

SERVICE DELIVERY DATA REPORT HEALTH CONSUMER SUPPORT SERVICE Reporting period:

Year: Jan to June 2019

Organisation Name: Health Consumers' Council

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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: <u>26</u>
- 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 holidays including;

28/1/19 – Australia Day

4/3/19 – Labour Day

19/4/19 – Good Friday

22/4/19 – Easter Monday

25/4/19 – Anzac Day

3/6/19 - WA Day

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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 X

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	156
Male	75
Unknown	4
TOTAL (Total of all tables in 2.1 should be the same)	235

b) Age

Age	Number
Under 20 years	12
20-29 years	20
30-39 years	44
40-49 years	56
50-59 years	43
60 years and over	57
Unknown	3
TOTAL (Total of all tables in 2.1 should be the same)	235

c) Ethnicity

Ethnicity	Number
Aboriginal/ Torres Strait Islander	11
Culturally and Linguistically Diverse Background 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.	26
Other This includes Australian born (not Aboriginal/Torres Strait Islander) and other main English speaking countries (Canada; Republic of Ireland; New Zealand; South Africa; United Kingdom; and USA)	162
Unknown	36
TOTAL (Total of all tables in 2.1 should be the same)	235

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	142
Private Health	10
Public Mental Health	74
Private Mental Health	1
Unknown	8
TOTAL	235

b) Geographical Location

Location	Number
Perth Metropolitan Area	221
Rural, Regional and Remote Western Australia	14
Unknown	0
TOTAL	235

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	13
Health – Rights	37
Health – Disputes Diagnosis/ Treatment	56
Health – Access	39
Health – Access to records	5
Other	4
Mental Health - Costs	1
Mental Health - Rights	28
Mental Health – Disputes Diagnosis/ Treatment	32
Mental Health – Access	16
Mental Health – Access to records	3
TOTAL	235

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KEY ELEMENT 1 – Individual Support

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 3.1 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	1007
Home Visiting	
Online Support – including email	875
Face to Face	64
Formal Referral/Active Linkages	75
TOTAL	2021

KEY ELEMENT 2 – Information and Linkages

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

Yes X

No \square

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	736
Active linkages for non-users of the service	638
TOTAL	1374

SERVICE ONE - HEALTH CONSUMER: INDIVIDUAL SUPPORT

KEY ELEMENT 3 – Community Education				
Was this Key Element selected as part of the service model in your Service Agreement?				
Yes	X	No	П	

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.

the number of people that attended.		
Type of Community Education Activities	Number Provided	Total No Attending
Workshops/Training		
Introduction to Consumer Representation workshop	1	5
Seminars/Presentations		
Consumer Representative Network Meetings	2	50
Health Engagement NetworkSHR Presentation		
Health literacy session (Rights and responsibilities in healthcare and choosing the right health service at the right time) at Red Cross	1	25
Community Activities (e.g. promotional stalls at fairs and festivals)		
Patient Experience Week	1	64
Harmony Day Stall: Mirrabooka Shopping Centre	1	61
Community Health & Harmony Fair	1	15
Cyril Jackson Health Festival	1	26
Taste of Diversity: Canning Community Event		22
Information Sessions		
My Health Record information booth - City of Perth	1	30
Cultural Engagement		
Community Conversation Bhutanese Community Balga, Giving Feedback to Health Services, Mirrabooka	2	18
TOTAL	12	316
Other – Media		
Meditalk Podcast – Informed Consent / Choosing Wisely Program		
Road to Recovery - 89.7FM - Perinatal Anxiety, Depression and F	Postnatal P	sychosis
Medical Forum - WA Research Comes Home To Roost		
Medical Journal of Australia – Heritage Identification study and Po	dcast	
Letter to the editor re: abortion and safety zones, Have You Heard	May editio	n
AHCWA E Bulletin – Patient Experience Week write-up & photos		
ABC News - Investigation launched after woman takes her life at F emergency department	iona Stanle	ey Hospital

SERVICE ONE - HEALTH CONSUMER: INDIVIDUAL SUPPORT

KEY ELEMENT 4 – Interagency Collaboration			
Was this Key Element selected as part of the service model in your Service Agreement?			
Yes	Χ	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	
Aboriginal Patient Journey Continuum of Care (APJCC)	10
Adverse Childhood Experiences (ACE) Aware WA Consumer Forum	4
Connect Groups - Community Link Booth @ Fiona Stanley Hospital	7
Positive People WA – Consumer organisation support and networking	1
Number of relevant interagency forums or networks participated with	
Re-imagining Australia: Voices of Indigenous Australians of Filipino Descent	1
TOTAL	23

SERVICE TWO - HEALTH CONSUMER: SECTOR SUPPORT

KEY ELEMENT 3 – Commun	nity 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		
Supporting Cultural Diversity in Healthcare	1	3
Obesity Collaborative – community workshop	1	13
School for Change Agents	5	34
Seminars/Presentations		
Presentation - HaDSCO National Health Complaints Commissioners' Conference	1	12
Presentation - Senior Registered Nurse Masterclass QEII	1	35
Presentation - Policy Essentials Program Department of Health	1	37
Physiotherapy Planning Day (Clinical Leads) - The essential Consumer Perspective	1	25
WA Primary Health Alliance – Better Health Together Forum presentation	1	120
Presentation to COMHWA on HCC advocacy service	1	10
Community Activities (e.g. promotional stalls at fairs etc.)		
AHCWA State Sector Conference	2	120
SJOG Midland Expo	1	68
Cultural Engagement		
Other		
Sustainable Health Review - Carer & Consumer Peaks recommendations	2	6
TOTAL	18	483

SERVICE TWO - HEALTH CONSUMER: SECTOR SUPPORT

KEY ELEMENT 4 – Interagency Collaboration			
Was this Key Element selected as part of the service model in your Service Agreement?			
Yes	Χ	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	
National Justice Project with George Newhouse – National Justice Project, Aboriginal Health Council of WA Bila Muuji Aboriginal Health Corporation Inc	10
Obesity Collaborative - WA Healthy Weight Action Plan	2
Health Consumers' Council - State Peaks Meetings	4
Health Care Consumers Association (ACT) - Visit from Darlene Cox	1
Patient Experience Week network (WA Health Services, St John of God Midland, WA Primary Health Alliance)	3
Patient Experience Week Aboriginal Reference Group (Aboriginal Health Council of WA, Department of Health, WA Primary Health Alliance, WA Country Health Service)	2
Patient Opinion Community of Practice	3
Health Engagement Network	5
Mental Health Advocacy Service: meeting with advocacy groups	1
WA Primary Health Alliance – CEO regular catch-up	3
Carers WA – regular CEO Catch-up	1
Uniting Care West - Cultural safety in hospitals	1
United in Diversity – community events	2
Working with Migrant Clients & Communities - Metropolitan Migrant Resource Centre	
Establishing a CaLD reference group - Office of Multicultural Affairs (Helen Maddocks)	2
Ear Health - Murdoch University	1
Rural Health West Networking Meeting	1
Health Equity Symposium Convenors meeting	2
Palliative Care Summit Planning Meetings	2
CEDA event – SHR Launch - 'The future for WA health' – Panel Discussion participant	1
Alcohol and Other Drugs Consumer and Community Coalition	2
Australian Health Research Alliance Consumer and Community Involvement Steering Committee meeting	1

	1
Number of relevant interagency forums or networks participated with	
Aboriginal Health Practitioner - Top End Health Service	1
AHPRA - Agency Management Committee WA Stakeholder Breakfast Forum	1
CAMHS - Borderline Personality Disorder Workshop	1
Change the World Event	1
Community Conversation report, Input to WA Language Policy; Planning for cultural competency workshop	1
Diversity Awards - engaging young leaders state of the nation	1
Institute of Public Administration President's Address for 2019	1
National Reconciliation Week Breakfast	1
Research and Innovation Forum – WA Health - Consultation	1
Social Inclusion - Mirrabooka	1
WA Australian College of Health Service Management Conference	1
Educating the Nurse of the Future Consultation	1
Engaging Communities in Health	1
WA Health Translation Network – Science on the Swan Conference	3
WA Association for Mental Health & CoMHWA Forum on Mental Health Governance Review	1
WA Peaks Forum – WA Council of Social Service (WACOSS)	1
WACOSS Partnering in Procurement Consultation	1
Community Employers of WA	1
WACOSS Sector Breakfast	1
Mental Health Network Open Day	1
Public Health Institute of Advocacy Consultation - Obesity Advocacy Targets Forum 2019	1
Access Care Network Australia (ACNA) Ricki Smith – Networking Meeting	1
Australian Institute of Health & Welfare - Stronger evidence better decisions improved health and welfare	1
Wise Realities Inaugural Symposium 2019 Healthcare Immersive Technologies Event	1
TOTAL	76

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
WA Pelvic Mesh - National mesh implant forum	1	60
HIV related consumer groups	2	2
WA Pelvic Mesh Clinic – Consumer Survey	2	14
WA Pelvic Mesh Support Group - Meetings	1	4
Change, Choice, Continuity with Kylie Ekin	1	1
Cancer Costs Survey	1	108
Cancer Research Survey – Consumer Insights	1	101
TOTAL	9	290

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) participal committee or forum	ation on Departr	ment
Real time prescription monitoring	1	3
LGBTI Health Strategy	1	5
WA Men's Health Policy	1	1
WA Womens Health & Wellbeing Policy Working Group	3	5
WA Language Services Policy 2019	1	2
Clinical Senate Executive Committee meeting and Debate Attendance	1	4
Outpatient reform program	1	2
Clinical Simulation and Training Advisory Network	1	2
Sexual Health and Blood Born Virus Advisory Committee 2019 meetings	1	1
HIV Integrated Case Management Program guidelines	1	2
update Family Domestic Violence Action Group Meeting (KEMH, Women's Health Strategy & Programs)	1	1
Health Complaint Advisory Group (HCAG) Meeting	1	1
Mental Health Clinical Governance Review: Meeting with Consumers representative groups coalition	1	1
National Clinical & Community Advisory Group meeting	1	2
WA Women's and Newborns Health Network Executive Advisory Group Meeting	1	1
Health Networks Leadership Forum	1	2
Healthy Weight Action Plan Project Leadership Group	1	6
Consumer Advisory- participation on Department Co	ommittee or Fo	rum – where
Mental Health Commission - Advisory Group for the One- Stop Shop Project	1	1
NT/ WA Child Digital Health Checks Initiative Committee	1	2
WA Health Translation Network – Consumer and	1	8
Community Health Research Network Meetings		
WA Health Translation Network - Executive Board meeting	1	3
National Clinical Trials Governance Framework	1	1
Participation on (other) committees or forums whose propertment's strategic priorities	ourpose is align	ed with the
Curtin Health Administration Post Graduate Course Advisory Board	1	1
LAA Aboriginal Aged Care and Community Hub (AACCH), Community Reference Group (CRG)	1	2
Launch of Peer Work in Australia - CoMHWA, Curtin	1	1
University and WA Peer Supporters' Network Launch of the Centre for Molecular Medicine and Innovative	1	1
Therapeutics - Murdoch Palliative Care - CEO Roundtable	1	1
Centre for Social Impact UWA Advisory Council Meeting	1	2
School of Medicine Fremantle External Advisory Board Meeting	1	3

