Government of **Western Australia**
Department of **Health**

SERVICE DELIVERY DATA REPORT

HEALTH CONSUMER SUPPORT SERVICE

Reporting period:

Year: **January – June 2020**

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: 26

1.3 If appropriate, description and explanation of any periods of time during the reporting period when the service was not available at 100% funded capacity:

1-5 January 2020 – Christmas Closure

27 January 2020 – Australia Day

2 March 2020 – Labour Day

COVID OFFICE CLOSURE: Pivoted to 100% online operation from 16th March 2020

10 April 2020 – Good Friday

27 April 2020 – Anzac Day

COVID OFFICE PARTIAL RETURN from week beginning 1st June 2020

1 June 2020 – WA Day

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	115
Male	56
Unknown	4
TOTAL ***(Total of all tables in 2.1 should be the same)***	**175**

b) Age

Age	Number
Under 20 years	10
20-29 years	15
30-39 years	31
40-49 years	35
50-59 years	33
60 years and over	51
Unknown	0
TOTAL ***(Total of all tables in 2.1 should be the same)***	**175**

c) Ethnicity

Ethnicity	Number
Aboriginal/ Torres Strait Islander	7
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.	24
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)	132
Unknown	12
TOTAL ***(Total of all tables in 2.1 should be the same)***	**175**

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	107
Private Health	5
Public Mental Health	60
Private Mental Health	0
Unknown	3
TOTAL	**175**

b) Geographical Location

Location	Number
Perth Metropolitan Area	165
Rural, Regional and Remote Western Australia	10
Unknown	0
TOTAL	**175**

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

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

Type of Presenting Issue	Number
Health – Costs	7
Health – Rights	27
Health – Disputes Diagnosis/ Treatment	47
Health – Access	21
Health – Access to records	4
Other	9
Mental Health - Costs	3
Mental Health - Rights	16
Mental Health – Disputes Diagnosis/ Treatment	27
Mental Health – Access	9
Mental Health – Access to records	2
Other	3
TOTAL	**175**

3. SERVICES PROVIDED

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	640
Home Visiting	0
Online Support – including email	992
Face to Face	59
Formal Referral/Active Linkages	232
TOTAL	**1923**

KEY ELEMENT 2 – Information and Linkages

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 3.4.

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

Type of Information and Linkages	Number
Information provision	149
Active linkages for non-users of the service	106
TOTAL	**255**

KEY ELEMENT 3 – Community Education

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

Yes X No ☐

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

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

Type of Community Education Activities	Number Provided	Total No Attending
Workshops/Training		
Introduction to consumer rep training	1	17
Advanced consumer rep training	1	20
Introduction to Zoom – telephone meeting	1	10
Introduction to Zoom – online	1	25
Introduction to using Zoom to host meetings	1	23
Standard 2 training and follow up session	2	18
Seminars/Presentations		
Consumer Rep networking sessions March (x 2) and June 2020	3	39
Consumer rep drop in sessions	5	120
Community Activities (e.g. promotional stalls at fairs and festivals)		
Information Sessions		
Cultural Engagement		
TOTAL	**15**	**272**

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 X 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	
Empowering Health Consumers with disability on advance care planning and goals of care	1
Partnership – discussion with Health Issues Centre Victoria and HCCWA	1
Diabetes WA – discussion about possible project on total meal replacements under Healthy Weight Action Plan	1
Meeting with Cancer Council to discuss election asks	1
Number of relevant interagency forums or networks participated with	
Individual Advocacy peaks meeting re: voluntary mental health advocacy	1
TOTAL	**5**

SERVICE TWO - HEALTH CONSUMER: SECTOR SUPPORT

KEY ELEMENT 3 – Community Education

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

Yes X No ☐

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

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

Type of Community Education Activities	Number Provided	Total Number of People Attending
Workshops/Training		
Health Engagement Network virtual engagement – with Aha Consulting	1	20
Presentation to WACHS leaders ACHSM & Co-design	1	25
Seminars/Presentations		
The Future of e-Health (partnership events with EY, Innovation Hub, WA Health Translation Network's Consumer and Community Health Research Network	4	160
Immersive Technologies Conference	1	86
Curtin University 3rd Year Medical Student Presentation	1	58
Community Activities (e.g. promotional stalls at fairs etc.)		
Cultural Engagement		
Cultural Diversity in Health training	1	26
Other		
Consumer engagement Chairs Network	3	34
Fireside chats with WA Health staff	4	120
TOTAL	**16**	**529**

