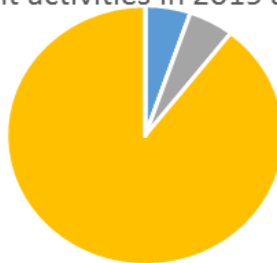
Evaluation of the December session shows that there was strong agreement with the statements below:

We had an opportunity to develop a shared understanding of what is working well in community advisory committees currently across NMHS



■ Strongly disagree ■ Disagree ■ Neither agree nor disagree ■ Agree ■ Strongly agree

We had an opportunity to explore together what committee and group members and staff would like to achieve through consumer engagement activities in 2019 and beyond



■ Strongly disagree ■ Disagree ■ Neither agree nor disagree ■ Agree ■ Strongly agree

Next steps will be key to building on this positive start.

9 The Department of Health and Area Health Services are informed on emerging trends and issues affecting health consumers.

9.1 The extent to which the Department of Health and Area Health Services are informed on emerging trends and issues affecting health consumers.

Mesh and implants

On 6th December, HCC staged a filming of the Netflix documentary, Bleeding Edge. This documentary highlights the flawed processes across the western world for how medical devices are registered with the Therapeutics Goods Administration (TGA).

In summary, devices are registered on the basis of assurance of medical device companies, with significantly less research required than for medications being registered. There is an assumption of two things- that consent processes between surgical specialist and consumer will be comprehensive, and that post-market surveillance will occur. As the Senate Inquiry into the number of women impacted by transvaginal mesh and other issues highlighted, neither of these things are reliably happening. While the Bleeding Edge is sent in the US, approval of devices is linked worldwide. A European kite mark can then prompt the listing of a device with the US's Food and Drug Administration. As noted in the documentary, it had been possible for clinicians to register the netting from a bag of oranges as a transvaginal mesh device. This has highlighted serious weaknesses in the system and while changes have been made in Europe in the wake of this, overall patient safety has been compromised by our current system of device registration.

The Assistant Director General, Assistant Director General, Clinical Excellence Division attended the film screening, and HCC liaised with the Medical Advisor, Medicines and Technology Unit from Patient Safety & Clinical Quality Directorate on the Essure device information sheet for consumers to be ready in time for the film screening.

As previously noted, HCC is working on a national level with other HCCs to continue to raise awareness of the issue of medical device registration beyond pelvic mesh, and will continue to liaise with key WA Health staff to keep them across the emerging issues.

Other

Key projects and initiatives funded through other sources

In this reporting period, HCC has undertaken a number of activities as part of projects which were separately funded by WA Health or other agencies. Reports are attached for interest.

Sustainable Health Review Engagement

HCC was separately funded by WA Health to undertake consumer engagement to support the Sustainable Health Review. A full report is included which contains valuable consumer insights.

Obesity Collaborative

WA Primary Health Alliance funded HCC to support the work of the Obesity Collaborative, a Health Networks initiative. HCC utilised online engagement and other tools to create a very strong direction for the initiative. See the report attached.

Empowering Health Consumers with a Disability

People with Disabilities WA and the HCC were funded through a grant from the Department of Communities in 2018 to develop a program which sought to empower health consumers with disability and their families and carers and to increase their knowledge of their rights in health, their options when giving feedback and ways they could be involved in making sure disabled Western Australians have a voice at the various health tables. The project lead organisation is PWDWA with HCC providing support, resources and training staff to assist with the development and delivery of a series of 8 workshops for consumers, and 3 panels with services. These activities are going to be running mid-2019 and the project finalised by the end of the year. It is envisaged that the training for consumers will become a part of the suite of training available to health consumers into the future.

Alcohol and Other Drugs Advisory Group – now Alcohol and Other Drugs Consumer and Community Coalition - AODCCC

HCC was funded by the WA Primary Health Alliance to assist consumers in the AOD sector to become incorporated. The AGM was held in November 2018 and the organisation has already received Lotterywest funding to consult consumers to inform a submission–this was always the vision, for AOD consumers to have a say at the policy level, not just the service level.

ADDITIONAL INFORMATION AND FEEDBACK FOR SERVICE ONE AND TWO

10 ADDITIONAL FEEDBACK IMPACTING ON SERVICE DELIVERY

10.1 Were there any factors that affected delivery of the service during the reporting period (i.e. contributed to the success or limited success)?

During this reporting period, HCC undertook a staff restructure process for the consumer engagement part of the organisation. There was been some periods of time without a full complement of staff however we feel we have managed to achieve a significant amount despite this.

10.2 Are there any emerging trends or issues that will impact on the delivery of your service in the next reporting period – what do you expect that impact to be and what strategies will be put in place to respond (not seeking information on general community issues just those that affect your service delivery).

- As noted a key focus will be on reviewing and evaluating what we do in this final two years of the contract, including updating the outcomes we are hoping to achieve.
- We plan to link these in with the Supporting Communities Forum intergovernmental agency group's work out a WA outcomes framework.
- The Sustainable Health Review will also inform some of our direction in the next reporting period and beyond.

10.3 Has there been any change (or do you anticipate any) to the service model (including the Key Elements and Service Activities) that your organisation submitted in the Offer to the Department of Health?

Yes

No

As noted in the Consumer Representation Review, further work is progressing on determining the needs of services in engaging with consumers, and for consumers being supported to be effective representatives.

In 2018 there has already been a new initiative to undertake “School for Change Agents” as a capacity building activity for consumers and staff with WA Country Health Service. Depending on how this goes, this may be repeated each February and March and may take the place of some or all of the Consumer Representative Network meetings which were poorly attended.

Your Contract Manager will be in contact with you to discuss any changes.

SECTION 3: DISCLOSURE REQUIREMENTS – INSURANCE

As part of the funding arrangements, organisations are required to confirm they have the required insurances in place as specified in the Service Agreement Details. Services are required to complete the following table to confirm that their organisation is complying with this requirement and have the relevant insurances in place.

Please refer to the insurance provisions (including limitations) in your Service Agreement document.

Insurance Type:	Insurer	ABN	Policy No.	Insured Amount	Expiry Date	Exclusions (if any)
1. Public Liability Insurance	Berkley Insurance Australia	93004727753	2016112-0272 BIA	20 Mil	30.11.2019	N/A
2. Professional Indemnity	Berkley Insurance Australia	93004727753	201612-0266 BIA	20 Mil any one claim 40 Mil in aggregate	30.11.2019	An act, error or omission of a Medical Practitioner, Midwife or Dentist in their capacity as an employee Medical Treatment arising from failure to provide medical diagnosis, treatment or supplying medication that breaches any federal health or medical laws
3. Workers' Compensation including common law liability of \$50 million	Zurich Australian Insurance	13000296640	262309P GWC	50 Mil Common Law	30.11.2019	
4. Personal Accident Insurance for Volunteers	AFA Pty Ltd	83067084333	5575005	1 Mil	30.11.2019	
5. Motor Vehicle Third Party Liability.	RAC Insurance	59 094 685 882	MGP321 194531	Agreed value \$21,700 includes accessories	05.07.2019	
6. Other Business Insurance	AIG Australia Limited	93004727753	9637274 CMB	Replacement Value	30.11.2019	Management Liability, Loss or spoilage of stock, Outstanding accounts receivable, Building, Public & product liability

END OF REPORT