Australian Institute of Health and Welfare – Data	1	1
Development Plan		
WA Arts and Health Consortium Meeting	1	1
Choosing Wisely – National Meeting, WA Champion Health	1	3
Services discussion		
WA Child Digital Health Checks Initiative Committee	1	1
Prison Heath - Clinical Governance Advisory Committee	1	3
meeting		
Formal or documented responses to policy issues alig	gned with the De	epartment's
strategic priorities		
Voluntary Assisted Dying Legislation Submission	1	1
Safe Access Zones Submission	1	1
Institute for Health Leadership – Consultation Interview –	1	2
Health Leadership for the Future		
Meetings with (Department's) Minister, Ministerial staf	f and/or Departi	ment staff
A/Assistant Director General - Systems Policy and Planning	1	2
(Leon McIvor) - SHR		
Director General WA Health Regular Meeting	1	2
Minister for Health	1	1
Pip Brennan and Alanna Clohesy	1	1
WA Advanced Care Planning Consortium Meeting with	1	1
Simon Millman MLA		
Sarah Cowie - HaDSCO	1	2
WA Pelvic Mesh Support Group, Senator Siewert	1	1
Individual Advocacy Prison Health Ministerial Complaint	1	1
TOTAL	47	91

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	
Consumer consultation plan - Michelle Mcguirk	1
Sustainable Health Review Implementation advice	3
East Metropolitan Area Health Service	
EMHS - Ros Elmes – regular catch-up	1
EMHS - Aboriginal Engagement group - Joanna Hamilton	1
Royal Perth Bentley Group	1
Armadale Health Service - meeting with midwives re: diversity dialogues	3
North Metropolitan Area Health Service	
NMHS Board - People, Engagement and Culture Committee	5
Debrief of Minister for Health - Your Voice in Health Staff Survey	1
NMHS (Vilma Palacios) health programs	1
SCGH CAC Meeting	4
South Metro Area Health Service	
Fiona Stanley Hospital - Group Executive Committee	1
SMHS Chair (Rob McDonald)	1
Family Birth Centre Working Group at FSH	1
Fiona Stanley Hospital - Executive Director meeting	1
Child and Adolescent Health Service	
Perth Children's Hospital CAC	4
CAHS Policy & Pamphlet review	2
CAHS consumer engagement strategy	1
Standard 2 Committee Meeting	2
Unifying Systems for Recognising and Responding to Paediatric Clinical Deterioration - Escalation Project Steering Group (CAHS)	1
Child and Adolescent Health Network - Aresh Anwar	1
WA Country Health Service	
WA County Health Service: consumer engagement	2
Steering Group for development of Maternity Mobile Choices App Project	8
State Government (other agency)	
Supporting Communities Forum and Working Group Meetings	8
TOTAL	54

COMMENTS ON SERVICE DELIVERY DATA OUTPUT MEASURES

SERVICE ONE – INDIVIDUAL SUPPORT Advocacy Activities - Outputs

Advocacy Activities

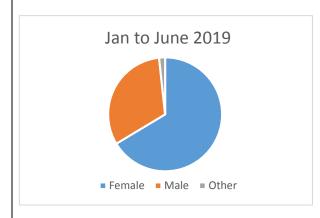
The HCC provides a flexible Individual Advocacy Service for West Australians seeking assistance with access to health service and/or redress processes.

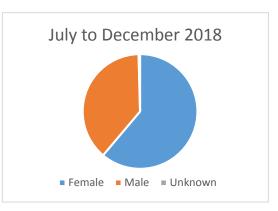
In this reporting period, there were 235 individual advocacy cases compared to 242 in the previous period. 83 cases were assessed to be complex in nature and 159 were non-complex.

1374 consumers were provided with information and linkage services through our triage system compared to the lesser number of 1066 in the previous period.

The HCC's triage system is provided by our reception staff, who are able to offer consumers a range of self-advocacy suggestions and tools. This information provision appears to be effective in empowering some of our consumers to self-manage their issue and ultimately not require an Advocate to assist them.

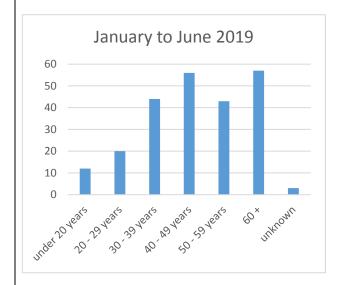
Advocacy Activities – Gender

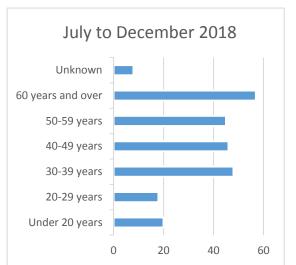




When looking at a comparison of the six months from July to December 2018 to January to June 2019, there are some changes to the proportion of females to males. This contract period saw 156 females, 75 males and 4 other access the Advocacy Service.

Advocacy Cases- Age Range

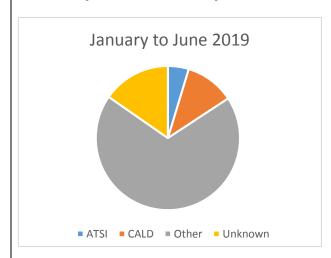


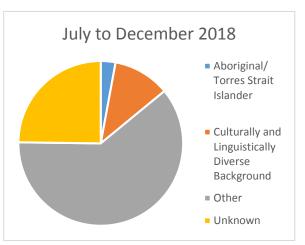


The comparison graphs above show a decrease in the under 20 cohort, increase to the 40-49, with the other groups remaining fairly similar.

The Advocacy Service were only unable to ascertain 3 consumers' age ranges compared to 8 in the previous period.

Advocacy Cases- Ethnicity

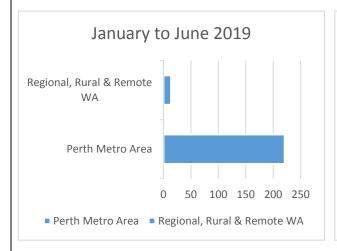


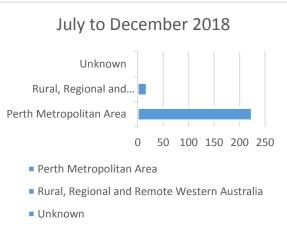


There has been a 57% increase in Aboriginal and Torres Strait Islander consumers who received Advocacy services compared to the previous period. Despite this increase, HCC are acutely aware that we could engage with countless consumers from this cohort however, current resources do not allow for awareness raising of the service.

Advocacy Cases-Iocation

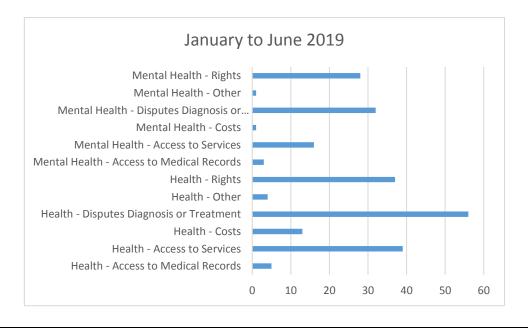
This reporting period has seen an increase in rural, regional and remote consumers who have accessed the service.

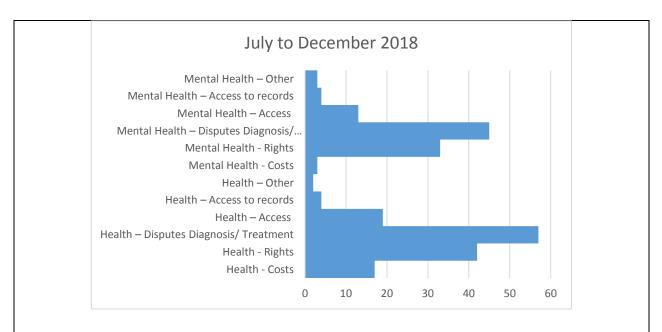




Advocacy Cases- Presenting Issue

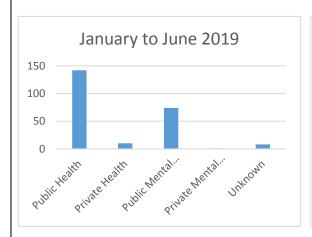
This reporting period has seen a significant increase in the consumer issue of 'access to services' in health rights, disagreement with diagnosis and treatment remain the dominant presenting issue.

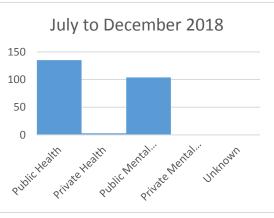




Advocacy Cases- Health Setting

This period has seen a slight increase of consumer issues having issues in private health, and a decrease in public mental health settings.





Advocacy Activities - Case studies

Case Study 1 – Prison Health (violation of rights leading to an adverse outcome)

B was serving a custodial sentence in a WA Prison. He had experienced severe back pain, which escalated to him being unable to mobilise. Despite alerting staff to this, it took several weeks for him to be taken seriously. He was eventually transported to hospital where investigations revealed a significant spinal infection; Doctors' advised that he might not walk again. He underwent surgery and commenced an intensive treatment regime. He remained an inpatient for 6 weeks, during which time HCC worked alongside the health service senior management to ensure a clinically sound discharge plan. Sadly, when he was transferred back to the prison, staff failed to adhere to the plan and did not facilitate adequate physical therapy and hospital follow up.

Within a few weeks, B reported that the pain had returned along with an inability to mobilise. Despite his pleas for appropriate medical review, and HCC's assertive advocacy attempts, staff did not organise timely follow up to ascertain whether the infection had cleared. It took several weeks for appropriate follow up to take place by which time infection had eroded his vertebrae. Advocacy now focused on trying to ensure the system did not fail this consumer again and wrote to the prison with the following requests 1. A need to ensure the prison's capacity to facilitate the discharge plan. 2. Staff to take B's reports of pain seriously 3. Staff to work collaboratively with HCC and B's family.

Sadly, the prison did not respond to the requests therefore, HCC escalated the matter to the Minister for Corrections. This led to positive changes within the Prison Infirmary to include the implementation of processes to monitor patients discharged back from hospital.