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 X 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	
Healthy Weight Action Plan implementation – with DoHWA and WAPHA	1
National health consumers agencies – response to COVID-19	24
Aboriginal Health Council WA • Traditional healing • National Justice Project • Health information during COVID-19	3
WA Primary Health Alliance • Health Engagement Network • See your GP (Marketing program) • Intake and Referral Project (New)	3
Consumer and Community Involvement Program, WA Health Translation Network • Guardianship • E-health • Discussions with Exec Director	3
Linkwest CEO Liaison	2
Obesity Collective	1
Weight Issues Network	1
Palliative Care WA • Compassionate Communities meeting • Community telephone support line • Sector consultation • National Palliative Care Week events • Consumer rep drop-in • CEO Roundtable	6
National Goals of Care Collaborative • National Steering Committee • WA Implementation Committee	2
Consumers of Mental Health WA • Datix consumer feedback	1
Digital Cooperative Research Centre • Diversity Dialogue discussions • Telehealth and patient experience	2
Consumers of Mental Health WA, Ethnic Disability Advocacy Centre, Mental Health Advisory Service, Developmental Disability WA	1
Liaison with Disability peaks in relation to COVID-19 concerns about end of life care conversations, discussing Minister for Health response to letter	1

Health Issues Centre event liaison	3
Innovation Hub, South Metropolitan Health Services, Consumer and Community Health Research Network, Ernst Young – The Future of E-health	5
Explorability – Aboriginal and Torres Strait Islander people with disability	1
Umbrella Multicultural Community Care Services	1
City of Bayswater meeting	1
City of Wanneroo meeting	1
Ethnic Communities Council of WA meeting	1
Ishar Multicultural Women's' Health Services meeting	1
City of Belmont meeting	1
Multicultural Youth Advisory Network WA	1
Aboriginal Traditional Healing Project – South Metropolitan Health Service	4
Number of relevant interagency forums or networks participated with	
Northern Corridor Multicultural Network Forum	1
Networking Forum: Capacity building in newcomer communities (hosted by City of Stirling)	1
TOTAL	**73**

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	No instances
Feedback on responses to COVID-19 among people in CaLD communities – incorporated in advice shared in meetings with DoH staff – Liaison with Local Government Authorities	4	1
Consumer feedback on goals of care and advance care planning and storing these on My Health Record – community forum	1	1
Datix consumer feedback	1	4
WA Health ICT Committee – consumer input into consumer engagement plan	1	1
COVID-19 Community and surveys	2	5
TOTAL	**9**	**12**

3.8 Mechanism for Provision of Advice and Information

Mechanism for Provision of Advice and Information (through)	Number of Activities	Number of Instances
Consumer Representation* (HCC appointed) participation on Department committee or forum		
Aboriginal Health and Wellbeing Framework Evaluation	1	2
WA Primary Health Alliance – national workshop on national primary care strategy for older people	1	1
Aboriginal and Torres Strait Islander Advisory committee	1	1
Perth Children’s Hospital Community Advisory Council	1	5
East Metropolitan Health Service Inner City Community Advisory Group	1	1
Sexual Health and Blood Borne Virus Case Management Advisory Panel	1	1
Obesity Collaborative	1	3
Child Digital Health Record (5-14 years) Initiative Committee Meeting	1	4
Clinical Senate of WA Executive Advisory Committee	1	6
Choosing Wisely WA Champions Meeting	1	1
National Goals of Care Collaborative Steering Committee	1	5
Consumer Advisory- participation on Department Committee or Forum – where HCC provides general support		
Sexual Health and Blood Borne Virus Advisory Group – Consumer members briefing before and after meetings	1	2
Participation on (other) committees or forums whose purpose is aligned with the Department’s strategic priorities		
Australian Digital Health Agency National Clinical & Community Advisory Group	1	1
Cancer Plan Launch Attendance	1	1
Empowering Health Consumers with Disability Focus Group	1	1
Ethical decision making – Health Issues Centre and Health Consumers Queensland	1	1
First People's Disability Network	1	1
Liaison with maternity consumer researchers to explore co-design opportunities	1	2
National Children’s Digital Health Collaborative	1	1
Patient Experience Week planning	1	2
Prison Health - Catch up - J Wallam Office of the Inspector of Custodial Services	1	1
Prison Health Clinical Governance Advisory Committee	1	3
Speech Pathology Information, Linkages and Capability Grant Project Advisory Committee	1	1
WA Health Translation Network – Executive Board, discussions on privacy, liaison with Consumer and Community Health Research Network	3	12
WA Primary Health Alliance Commissioning for Better Health Advisory Group	1	1
WA Primary Health Alliance Disability Working group	1	2
Formal or documented responses to policy issues aligned with the Department’s strategic priorities		
Feedback on User guide for health service organisations providing care for patients from migrant and refugee	1	1