HCC is currently working alongside the National Justice Project to bring justice to B and his family for the adverse outcome he has endured culminating in his permanent disability.

Case Study 2 – Lack of informed consent

F was experiencing moderate discomfort due to an abdominal hernia. He was referred to a public hospital and consulted with a surgeon who suggested hernia repair by way of hernia mesh. F was advised that the procedure was common and came with little risk. F was not given information around the specific and well-known risks of mesh (migration, adhering and pain).

F went ahead with the suggested surgery believing he would have a successful outcome. Sadly, he experienced severe pain immediately following surgery that did not ease. For months, he presented to the hospital in a bid to convey his concerns regarding pain but was dismissed and told what he was experiencing was 'normal'.

After consulting with three different surgeons and multiple hospital presentations, he was given the news that he has a significant mesh injury (mesh adhered to his tissues and was accidentally stitched to his nerve).

F was booked for an investigative surgery to determine if a partial removal of the mesh could be achieved however, this surgery was cancelled without explanation. Eventually, he was advised that removal was not an option and that nothing could be done other than pain management. F has a cardiothoracic condition, which means he cannot take any pharmaceutical analgesia therefore, lives with unmanaged pain.

HCC advocacy has included advocating for F during a complaint resolution meeting with senior hospital staff, conveying F's specific questions to the meeting and ensuring adequate and timely response, obtaining F's patient records, organising an independent review of the case

and arranging for him to meet with a medical negligence lawyer at HCC's legal Information Session.

Case Study 3 - Inappropriate imaging and lack of patient centred care

C is a 75-year-old who has had numerous surgeries and multiple metal devices in her body. Whilst an inpatient, she was experiencing post-operative complications following spinal surgery. Her surgeon ordered an investigative CT scan. She was taken to the MRI room of the imaging department at which point she queried why he was not having a CT scan as ordered by the surgeon. C told staff that she did not think an MRI would be appropriate given the metal devices in her body.

Staff assured C that the Doctor had referred her for an MRI. She recalls being in discomfort as she lay down adding pressure to the surgical wound, which contained multiple staples. Staff told C to stay still and relax. When the MRI commenced, C pressed the buzzer because she said it was excruciating and caused a severe burning sensation in her body. She repeatedly pressed the alarm button and called out to staff however, they told her to lie still or she would be in the machine for longer. The ordeal last for 45 minutes during which time C believes she passed out due to the pain.

Later, the surgeon visited C and said that the imaging department had apologised, as there had been an error (should not have had an MRI). C's wound reopened, which she believes is due to the MRI. C told HCC that the trauma of the incident had caused her immense anxiety about returning to hospital and she had since experienced a significant decline in her mental health. C had tried to resolve the matter herself however, the imaging department had insisted they had acted appropriately and carried out the correct imagining.

Advocacy focused on assisting C to formulate a formal complaint, followed by a resolution meeting with the department. The outcome of the complaint process included the radiology service providing C with an apology and an admission that she underwent an incorrect and inappropriate imaging procedure, and changes to their consent and information provision processes were implemented. The service also agreed to negotiate financial compensation for the pain and suffering that C had endured.

Self-advocacy

Self-advocacy is an important element of HCC's Advocacy Service; we recognise the value of empowering consumers to have the knowledge and confidence to manage their own healthcare journey. Alongside the self-advocacy resources available via the HCC website, we now strive to offer consumers' such resources at the initial enquiry stage of our service. This means that some consumers are able to navigate their issue without the assistance of an Advocate.

Consumer Consultation

During this period, the Advocacy Service hosted a Consumer Forum, which sought feedback on our Advocacy Service processes. The focus was on:

- a) how we deliver our services now and;
- b) how we may shape the individual advocacy services in the future.

The Forum was hugely successful, with consumers' offering rich and valuable ideas to the session; we are committed to implement these suggestions where possible/appropriate within the coming months.

Partnering

HCC has continued to work with the Mental Health Law Centre (MHLC) in further developing the language and visuals for the Guardianship & Administration video guides for consumers' who find themselves involved in the process. During this period, we have collaborated further with the MHLC in the development of additional material. The MHLC have thanked HCC for our contributions in ensuring the content is fully accessible to all consumers', "This is really helpful – we know our language can be legalistic at times". (Shayla Straps MHLC CEO, June 2019).

Student Placement

During this period, HCC have worked with Curtin University's Social Work faculty. We welcomed a third-year social work student to the Advocacy Service, which has proven to be a great success. The reciprocal learning for the University and HCC has been significant and we look forward to hosting two students each academic year moving forward.

Clinical review of medical records

Advocacy cases often require clinical review of patient notes deciphering, which our Advocates are not able to undertake, given we are not clinically trained. In light of this, we have collaborated with a clinician who has volunteered their time to offer factual clarification when required. This allows us to offer an easier to understand summary of clinical information to our consumers.

Sustainability

The HCC Advocacy Service has seen an increase in the complexity of advocacy cases in recent years, which is un-sustainable with our current team of 3.4 FTE. We now operate a waitlist for advocacy of up to 4 weeks and note an inability to follow through on our previous agreement to contact consumers' within 48hrs of their initial enquiry.

The service has made efforts to ensure those most vulnerable consumers' (live advocacy need) are expedited however, resources mean this is not always possible.

Consumers' are contacting HCC with more complex and broader systemic issues than in previous periods, which is exceedingly time consuming for our Advocates and Reception staff.

Anecdotally, we hear that departments and community support organisations are experiencing cuts to funding and resources. We consider that this may have impacted negatively on those who experience mental ill-health.

There is currently a recognised gap in service delivery between the support available for mental health consumers who are involuntarily (under the Mental Health Act 2014) and those that are voluntarily treated. The Mental Health Act does not specifically identify where or how voluntary mental health consumers can access advocacy; the reality is that no such service exists in Western Australia.

Historically, HCC has undertaken mental health advocacy without specific funding to do so however, the increased demand for voluntary mental health advocacy services has significantly impacted on the workload and wellbeing of our staff, which is no longer sustainable. Further, we are now aware of the negative impact this issue is having on the quality of service we are able to offer to consumers with health, dental and allied service complaints (the cohort that HCC is specifically funded to service). There is an urgent need to either secure additional funding or to retract our scope to include physical health issues only.

To note, HCC does not advertise the Advocacy Service due being unable to meet any further demand. We know this means that there are cohorts of vulnerable consumers across Western Australia who do not know that HCC exists and are therefore unable to access advocacy.

Business case to the Mental Health Commission

In an attempt to go some way to mitigate our capacity issues, we recently submitted an unsolicited funding application for specific mental health advocacy. Unfortunately, this application was unsuccessful.

Health Rights Information for Consumers

During this contract period, we have continued to add to the Self-Advocacy Resources on our website, including adding 42 Lite Procedure Specific Information Sheets (PSIS) under licence from EIDO Healthcare Australia. These supplement the more detailed PSIS that people receive from their clinician during a visit to the health service. These Sheets have been developed by healthcare professionals and reviewed by health consumers for clarity and accessibility.

https://www.hconc.org.au/procedure-specific-information-sheets/

Health Rights and Responsibilities Presentations

We have initiated a partnership with Red Cross to deliver health literacy information as part of their orientation program to newly arrived refugee and asylum seeker background. Topics include health rights and responsibilities, choosing the right health service at the right time and providing feedback.

We also partnered with English conversation classes in local governments of Canning, Gosnells and Belmont to deliver health literacy topics.

HCC website information and resources for consumers

HCC started tracking website usage in April 2019. Since that time, website content relating to healthcare rights, making a complaint, patient opinion and self-advocacy and being involved in one's own healthcare have been accessed by over 2,700 unique visitors.

Using social media to extend reach

We believe that social media is an effective relatively low-cost way to promote information about healthcare rights, self-advocacy and consumer involvement opportunities to a broad audience. HCC is active on Facebook and Instagram. The HCC Executive Director is also active on LinkedIn and Twitter.

Over this reporting report, we have recorded:

- Facebook
 - Page likes of 1,500 people, an increase of over 12% since Dec 2018.
 - Page reach of 81,223 people
 - 10,054 page engagements
- Instagram
 - 290 followers
 - Reach of 2,709 people
- Twitter
 - 1,297 followers
 - 51,000 impressions
 - 102 retweets

HCC's electronic newsletter is sent to 819 subscribers, as well as HCC's members (over 290 people for this period).

Experimenting with social media groups for peer support for consumer representatives and community engagement

HCC hosts a number of Facebook groups as a mechanism to enable consumers with shared interests to connect with HCC and each other. These groups have varying levels of engagement. A key factor is the availability of HCC staff time to be able to nurture and encourage participation and connection in these groups.

- Source a group for current and potential consumer representatives https://www.facebook.com/groups/hccsource/about/
- Partners in Change Obesity Collective a group for people interested in the topic of obesity and weight management https://www.facebook.com/groups/248123835784261/
- WA School for Change Agents a group for people interested in creating positive change in the WA health system https://www.facebook.com/groups/WAschoolforchangeagents/

Traditional Media

We continue to respond to requests for consumer comment (e.g. tragedy at Fiona Stanley Hospital where a patient completed suicide in an Emergency Department, Medical Journal's request for a comment regarding safe zones at abortion clinics)

We did proactively engage the media in relation to Patient Experience Week but this was not taken up. We are also seeking podcast and radio opportunities where possible (e.g. MediTalk Podcast on informed consent, RTR FM's Road to Recovery.)

This is definitely an area of great interest and we will aim to work more proactively with media so we can also set agendas, rather than just responding.

COMMENTS ON SERVICE DELIVERY DATA OUTPUT MEASURES

SERVICE TWO – SECTOR SUPPORT Health Consumer Council Consumer and Community Engagement Program

School for Change Agents

This is a five module online course developed by NHS Leadership Academy. Sessions are an hour long, and can be viewed via the Futurelearn online learning platform. The program runs annually and provides an opportunity for people across the world to learn similar material about how to effect change in the health system as either a consumer or a health service provider. Building on the initial test of this approach in 2018, we promoted this program through our networks and to members and consumer representatives. The program started in May 2019 and the final session is planned for 9 July 2019. Sessions were two hours – one hour for viewing the material, one hour for discussion, with the session also being offered via zoom. Modules included: Change Starts with Me; Resilience is an Act of Defiance; Purpose and Power; Moving to Action; Being a Change Agent in a Complex World; and Personalised Care. We also established a Facebook group to enable people to share resources and discussion between sessions - https://www.facebook.com/groups/WAschoolforchangeagents/

In addition to the sessions hosted by HCC, we draw on School content for other consumer, carer, community and family representative activities.

Consumer Representative Networking sessions

Alongside the School for Change Agents, we ran two consumer, carer, family and community representative networking sessions – in March and on 1 July.

In March, we ran this as a combined session with the Health Engagement Network umbrella. This enabled us to promote Health Engagement Network to this audience, as well as to fund the participation of consumers in the planning and organisation of the event.

The sessions were planned based on feedback from the consumer rep community that was undertaken in 2018. The aims of the sessions were to:

- Provide an opportunity for consumer, carer or community reps and members to connect with other reps across the health system in WA
- Hear updates on key issues in the health sector and from Health Consumers' Council
- Build capacity by including a facilitated learning opportunity
- Discuss how consumer reps across WA health services can use the Health Engagement Network to promote best practice and build capability in consumer/carer engagement and participation across the health sector in WA

March 2019 - quarter 3

For this session, attendees were invited to submit suggestions for topics for discussion when they registered for the session. Based on that feedback, three topics were identified for facilitated group discussion during the session:

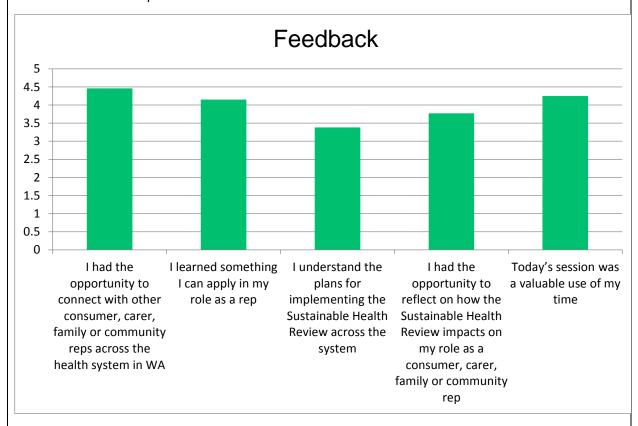
- Collaboration, communication and relationships
- Use of networks
- Reducing tokenism

The report from that session is on the HCC website https://www.hconc.org.au/wp-content/uploads/2019/04/190320-HEN-cons-rep-network-discussion-notes.pdf

See next section for feedback from this session.

July 2019 – quarter 4

This session took place on 1 July 2019 due to the availability of rooms and speakers. The focus for this session was the Sustainable Health Review and in particular, the focus on Enduring Strategy 1, Recommendation 4: "Commit to new approaches to support citizen and community partnership in the design, delivery and evaluation of sustainable health and social care services and reported outcomes".



Many people commented that they plan to discuss the SHR with their peer and networks as a result of this session. We plan to focus the next session on new models of engagement, including idea generation for consumer, carer, community and family reps who are keen to engage with other community members.

The report from this session is on the HCC website https://www.hconc.org.au/what-we-do/consumer-involvement-program/consumer-carer-family-or-community-representative-network/

Range of ways for consumer reps to engage and seek and offer support In addition to the consumer rep networking sessions, HCC offers current and potential consumer reps a range of ways to connect with each other and HCC. These include:

- The HCC's Source Facebook page https://www.facebook.com/groups/hccsource/
- HCC's consumer reading list for people who would like to receive additional information about health consumer issues. Currently we have 76 subscribers to this list.
- Health Engagement Network <u>www.healthengagement.org.au</u>

Liaison with Community Advisory Councils (CACs)

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

During this reporting period, we participated in the follow up session with NMHS CACs, Community Advisory Group and Aboriginal Cultural Advisory Group members. The aim of this session was to agree the foundations for a coordinated approach to engagement with these groups across NMHS. The session identified a number of the elements that were considered to be important for inclusion in the Terms of Reference for all these groups – for consistency.

Those items include:

- Purpose that the Community Advisory Council is a structured partnership between consumers, carers and the community and the (respective Health Service or Hospital).
- Functions and Responsibilities that these are to:
 - Provide a consumer perspective on activities, initiatives, and projects that will impact on patients using services within the hospital/ health service with particular attention paid to the needs of those who are of Aboriginal or Culturally and Linguistically Diverse backgrounds, live with a disability, are vulnerable, disadvantaged, and/ or from a minority group.
 - Activities and initiatives may include:
 - Safety and Quality indicator reporting, including patient satisfaction measures.
 - New and updated policies, patient information, reform projects
 - Implementation and evaluation of consumer related issues for the National Safety and Quality Health Services Standards especially in relation to Standard 2, Partnering with Consumers.
 - Ensure the impact on patient experience is considered in all decision making.
 - Assist in providing consumer representation on the Executive Committee and other hospital committees, as required.
 - Develop and contribute to networks with other consumer groups within the hospital/ health service such as Consumer Advisory Groups.
 - Initiate and participate in special projects as agreed to by the CAC that aim to improve the patient experience, with the approval of the Executive Director or Executive Sponsor.

The draft minimum terms of reference also clarifies and standardises the minimum expectations for accountability, membership, attendance, election of members, Term of Appointment etc.

Other issues that were discussed include the value of proactive and dedicated secretariat support to aid CACs and other groups to achieve outcomes.

Workshops

Consumer Representative Workshops

In this six month period, one of each workshop – the Introductory and Advanced Consumer Representative Workshops – were scheduled for open invitation. At the Introductory session in February, 20 people registered to attend, with only 5 people attending on the day. Attendees included two people who have been involved in consumer representative activities for over 10 years. While the discussion during the session was of value, there is clearly an opportunity for this training to reach more people.

We had also received a request from a WACHS staff member as to whether they could attend this session by videoconference as they would be supporting a consumer and carer engagement process later in the year. While the session content has been developed for consumer representatives, we took the staff member through the content to support them in the planning of their consumer engagement activities. This may be an opportunity for future work – running sessions for staff who will be planning consumer engagement activities about the role of a consumer representation and what is involved in working with a consumer group or committee.

For the Advanced session in May, a high number of late cancellations led us to cancelling this session. These attendance rates are despite the mitigation strategies including a pre-workshop survey and an SMS reminder being implemented.

The Engagement team are in the process of reviewing the training needs of CACs and other consumer representative groups with a view to delivering content that is adding most value. A training needs analysis process is in progress. Discussions have been held with Executive Sponsors at Area Health Services. The next step is to distribute a survey to Chairs of consumer representative committees and other representatives.

We are also in the process of recording the content from these two training sessions into short chunks that will be posted on the HCC website. Doing this will enable us to test the level of interest and participation with online modules. It also means that the content of these sessions will be available on demand and accessible to people who are outside of Perth.

Lessons from Fee for Service work

During this reporting period, HCC was commissioned to deliver consumer rep training for two organisations: Child and Adolescent Health Service who are running two community working groups (one for young people aged 14-18; and one for parents and carers of school age children) as part of the review of school-aged health services; and Bethesda Hospital.

HCC developed tailored workshop content for all of these sessions which were delivered to the consumer members, and to the staff supporting them. One outcome of these sessions is that delivering this content to both consumer reps and staff at the same time gave each group an opportunity to hear each other's perspectives on the same content. Another outcome was that members of the committee were able to develop relationships and explore how they would work together as a group.

We believe these reflections are valuable for the consumer rep training that we deliver under this contract.

Cultural Diversity Program

Diversity Dialogues Forum

Diversity Dialogues forums were developed to facilitate conversation, learning and understanding between members of CALD/new and emerging communities and health service staff. They also provide an opportunity for networking between agencies and individuals and support further engagement between medical staff and community members for further engagement. Panel members are people from CALD backgrounds who provide cultural and traditional insights to assist providers develop understanding and improve service provision to this cohort.

No forums were held between January and June 2019. Considerable planning work was done, including identifying and briefing speakers, with the intention of holding a session at an East Metropolitan Health Service (EMHS) site focused on cultural safety in antenatal care in June. Planning has since been put on hold pending clarification from EMHS of the topic and other details.

Supporting Cultural Diversity in Healthcare Workshops:

This three-hour workshop is designed to assist health care staff, from front line to clinicians, to develop skills and understanding around areas such as:

- Culture and its influence on service delivery methodologies, patient/provider engagement, attitudes and values
- Increasing and improving engagement with people from CALD and new and emerging communities
- Providing medical environments which support people with low English language skills

In this reporting period, planning took place for this workshop which will take place on 7 August. Within 2 weeks of the session being advertised, it was fully booked and at the time of writing we have approximately 20 people who have expressed interest in attending this session.

Given the high level of interest in this session, we propose to run an additional workshop on this topic in the 2nd half of 2019.

Community conversations

An important part of increasing health equity in the system is ensuring that diverse voices are heard. We know from discussions with CAC members that hearing the perspectives of people from culturally and linguistically diverse backgrounds is important, but also challenging. Participating as the only CaLD member of a committee may not be an attractive option for many community members – even if they are aware of the opportunity in the first place.

For this reason, Karen Lipio, HCC's Cultural Diversity Engagement Coordinator, has been keen to organise opportunities for people from a range of CaLD backgrounds to meet and discuss "what matters to you?" with regards to the health system.

HCC has made initial contact with a diverse range of community organisations who connect with people from a wide range of cultural backgrounds to try to set up these discussions. In February we held a session with 10 attendees from the Association of Bhutanese community. In March we met with 8 attendees from the Burmese community at Mirrabooka. In these sessions we learned that:

Many people who are from CaLD backgrounds find out about how to navigate the
health system from trusted members of their communities. For this reason, health
services may find it helpful to work with existing community groups to ensure that
newly arrived migrants are connected to appropriate services.

- None of the people we spoke with had experience of providing feedback to health services – either positive or otherwise. This is influenced by a number of issues:
- The quality of the health services is high compared to health services in some other countries
- People are grateful that they have the opportunity to access free or low-cost healthcare
- People believe that "complaining" is a bad thing. When we discussed that in fact, complaints are a valuable way of helping health services to continue to deliver high quality services, people commented they may be more likely to provide that kind of feedback.

The people who have participated in these sessions expressed their desire and interest in being kept informed about similar sessions and other opportunities to find out more about the health system in WA.

Information from these sessions is being provided to Health Services through the CACs.

In this reporting period, we have had early discussions with a couple of other groups and plan to hold one or two more community conversations between now and December 2019.

Aboriginal Engagement

HCC is committed to ensuring Aboriginal health is a core part of HCC's focus and services. We have continued to evolve how we work and have returned to a focus on consumer engagement rather than individual advocacy, as this provides the best way to leverage the time of the one very valuable Aboriginal staff member (0.7 FTE) we have.

Representation on committees relating to child and adolescent health both at state and federal level, prison health and sexual health and blood borne virus committees are ongoing priorities. Representation at the Aboriginal Health Council of WA's annual conference has also been important to ensure HCC is maintaining currency with key areas of systemic advocacy.

In addition to these ongoing commitments, the Engagement team and the Aboriginal Engagement Coordinator has worked on a number of important projects during this reporting period.