backgrounds for Australian Commission for Safety and Quality in Healthcare.		
Confirming the Best Practice in Consumer and Community Involvement (CCI) workshop – Australian Health Research Alliance Project	1	1
Australian Communications Consumer Action Network WA Roundtable No Western Australian Left Offline	1	1
COVID-19 Research Grants Meetings and Panel judging	1	8
National Health Information strategy meetings and feedback	1	2
Meetings with (Department's) Minister, Ministerial staff and/or Department staff		
Meeting with the Minister for Health's Chief of Staff	1	2
TOTAL	**34**	**77**

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	
Disability Health Network leads – March 2020	1
Palliative Care Network – consumer involvement	1
Systems and Governance – SHR recommendation 4, meetings	5
East Metropolitan Area Health Service	
North Metropolitan Area Health Service	
WA Mesh Clinic – consumer input on clinical service	2
Consumer member of Interview Panel for Manager Health Strategies & Programs	1
South Metro Area Health Service	
Connect Group Booth Project Control Meetings	2
Family Birth Centre – consumer input on clinical service	1
Child and Adolescent Health Service	
Midland Hub Project Control Group	8
WA Country Health Service	
Palliative Care Project Control Meetings	2
State Government (other agency)	
Roads to Recovery Ministerial Roundtable - Health	1
Service (self-initiated)	
Care Opinion site meeting, Brisbane (February 2020) to discuss consumer input into moderation and operations of the platform	1
TOTAL	**25**

SERVICE ONE- INDIVIDUAL SUPPORT

Advocacy Activities- Outputs

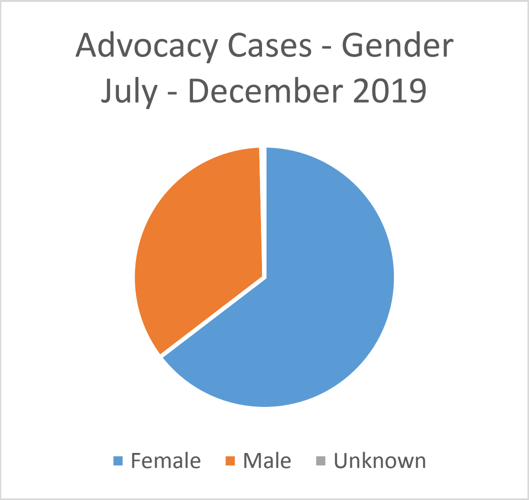
The HCC provides a flexible and Individual Advocacy Service for West Australians seeking assistance with access to health service and/or complaint resolution processes. In this reporting period, there were 178 advocacy cases. 74 cases were assessed to be complex in nature and 104 were non-complex.

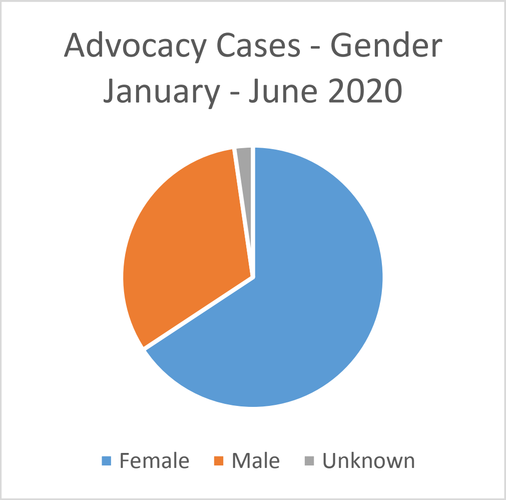
Our reception/triage staff have provided information and active linkage to 256 individuals during this period. Such provision includes information and linkage support to stakeholder enquires, offering individuals a range of resources and self-advocacy tools. Many consumers are empowered by this strengths-based approach and are able to self-manage their health-related issues.