Justice Health Project/cultural competency workshops for staff

HCC was approached by George Newhouse from the National Justice Project (https://justice.org.au) to design some training in Aboriginal health advocacy for community service workers and community members. The purpose of the training is improve Aboriginal people's access to healthcare by training workers and community members in basic Advocacy skills, Health system navigation knowledge, Health Rights knowledge, and information on recognising racism that exists in our health system. The training covers 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.

As well as the National Justice Project and AHCWA, this national project is also a collaboration with Bila Muuji Aboriginal Health Organisation Inc in New South Wales.

During this reporting period, the project has progressed to the point where the training content has been developed and tested and is now being finalised. A Reference Group

is in place, and the MOU is in the process of being finalised. HCC received some grant funding from the National Justice project as a contribution towards some of the costs of this activity. Delivery of the course content will be delivered on a fee for service basis (per attendee).

Consumer input into research project

HCC's Aboriginal Reference Group 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." This paper was published online in the MJA in March 2019: https://www.mja.com.au/journal/2019/210/5/identifying-cultural-heritage-patients-during-clinical-handover-and-hospital

"In the first study to formally document the frequency of references to patients' cultural heritage during medical handovers and in hospital medical records, we found that, after adjusting for demographic, socio-economic and medical factors, Aboriginal patients were significantly more frequently identified than patients with other ethnic—national backgrounds.

"In an era of increasing cultural awareness, our results highlight inconsistencies in identifying the cultural heritage of patients when transferring clinical information. Research and community consultation should assist understanding the reasons for this practice."

Tania Harris from HCC who is listed as a co-author of this paper, also took part in an MJA podcast with lead author Dr David Morgan:

https://www.mja.com.au/podcast/210/5/mja-podcasts-2019-episode-11-identifying-cultural-heritage-dr-david-morgan-and-ms

HCC's Aboriginal Reference Group

HCC convened an Aboriginal Reference Group some two years ago, and in this reporting period it has met twice, focused on the plans for Patient Experience Week 2019.

Liaison with other Aboriginal Reference Groups

As reported previously, given that the members of our Reference Group have many calls on their time, we continue to shift our focus to working with other Reference Groups. For example, Tania Harris presents and meets regularly with the North Metropolitan Health Service Aboriginal Peer Review Group, with around 50 attendees. Tania has also been invited to join the LAA Aboriginal Aged Care and Community Hub (AACCH), Community Reference Group (CRG).

Patient Experience Week 2019

Patient Experience Week (PXW) is a global movement which began in the US with the <u>Beryl Institute</u>. It provides a focused time to celebrate accomplishments, re-energise efforts and honour the people who positively impact the patient experience every day. HCC has been leading the conversation about patient experience in WA since 2016 with momentum building each year.

In 2019, based on the high number of nominations for the Aboriginal and Torres Strait Islander Consumer Excellence Award in 2018, HCC decided to make Aboriginal health the focus on our 2019 Patient Experience Week activities.

PXW activities in 2019:

- A Ministerial breakfast to mark two years since the state-wide sign-up to Patient Opinion where the Minister for Health announced the winners of the inaugural Patient Opinion Award. This was awarded to WA Country Health Service.
- An Aboriginal Patient Experience Gathering outdoors at Pelican Point including a
 whispering tree with people's visions for Aboriginal health, stories of healing, bush
 tucker lunch, yarning circles, Aboriginal clown doctor, and travel scholarships for
 community members from regional areas. We created three short videos of this
 event which are on the HCC website

https://www.hconc.org.au/services/hccpxhome/



- Consumer Excellence Awards these were also held outdoors at Pelican Point
- Coordination of a network of health services to support their PXW activities this year we held a number of planning sessions to enable health service providers to meet and exchange ideas for marking and promoting Patient Experience Week in their health services.

A full report of the PXW activities is available on the website https://www.hconc.org.au/services/hccpxhome/

Grant funding was sought from Lotterywest to cover some of the event costs associated with the PXW activities. Sponsorship was also secured from the WA Primary Health Alliance and the Department of Health which contributed to some of the costs of the week's activities. The Aboriginal Health Council of WA also supported the event through the provision of a beautiful hand-painted chair which tells the story of the

Aboriginal patient experience. This chair was a prize to encourage people to submit evaluation forms and was won by Murray Collard of the South West Aboriginal Medical Service.



"Kindness, Connection, Community – see the Whole Person"

Djinang Kwop Wirrin

After a debrief session with HCC staff and health services staff, plans are being developed for a larger scale program of activities for 2020 that will aim to extend the focus on patient experience beyond one week of activities. The aim is to gather stories from consumers and staff in the health system – based on the theme that the patient experience is the human experience.

Consumer Representation – State Level

Sexual Health and Blood Bourne Virus Advisory Committee (SHaBBVAC)

The Executive Director is Co-Chair of this Committee which meets three times per year. A key focus for HCC on this committee is to support the inclusion of consumers. After a year of operation, the inclusion of three consumer members with lived experience of HIV and other sexually transmitted infections has been confirmed, including the terms and conditions of consumer attendees. HCC will be assisting with recruiting, training and mentoring these three consumers.

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.

The WA Case Management Advisory and Coordination Panel (the Advisory Panel) provides independent, expert advice to the Integrated Case Management Program on the management of cases classified as Level 2 or above and if required, provides advice and support to clinicians and service providers involved in the care of a client whose behaviour places others at risk of HIV infection. The panel meets at least every six months, and extraordinary meetings are convened at the request of the Chairperson. The panel's role is to review the cases that the ICMP presents and determine whether a client should be escalated to a higher level or de-escalated to a lower level or discharged from the program. Clear and appropriate documentation about the rationale for decisions made are maintained by the department at all times. As a consumer advocate on this panel, HCC's Aboriginal Engagement Officer's role is to bring a consumer perspective to the discussions, to use her experience as a health consumer advocate to raise any concerns around the health rights of clients. As a considerable number of the clients are often Aboriginal, it is important that an Aboriginal perspective can be brought to the panel through her membership.

HCC has provided advice that the program team should consider how to ensure that the program is culturally safe, particularly for Aboriginal people. Given that the numbers of people subject to the higher levels of management under the program are very low, many of the policy details are not clear as they have not had to be developed in detail. However, this means that the experience of people who are subject to that level of management is less than optimal.

During this period, the program team started to review the guidelines for the program, including discussing how to get consumer feedback on these. This is a complicated issue given community attitudes to HIV and low awareness and understanding of the issue in the general community. Also, the likely diverse views that may be held by people who are in the program and people in the community. The DoH public health team are managing the consumer consultation process themselves and a consultation session is planned for 31 July which HCC will host and attend.

HCC has also been actively engaging with HIV related consumer groups as there has been some concern among consumers regarding recent changes at the WA AIDS

Council. This can happen from time to time and further work is being explored to continue to support the consumer voice being heard in this important area.

WA Women's Health and Wellbeing Policy

HCC contributed on the WA Women's Health and Wellbeing Policy, by sitting on the Women's Health Conference Organising Committee, the Policy Working group including the Writing sub-working group. We had suggested that stronger consumer involvement (rather than service providers across government and non-government sectors could enhance the policy and conference) and had pitched an engagement plan to be funded but this was not supported. When extra funding was received to increase places at the conference, it did not necessarily address this key next step of more inclusion of services users in policy and service review.

WA Men's Health Policy

HCC provided representation on the Men's Health Policy Working Group and attended the policy launch.

https://ww2.health.wa.gov.au/~/media/Files/Corporate/general%20documents/Health%2 0Networks/Mens-Health-and-Wellbeing-Policy.pdf

WA Language Services Policy

The existing 2014 policy is due to be updated to ensure that in a linguistically diverse community, limited competence in the English language is not a barrier to accessing services. Western Australians who may require assistance to communicate effectively include people who are Deaf or hard of hearing, Aboriginal people and people from culturally and linguistically diverse (CaLD) backgrounds.

LGBTI Health Strategy

"Individually we are broken by shame, isolation and discrimination, collectively we gain strength to share our stories and let our voice be heard"

LGBTI populations have faced decades of inequitable treatment, stigma, exclusion, isolation, discrimination and abuse. Throughout the development of this strategy, and involvement with the reference group, I have heard firsthand the extent of the damage this treatment has caused for people. It is these stories of people's real experiences of care in the health system that has reinforced the need for this strategy to be adopted and integrated into everyday practice.

The strategy aims to raise awareness of the physical health and mental wellbeing of LGBTI people across the lifespan and to provide a framework of supporting strategies to enhance equity in access and health outcomes.

Overall, 14 workshops were held across WA attracting input from LGBTI community representatives with over 500 people participating in the consultation. This data provided the reference group with raw material to determine key themes, priorities, quotes and recommendations. Mostly, it highlighted that many voices may have remained silent, which demonstrates some of the barriers and challenges that the strategy seeks to address. Members of the reference group, including HCC's Operations Manager have drawn from personal experience, deep reflections and insight as well as the hundreds of stories that were heard and understanding that thousands of lives have been negatively impacted. The opportunity to participate in forming this strategy has created a hope for change in the future.

Interagency collaboration and policy advice My Health Record – Opt Out Option

HCC staff and staff from the WA Primary Health Alliance were available to talk with members of the public about My Health Record at a stall in Forrest Place in Perth CBD in January. There was a low of interest in the topic from passers-by, but those who approached the stall had the opportunity to talk with staff about their questions. We also connected the Glengarry Probus club with a speaker from WAPHA on My Health Record for their February meeting.

Supporting the WA consumer voice at a national level

Input to national digital health activities

NT/ WA Child Digital Health Checks Initiative Committee

The Child Digital Health Record – CHDR - (5-14) (previously called the Child Digital Health Checks) commenced in October 2018 with the Northern Territory as the project lead and WA as the evaluation partner. The project is looking into what health checks are conducted for school age children and how these checks can be represented as part of the vision for a longitudinal child health record. Tania Harris in the HCC team is the Consumer Representative on the working group whose role is to give a consumer perspective on the plan, suggest potential stakeholders, review and make suggestions to their consumer engagement plan and to contribute to discussion on what consumers may want from a record of this type.

The CDHR (5-14) is currently at Phase 2 (Discover, Define, Design) and engagement with consumers in the NT is starting. The Working Group meets monthly for two hour updates and discussions (Tania attends via teleconference), and usually this is preceded or followed by a phone conversation with the project lead where we discuss consumer specific concerns or perspectives. The outcomes from these meetings are shared with community during our regular Peer Review meetings, at CAC meetings.

National Children's Digital Health Collaborative – National Clinical and Community Advisory Group

The NCCAG meets quarterly (Tania attends via teleconference usually) and is responsible for ensuring the NCDHC initiative Proof of Concepts is adequate in meeting the needs of consumers and clinicians across the national health sector. The group provides advice and makes recommendations for all of the Collaboratives Initiative Governance Committees and provides advice on consumer and clinical engagement and consultation activities. Like the CHDR(5-14), Tania's role is to ensure a consumer perspective is considered when discussing the different Child Digital Health initiatives. The consumer members of the group usually meet prior the meeting to discuss the agenda, to ensure we have an understanding of the technical aspects of the Initiatives and are able to raise concerns or questions from a consumer perspective and have those added to the agenda. The outcomes of these meetings are shared with community and at CAC meetings.

This model – of pre/post contact with the project lead to talk through consumer perspectives on issues outside of the main committee discussion – is a valuable approach for getting the most from consumer participants in working groups at this level.

Supporting the WA consumer voice at a national level (cont)

Medical Devices

HCC meets monthly with the health consumer state bodies across Australia, to ensure we are collaborating wherever possible on key strategies. The most important issue we have tackled jointly is the issue of medical devices. On 5th April 2019 we convened a Mesh Forum to ensure the Recommendations from the Senate Inquiry into pelvic mesh remain high on the agenda. The Therapeutic Goods Administration released a Strategy the day before the event (which had had no consumer input) and this Strategy is now being enacted. We were asked by Consumers Health Forum to assist with their strategy with the TGA on how better to engage with consumers, but there is a significant amount of change required before their consumer engagement activities are likely to be inclusive and effective.

Australian Commission on Safety and Quality in Health Services

HCC was commissioned on a Fee for Service basis by the Australian Commission on Safety and Quality in Health Care to host two consumer and carer consultation sessions: on the review of the Australian Charter of Healthcare Rights; and on the plan to develop national safety and quality health service standards for primary care services. At these sessions invitees were sought from a diverse range of backgrounds to try to ensure a range of perspectives were heard. These included carers, mental health consumers, people with disabilities, Aboriginal people, people from CaLD backgrounds, and LGBTIQ+ people. For the session on healthcare rights we facilitated the organisation of a specific session with people with disabilities. HCC is able to promote these opportunities to diverse groups of consumers because of our strong networks with a wide range of people and organisations.

Advanced Health Research Alliance

HCC has been on the Board of the WA Health Translation Network (WAHTN) for some time, and now that WAHTN is an Advanced Health Research Translation Centre, we had the opportunity to be part of the Consumer and Community Involvement Project with Sydney Health Partners. The WAHTN Strategy is being worked on in the second half of 2019 and keeps HCC right at the centre of health research translation and community involvement in research.

WA Health Translation Network - Consumer and Community Health Research Network (CCHRN)

During this period, the HCC Executive Director has worked closely with the new Head of the Consumer and Community Health Research Network (CCHRN) to support the Network's aim of securing additional funding for their work. Fortnightly catch-up meetings have ensured a close connection between the two services, with a future consultation workshop planned for the two agencies in October. We believe it is essential to ensuring active consumer and community participation at all stage of the health and medical research process.

In line with this commitment, HCC worked (on a Fee for Service basis) with the WA Cancer and Palliative Care Network and the Research and Development Unit to facilitate consumer and community feedback into two forums: the Health and Medical Research and Innovation Forum in May 2019, and the Cancer Control Forum (planned for 26 July 2019). HCC worked with CCHRN to promote these engagement opportunities to their networks to seek broad participation in two surveys.

Helping to connect the health system in WA

It is in the interest of health consumers and the community that the health system in WA is coordinated and joined up. For this reason, HCC supports and facilitates a number of cross-system networks and groups which aim to facilitate shared learning, reduce duplication and enable a coordinated and consistent approach to issues facing the system.

In this reporting period we've coordinated discussions relating to:

- Patient Opinion
- Patient Experience Week
- Responses to the Sustainable Health Review

Participants in these groups regularly comment on the value of the opportunity to connect and share with colleagues across the system, and how it is challenging for them to facilitate these opportunities from within the system.

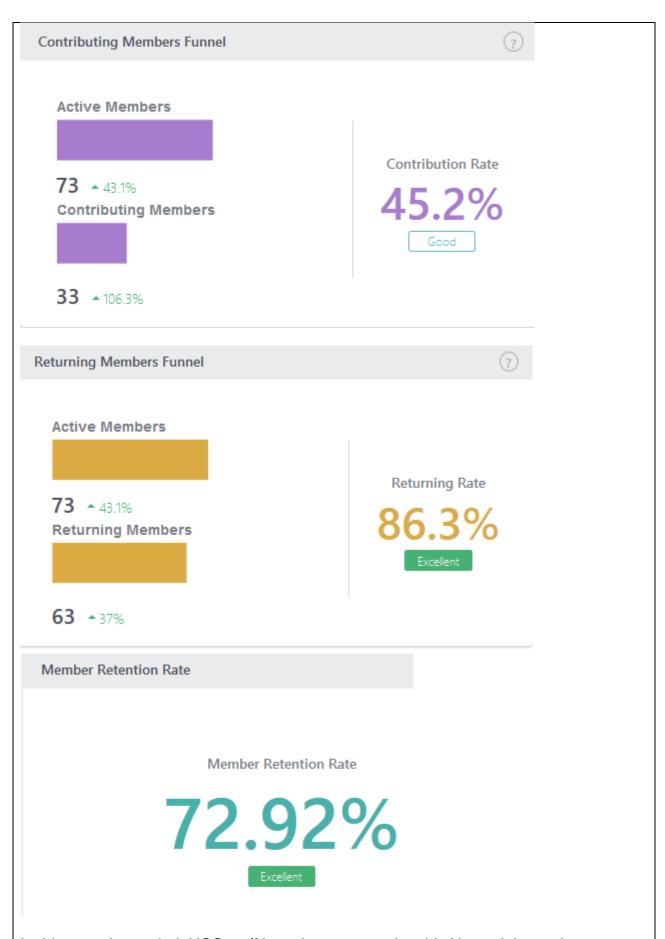
Health Engagement Network

This Network was established in 2018 with seed funding from the WA Primary Health Alliance and had a launch event in July that year. There are 281 members registered with the online platform – www.healthengagement.org.au – and approximately 70 other people who have expressed interest but have not joined up online.

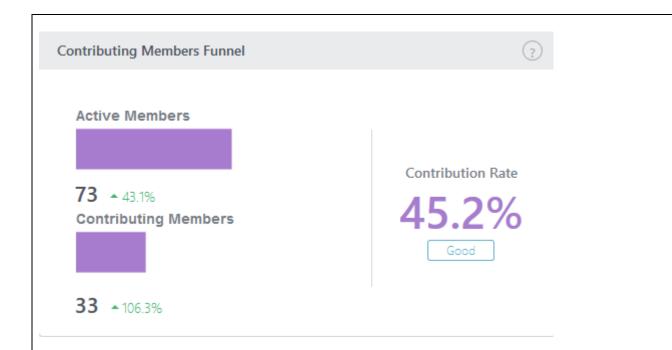
Three meetings were held during this reporting period. Two meetings (one face to face and one via zoom) to discuss plans for Network activity in 2019, and one online meeting to discuss opportunities to make the most of the online network.

One suggestion for improving engagement with the online platform was to circulate a regular email update about some of the recent updates to the site. This is being implemented and will be reported on further in the next reporting period. An online survey was also distributed to Network members. Participation in the survey was low. Feedback was mixed with people commenting on the value of the network, but also noting the lack of follow up from Network members on ideas and suggested activities. This is a challenge without dedicated resources to support Network activities.

According to the Mighty Networks analytics (the platform that is used to host the Health Engagement Network), HEN has a good rate of contribution from Network members, an excellent returning rate, and an excellent member retention rate (when compared with other networks that use the platform).



In this reporting period, HCC staff have been supporting this Network in a volunteer capacity (outside their paid working hours). Another event is planned for 31 July for staff and consumer reps – on the topic of "conversations of change".



Empowering health consumers with disabilities

HCC has been working with People With disabilities WA on a joint project which aims to empower consumers with disability to have a more positive experience when accessing the health system. The majority of HCC's contribution to this project has been partially funded by an Information, Linkages and Capacity Building grant as part of the NDIS program. The remaining contribution by HCC has come from the DoH grant as it aligns with the grant's purposes and outcomes.

A diverse group of people with disability, their carers and families is providing suggestions, advice and expertise on the communication, training needs and formats of people with disability to Health Consumers' Council Trainers. Training sessions are being delivered to people with disability, their carers and families, and health information resources are being provided and distributed in user-friendly ways to improve knowledge on healthcare needs and services available. In the next reporting period, seminars will be delivered to health service staff to increase their knowledge of the needs and rights of people with disability.

The resources developed as part of this project are on the HCC website at https://www.hconc.org.au/projects/empowering-consumers-with-a-disability/

Promoting consumer representative opportunities to consumers

HCC is often approached by public and private health services to provide "help finding a consumer rep". As this is a resource intensive activity it is not possible for HCC, unless separately funded, to identify suitable candidates. However, we do promote these opportunities where possible in a range of ways including circulating vacancies to our mailing list of consumer reps, on the HCC website, via the Source Facebook page, and where appropriate, via direct email to consumers who have indicated the topic is an area of interest.

During this reporting period, HCC has advertised 30 consumer rep opportunities, of which 10 were for WA health services or organisations.

Sustainable Health Review

The Sustainable Health Review Final report was formally launched o 10th April at a Council on Economic Development of Australia breakfast. The Executive Director was one of the panellists for the launch, and noted that the Report and its recommendations won't make any difference to consumers unless they are implemented. A web page for the Sustainable Health review has been created and will be updated. The Final Report is a key focus of HCC for the systemic advocacy we will undertake. We have noted a key dependency for all recommendations is the implementation of new ways of engaging with consumers. As noted elsewhere in the report we are continuing to partner with other NGOs and health service providers to ensure momentum for change is ongoing. https://www.hconc.org.au/what-we-do/policy-development/sustainable-health-review-consumer-view/

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.

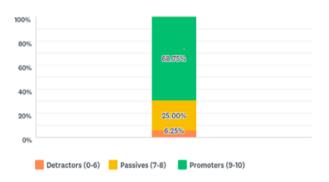
Evaluation of HCC Advocacy Service outcomes

HCC seeks feedback on all advocacy undertaken, both complex and non-complex interactions. For non-complex cases we seek consumer feedback by way of a 'short survey'. A link to the survey is accessible on every Advocates email sign-off and can be text messaged or posted to consumers according to their preference.

Consumers are able to provide feedback anonymously if they wish, which may mitigate concerns around not wanting to damage the Advocate/Consumer relationship.