This period has been very busy particularly as our advocates carried many advocacy cases over from the previous period(s).

Advocacy Cases- Gender

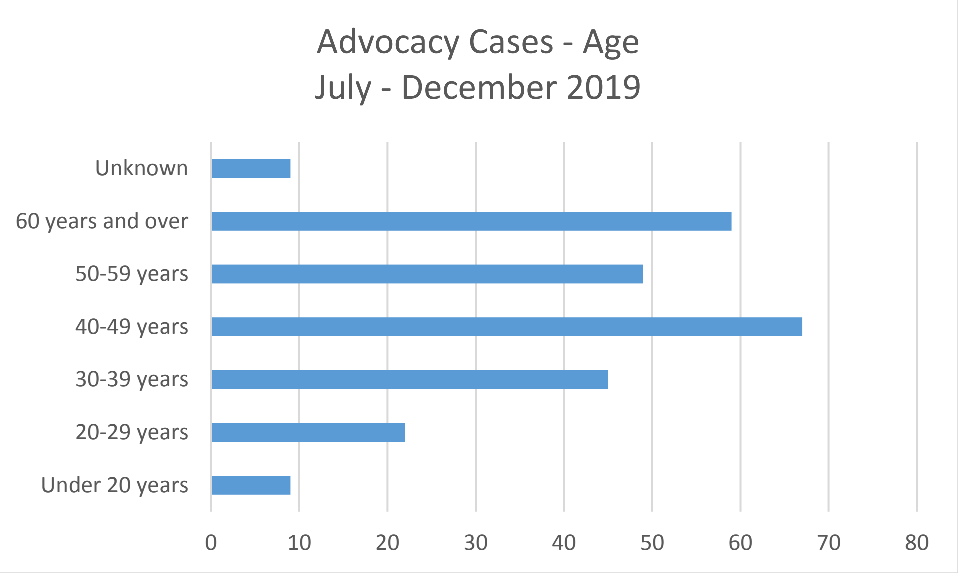
The comparison reveals some changes to the proportions of gender identification for those who accessed the service, with individuals identifying as female in 115 cases, male in 56 cases and 4 consumers identified as gender binary.