Take up of the survey for this period either through the text prompt, post or email sign-off link was sixteen compared to 19 from the previous period. The survey responses reveal that the majority of consumers would be happy to recommend the Advocacy service to their friends and colleagues.

Q8 How likely is it that you would recommend HCC's advocacy service to a friend or colleague?



Comments included:

"Kerrie has helped simplify my complicated problems and I now know how to get positive help".

"Thank you for your time & energy. Your support is appreciated"

"Bronte did everything that she could have done, but unfortunately the situation was outside of her control"

Complex case survey

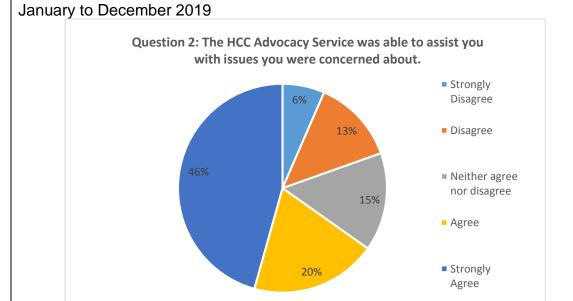
The service's more complex cases continue to be evaluated through a surveybased interview that was conducted by a University Student on placement with HCC. The student contacted those consumers who have been assisted in more complex interactions.

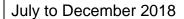
HCC took on board staff and consumer feedback that some of the previous evaluation questions lacked clarity and/or appeared to duplicate others. In light of this, we have adjusted questions accordingly.

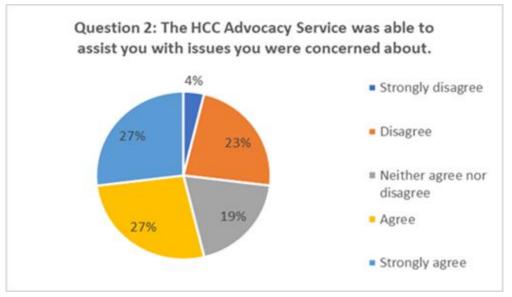
67 consumers who had received services between January 2019 and June 2019 were identified for inclusion in the survey. 46 consented to answering the questions. 14 did not wish to provide feedback, and 7 were unable to be contacted. The survey asked consumers 11 questions, which enquired about the following areas:

- How clients learned about HCC
- How effective clients found the HCC Advocacy Service (including its ability to assist with issues of concern, communication with health professionals, provision of information on agencies and consumer rights, and improving clients' access to health services)
- Clients' experience using HCC's online services
- Clients' expectations about HCC's Advocacy Service and their experience using the Service
- Clients' ability to access HCC's Advocacy Service
- Client suggestions for improvement
- General client feedback

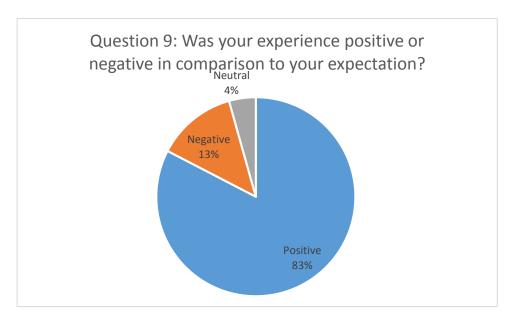
We note a 19% increase from the previous period in consumers reporting a 'strongly agree' that the service was able to assist them with issues they were concerned about.





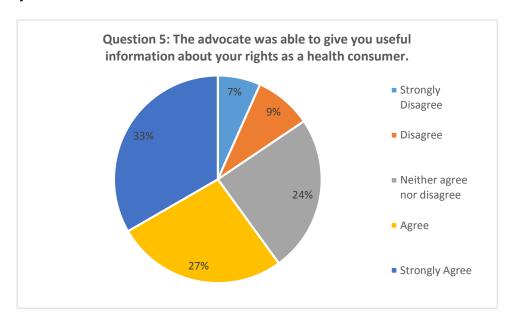


Overwhelmingly, consumers reported an overall positive experience of HCC's Advocacy Service. 83% of consumers commented that their experience with HCC was positive in comparison to their expectation. This question was changed from the previous survey ('Did the HCC advocacy service meet your expectations?') to better reflect the experience of consumers.

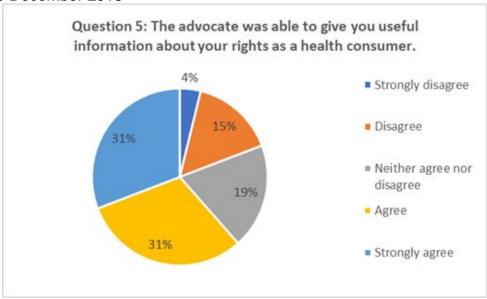


61% of consumers responded positively to the statement, 'The Advocate was able to give you useful information about your rights as a health consumer,' with 16% responding negatively. 24% of consumers responded neutrally. This represents a slight shift from negative (19% previously) towards neutral responses (19% previously), while the proportion of positive responses was very similar (61% compared to 62% previously).

January to June 2019



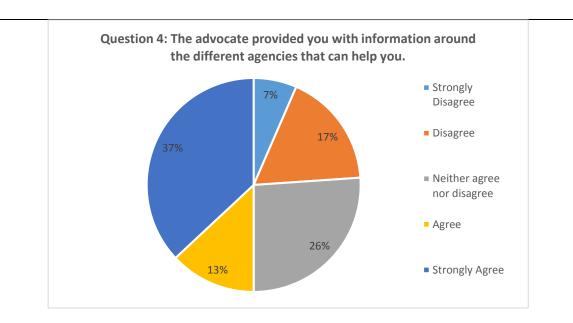
July to December 2018



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

In this reporting period, there is a significant increase in the number of consumers provided with information provision, 736 compared to 375 in the previous period. Further, we note an immense increase in consumers that The HCC linked with other agencies, 638 compared to 91 in the last period.

When presented with the statement, the Advocate provided you with information around the different agencies that can help you, resposes were as follows:

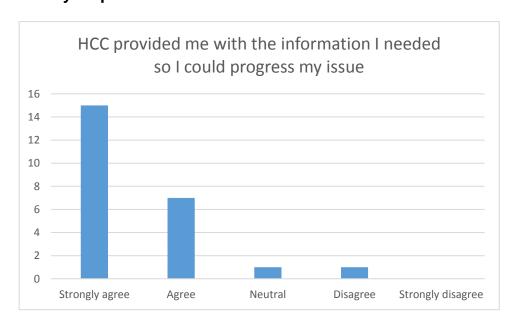


50% of consumers responded positively to this statement, with 24% responding negatively. 26% of consumers responded neutrally.

The positive responses mirror the previous survey (46% positive previously).

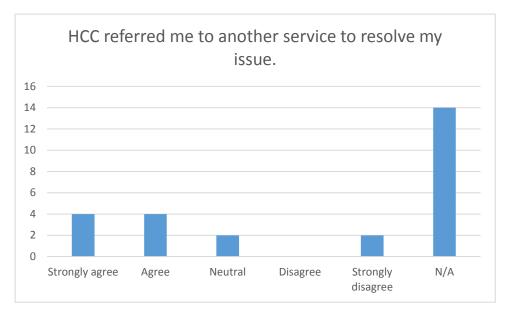
There is a slight increase in negative responses (24% compared to 19% previously) and a decrease in neutral responses (26% compared to 35% previously).

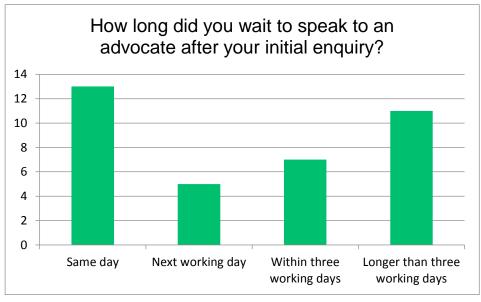
Short Survey responses



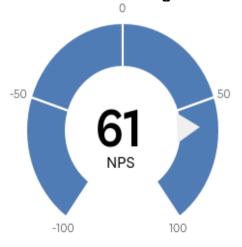
Overall, the majority of consumers had a positive experience and praised the organisation and their individual advocates. Feedback resulted in five recommendations to improve the HCC Advocacy Service. This included maintaining the different avenues through which consumers can find the organisation, being clear about the limitations of the HCC advocacy service to other organisations, managing consumer expectations, Advocates following-up

with consumers after their case has been closed and advocates engaging in mental health training.





How likely is it that you would recommend HCC's advocacy service to a friend or colleague?



Was there any way the service could have been improved? Responses to this question included:

- "Would like to see HCC base advocates in hospitals, as advocacy seems like an 'afterthought'".
- "More advertising and marketing so more people can know about the HCC".
- "Decrease wait times between the initial contact and when an advocate is assigned to the case".
- "More funding, as it is a wonderful service".

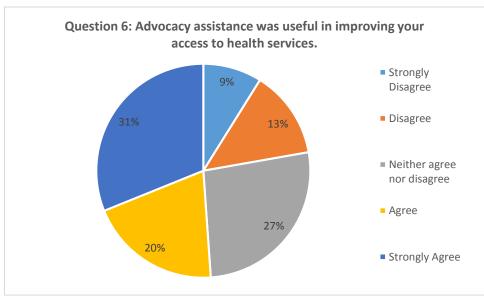
Positive comments included:

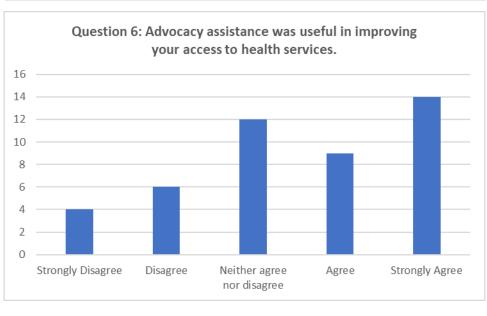
- "I felt like I was listened to and heard".
- "Nice to talk to someone about it".
- "I liked that the engagement was quick from start to finish".
- "I couldn't speak more highly of Kerrie and the department. Kerrie went beyond the call of duty to help and said the HCC is invaluable and would like to thank the HCC for what they do".
- "I was happy with how they treated me and dealt with my case".
- "Sam was absolutely beautiful, and I felt supported by her".
- "I was very satisfied with Carly and the whole team. I was really looked after. You're really doing a great job".
- "The service was very useful, and the advocate Bronte was very supportive during a very traumatic experience for our family"

- 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.

Consumers were presented with the statement, "advocacy assistance was useful in improving your access to health services."

51% of consumers responded positively to this statement, with 22% responding negatively. 27% of consumers responded neutrally. This reflects a significant increase in positive responses compared to the last survey (51% compared to 35% previously), and a significant decrease in neutral responses (27% compared to 42% previously). The proportion of negative responses was very similar (22% compared to 23% previously).