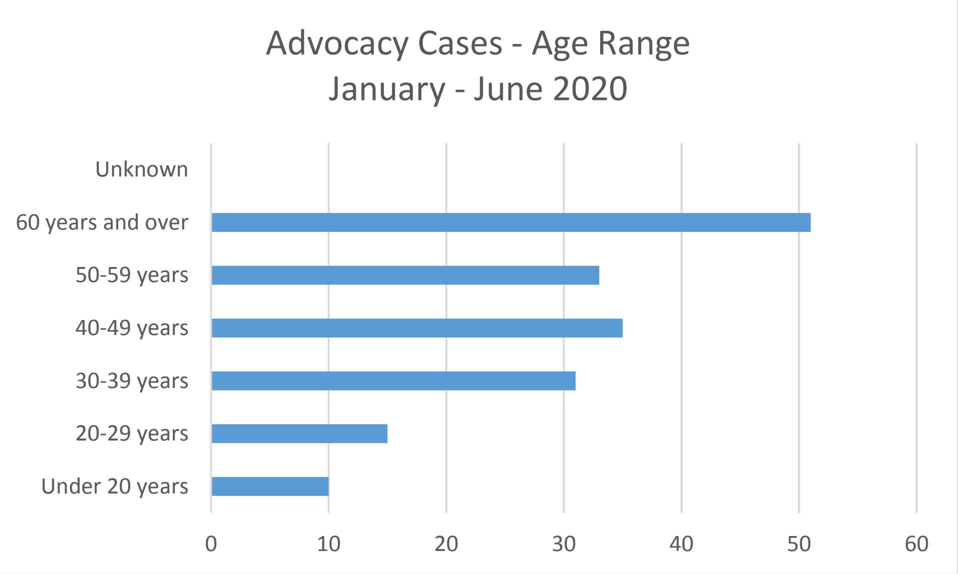




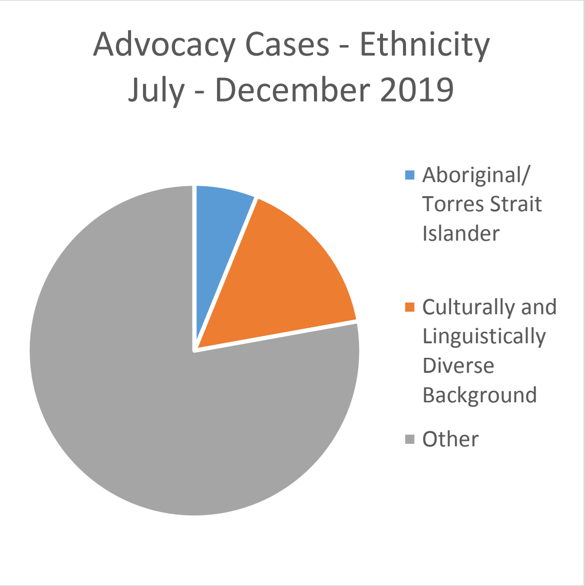
Advocacy Cases- Age Range

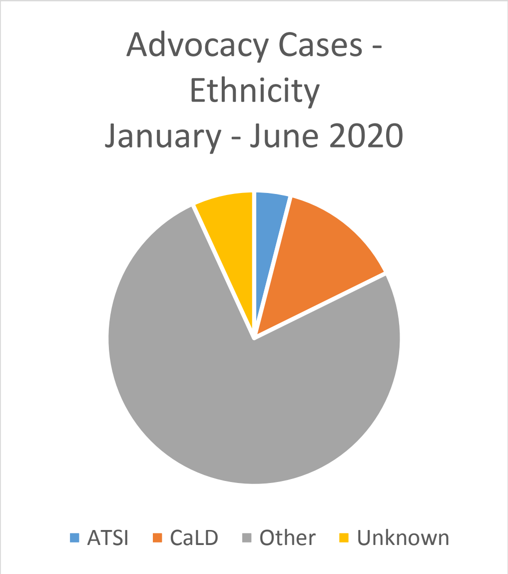
The comparison relating to age shows a slight increase in the 60/over and a decrease in the 40-49 cohorts, with the other groups remaining fairly similar to the previous period.


Advocacy Cases - Age
July - December 2019


Advocacy Cases - Age Range
January - June 2020

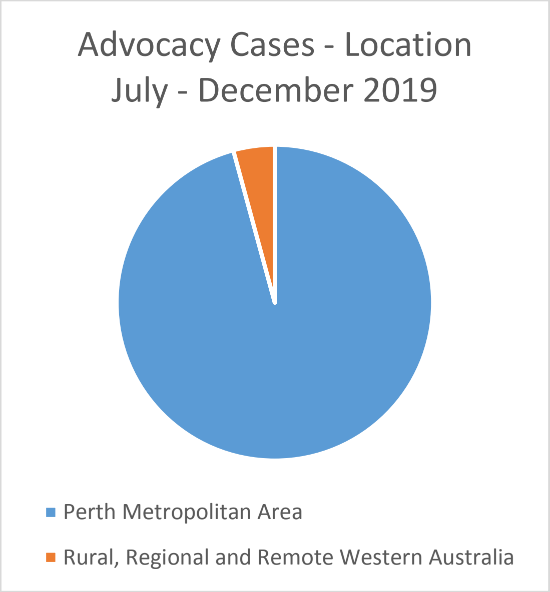
Advocacy Cases- Ethnicity
The comparison shows a decrease in consumers' from Culturally and Linguistically Diverse Backgrounds and decrease from the Aboriginal/ Torres Strait Islander group.

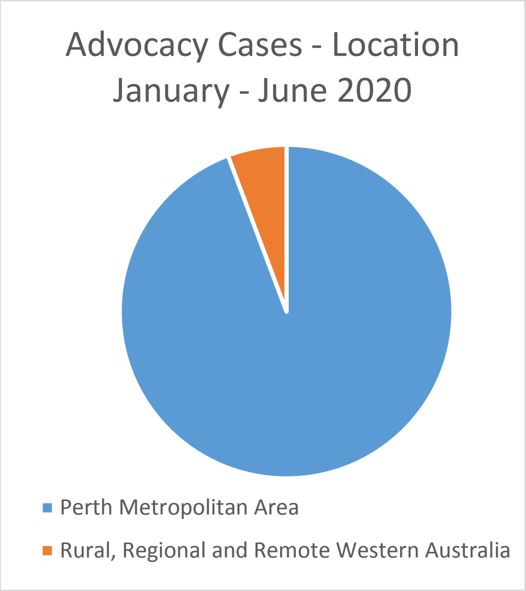

Advocacy Cases - Ethnicity
July - December 2019


Advocacy Cases - Ethnicity
January - June 2020

Advocacy Cases- location

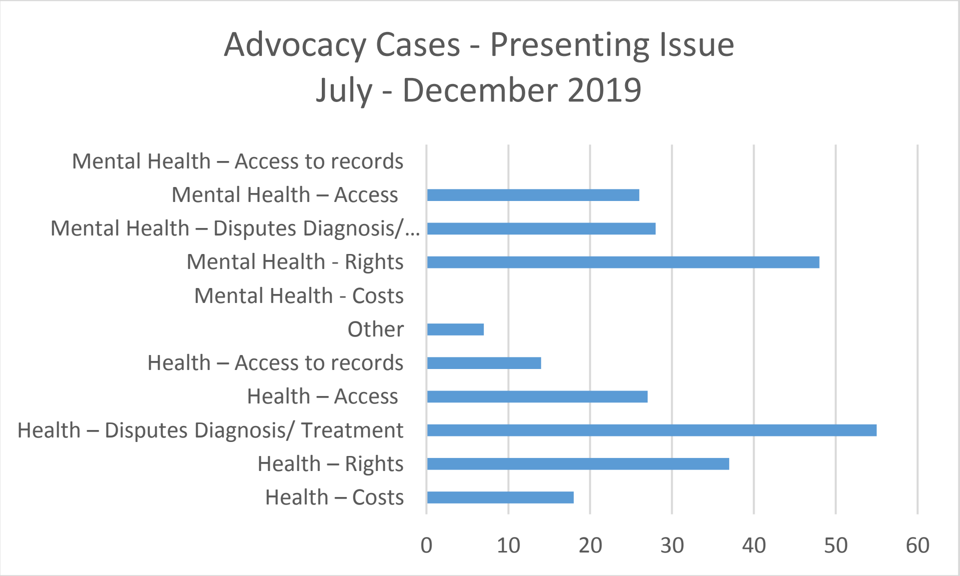
This reporting period has seen a decrease in Perth/Metropolitan consumers accessing the service with a similar figure to those consumers from Rural, Remote and Regional Western Australia.