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.

Workshops for Consumer Representatives

In this period, we ran one Introductory Consumer Representative Training Workshop. All consumers indicated they agreed that they were supported to better engage and work effectively in their roles. All consumers either agreed or strongly agreed that they had been supported to build their skills and knowledge by attending the session.





School for Change Agents

During this period, we hosted the WA branch of the School for Change Agents. By the end of the reporting period, we had hosted five out of six planned debrief sessions with 34 people registered to participate across the six sessions, some of those for multiple sessions.

We invited feedback after the first session. At that point, over 85% of attendees felt they had the opportunity to learn from others, and 50% of people said they would find it easier to reach out to others involved in positive change in the WA health system. Over 57% of respondents said there were opportunities to build their network through HCC's School of Change Agents.

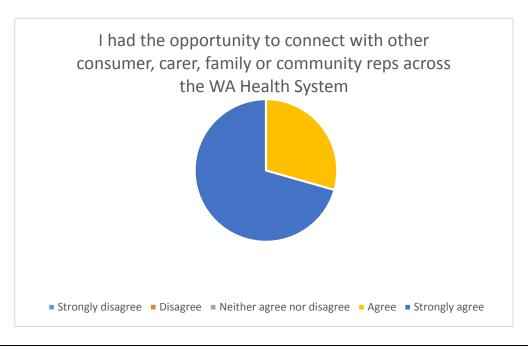
Further feedback from the post-program evaluation will be reviewed in the next reporting period.

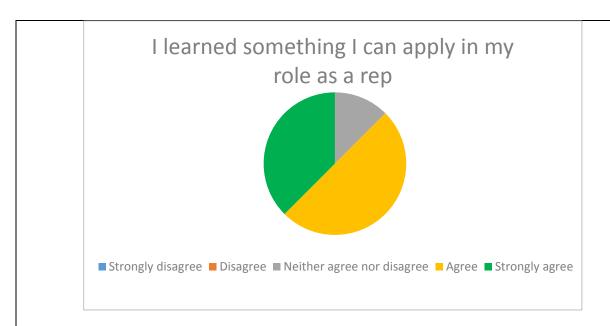
Consumer representative networking session

During this period we ran two networking sessions for consumer representatives.

March 2019

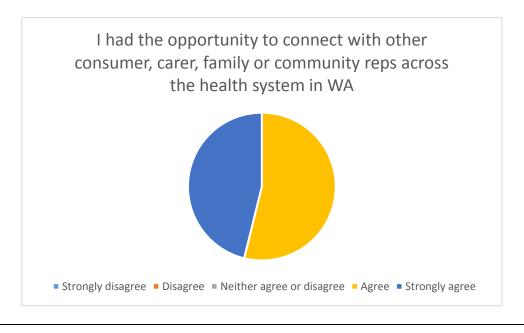
All attendees said they had they had the opportunity to connect with other consumer, carer, family or community reps across the WA Health System. 88% said they had learned something they could apply in their role.

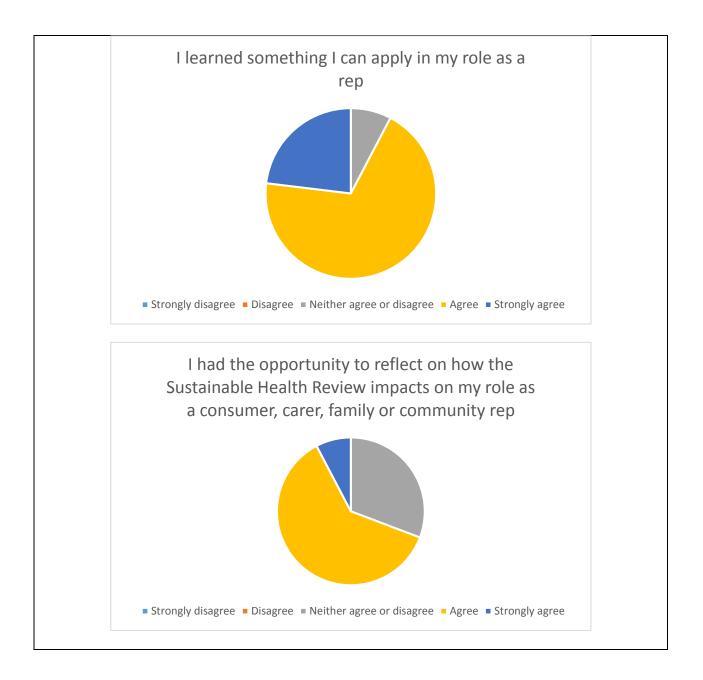




Winter (1 July) 2019

Everyone agreed or strongly agreed they had the opportunity to connect with other consumer, carer, family or community reps across the health system in WA. Over 92% agreed or strongly agreed they had learned something they could apply in their role. 70% agreed or strongly agreed they'd had the opportunity to discuss the implications of the Sustainable Health Review on their work.

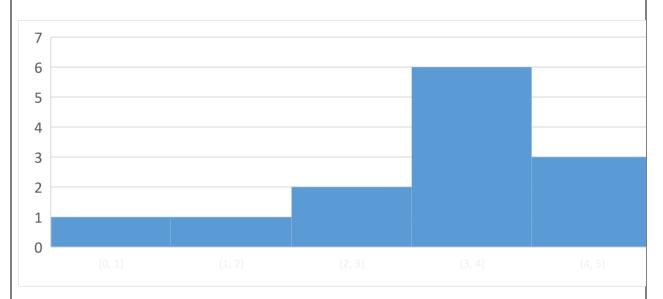




- 8 The Department of Health and Area Health Services are assisted to facilitate and promote active engagement with health consumers in the planning, delivery and review of health services.
- 8.1 The extent to which the Department of Health and Area Health Services are assisted to facilitate and promote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

Feedback from health service staff who participated in the PXW 2019 planning network was that they valued the opportunity to meet and brainstorm and share ideas and activities. There was support for future shared working and collaboration, including exploring how to extend the momentum of PXW activities beyond the week, and to other groups who may not usually get involved.

"I have improved my understanding of the patient experience from attending this event"



Comments from HSPs when asked what worked well for PXW 2019 included:

- "HCC provided good opportunity to hear about their planned events, and those of other HSPs."
- "Sharing of ideas across healthservices. Leadership and support from HCC WA"
- "The meetings to discuss ideas were helpful"

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.

Culturally and Linguistically Diverse (CaLD) and Aboriginal Consumers

HCC staff have provided information back to HSPs on the feedback gathered through Community Conversations with CaLD and Aboriginal people via their roles on Community Advisory Councils.

Obesity and weight management

HCC worked with the Department of Health and the WA Primary Health Alliance to provide opportunities for consumer feedback on their experiences of using WA health services to help them in their weight loss journey. In this period, HCC facilitated a workshop for the DoH team to get further feedback from consumers about the emerging priorities for the draft plan.

HCC staff also provided feedback on the draft action plan before it was circulated for a final round of consultation.

Clinical Incident Management and Complaints Policies

During this period HCC circulated opportunities to provide feedback to the Patient Safety Surveillance Unit at the Department of Health on these two policies. CAC and DHAC Chairs were invited to provide feedback to DoH directly on the CIM Policy. HCC will collate feedback on the Complaints Policy and provide it to DoH in July 2019.

Medical Devices

As noted above, in April 2019 HCC and other health consumer agencies across Australia convened a Mesh Forum to bring together the key regulatory and clinical players in the implementation of the Senate Inquiry Recommendations into pelvic mesh. It was also to alert people to the emerging issue of hernia mesh, and a report from consumers was provided to WA Health's Chief Medical Officer and Clinical Excellence Division. The Therapeutic Goods Administration TGA released a Strategy the day before the event (which had had no consumer input) and this Strategy is now being enacted so we will keep a close watch on this.

The current breast implant recall shows that exactly the same issues are at play as with mesh, i.e. that there is no clear way to know 1) how many women have the textured breast implants b) who they are and c) how that can be contacted to advise them of the health risk they now face. While the consumer expectation is that there would be a proactive recall (similar to when faulty airbags are identified by car companies), the reality is very far from this.

HCC is also advocating for a stronger co-design approach to the WA Pelvic Mesh Clinic and will collaborate on a Ministerial Mesh Summit, likely in October.

State Intergovernmental Initiatives

The Executive Director sits on the Supporting Communities Forum which aims to promote a more unified government and non-profit response to the "wicked" social problems that we try to address. HCC's role in this group is also to remind the members that it is the service users themselves who also needs to be at the table to ensure that the services created actually meet need.

In addition, work is unfolding in relation to a state Privacy Act. HCC's Executive Director is the Co-Chair of the Data Sharing and Privacy Working Group and is actively advocating for a broader community conversation on the issue. A community forum is in the planning stages for early October 2019.

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)?

Patient Experience Week is the last week of April and HCC again convened events for the health sector and consumers to jointly attend. The report on the PXW activities and the Health Matters edition for Patient Experience Week are included for reference. While the project has been successful and is important, undertaking the work impacts on the resources of such a small organisation.

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).

We will continue to monitor the dynamic environment of consumer engagement. We anticipate additional work relating to the Sustainable Health Review, particularly Enduring Strategy 1/Recommendation 4 relating to new models of citizen and community partnership.

We have received feedback from consumer and community leaders (CAC and DHAC Chairs) that they would value training content for new Chairs to be developed. We've also received feedback that there would be a value in creating and delivering training to staff who work with and support consumers and community members to support those staff to get the most from the engagement; and to support the raising of the profile of consumer engagement mechanisms within health services (beyond those staff who work directly with the groups).

We will consider options for developing training materials for committee Chairs.

	ts and S	ny change (or do yo ervice Activities) tha	• ,	, ,
✓	Yes		No	
	_	CC's logic model and curement and Policy		

identify a policy area as our previous contract was developed prior to the new Health

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

Services Act.

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	30/11/19	N/A
2. Professional Indemnity	Berkley Insurance Australia	93004727753	201612- 0266 BIA	20 Mil any one claim 40 Mil in aggregate	30/11/19	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	30/11/19	
4. Personal Accident Insurance for Volunteers	AFA Pty Ltd	83067084333	5575005	1 Mil	30/11/19	
5. Motor Vehicle Third Party Liability.	RAC Insurance	59 094 685 882	MGP323 406931	Agreed Value - \$20,200	8/2/20	
6. Other Business Insurance	AIG Australia Limited	93004727753	9637274 CMB	Replacement Value	30/11/19	Management Liability, Loss or spoilage of stock, Outstanding accounts receivable, Building, Public & product liability

END OF REPORT