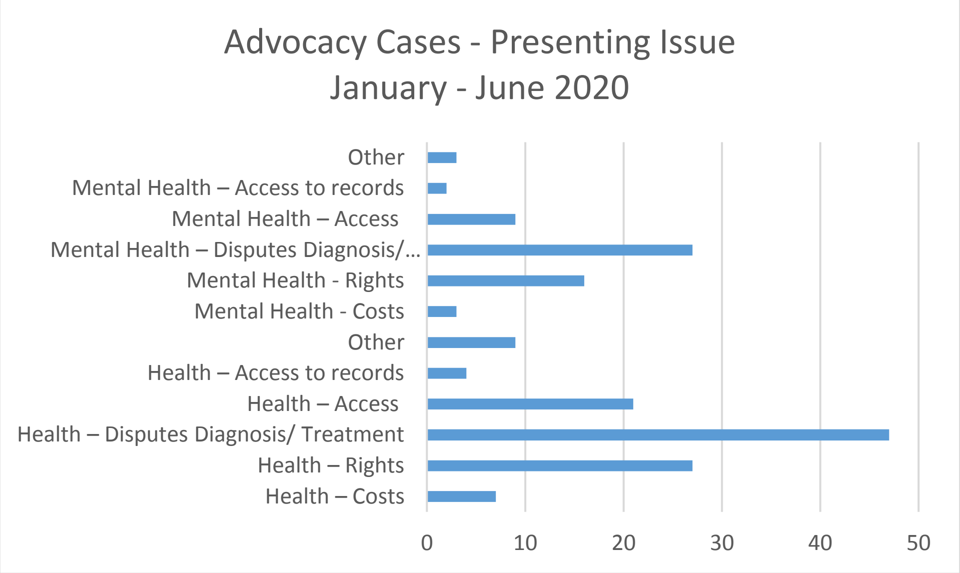




Advocacy Cases- Presenting Issue

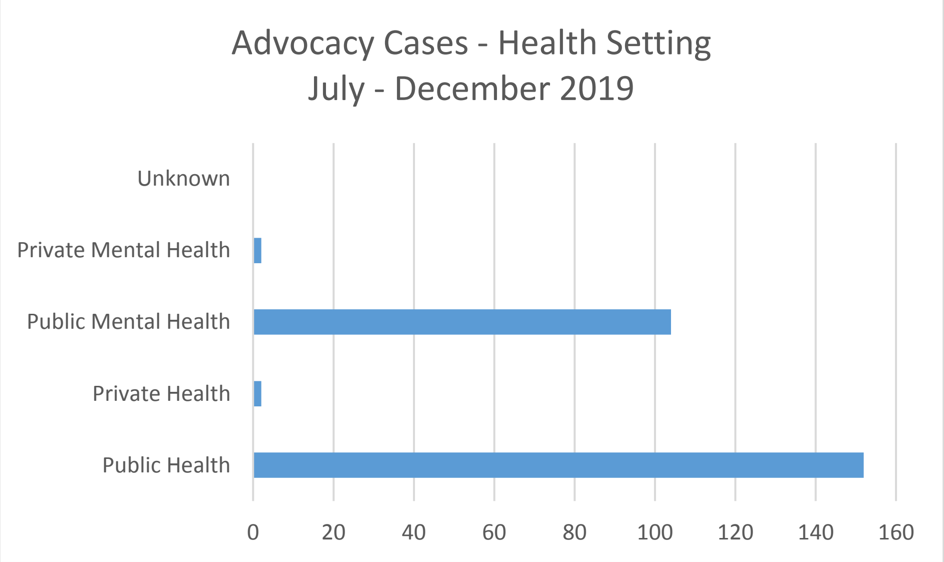
The comparison shows a decrease to all presenting issues. The dominant presenting issues remain as in previous periods as, rights, diagnosis and treatment.

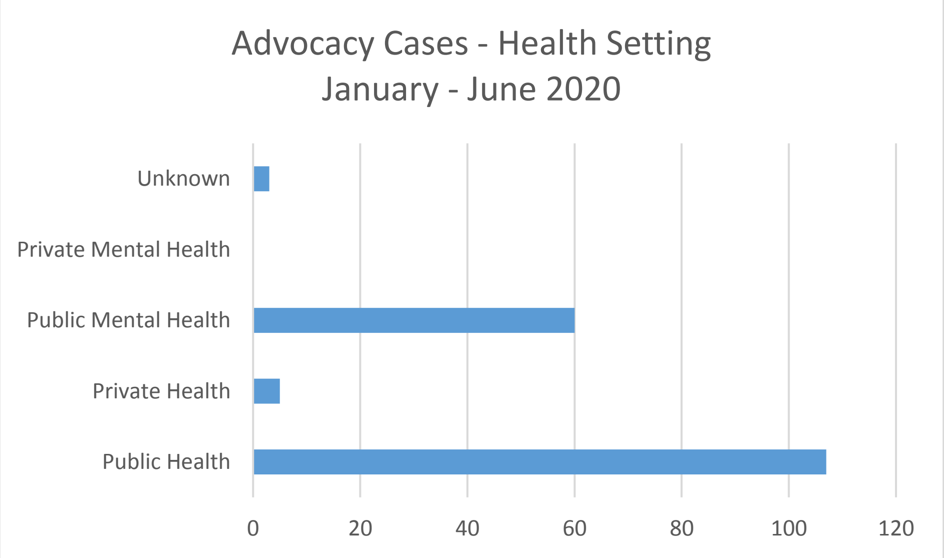




Advocacy Cases- Health Setting

The comparison demonstrates an increase to issues pertaining to the private health setting.





Advocacy Activities- Positive Stories of Change

Case Story 1-

The Consumer contacted HCC due to dental issues. He was born with a cleft palate and underwent numerous surgeries during childhood. Issues continued into adulthood and he was diagnosed with gingivitis, which caused 12 of his teeth to fall out. He had been referred to a public ENT specialist however, when he called to enquire when his appointment would take place, he was advised that the doctor had retired over 12 months prior.

The Consumer was battling ongoing infections and severe oral pain. He had attended numerous dental and myofascial clinics and had difficulty explaining to them that was told in childhood that his teeth will continue to move and fall out. He was fitted with a denture through a government subsidy, however because his teeth continued to move and fall out, the denture became inadequate and was in need of ongoing replacement.

Despite being on a pension, the government clinic would only agree to treat his pain via subsidy but that he would have to bear the cost of new dentures.

The Consumer tried in vain to communicate to the clinic that he would need replacement dentures on an ongoing basis given more teeth would certainly fall out however, he felt unheard. The clinic refused to support the Consumer to further investigate ways to achieve effective treatment. He requested second opinions from public hospitals which were repeatedly rejected without explanation.

The Consumer’s pain and inability to eat most foods, in combination with the difficulties in trying to access treatment, saw a significant decline in his mental wellbeing. During his time as an advocacy client, he had several mental health inpatient admissions due to his situation.

To make matters worse, his Disability Support Pension (DSP) was ceased which saw the deactivation of his Health Care Card and subsequent impact on his ability to claim government subsidy.

The HCC advocate assisted the Consumer to link with another community-based support agency who were able to help resolve the Centrelink issue, and money owed to him was backdated. The advocate, over a two-year period, tirelessly communicated with hospitals and clinics in a bid to reach resolution. The advocate attended appointments with the consumer at a government dental practice where, after much effort, a suitable treatment plan was agreed upon. The Consumer went on to access the treatment and care he so needed. Today, he reports being almost pain free! In the Consumer’s own words,

“The Advocate saved my life back then; when she stepped in, I was on my last leg! She helped me massively and got the ball rolling with the dental practice.”

Case Story 2.

The Consumer did not feel comfortable in meeting their new psychiatrist without an independent advocate being present. They had lost trust in the system and reported that their rights had not been previously afforded whilst accessing a public mental health service. They described incidents of confidentiality breaches, misdiagnosis, and misrepresentation. The Consumer believed that mental health professionals formed their assessments based upon inaccurate information held in their patient record. Consequently, the Consumer felt they were treated with prejudice and disdain by staff. The consumer asked the advocate not to speak for, or on behalf of them during the assessment, rather the role was to observe and take notes. The Consumer later explained that having the advocate present was a ‘game changer,’ in that, they felt supported enough to convey themselves effectively. Given the assessment period took place over several meetings, the advocate invested significant time to this case.

The Consumer also attended HCC’s Legal Information Session where he discussed pursuing a claim with regards to the confidentiality breaches that had occurred.

In the Consumer’s own words;

“Having you there really changed the power dynamic and allowed me to better express myself and my concerns. Prior to having you present, it was clear to me that the Dr, while very kind and considerate, was making several assumptions about me and that these were guiding our interactions. While having you there I could tell that he was more conscious of those assumptions and that it may have allowed him to reflect upon some of them. This in turn allowed me to talk more about my concerns regarding treatment and diagnosis and to express to the Dr that I had been mischaracterised, stigmatised and mistreated by other practitioners. While many of my issues with the mental health system are presently still unresolved some recent developments have provided some hope that I will find closure and justice with respect to what has occurred. Thanks again for everything.”

Case Story 3.

In 2017, a Consumer’s parent contacted HCC on behalf of her son who had a pre-existing chronic health condition and had recently sustained injury from a sporting accident. The Mother was seeking guidance regarding issues around the duty of care with her son’s treating hospital. The Mother was concerned that the hospital had failed to formulate a care/treatment plan at the time of her son’s admission to the Emergency Department. A delay with the confirmation of his private health status compounded the problem and, he did not have surgery until 28 hours after the Emergency Department admission.

Due to this delay, major infections arose, and subsequent hospital stays eventuated. Correspondence with the hospital to ascertain the reasons for the delays in treating her son’s injury proved difficult and inconclusive, hence the Mother’s request for advocacy to help navigate the complaint resolution process. For over two years, the HCC Advocate, supported and advocated for the family by way of communicating to the Hospital. Eventually, after much effort, a satisfactory outcome was achieved.

In the Mother’s own words;

“The Advocate has been very informative and professional at all times. Her advice and guidance has been fair and persistent and resulted in a satisfactory resolution, in favour of my son, being reached. At all times the Health Consumers’ Council were objective and professional in their approach to our complaint and I would have no hesitation in recommending them.”

<u>Consumer feedback the individual Advocacy Service</u>

“Many thanks to the advocate and the team for the efforts and consideration during the past few months. After making my complaint to the providers and then to the Health Complaints Office and receiving virtually, a brush off after 5 months of inaction, the advocate, during this time, was the lone voice standing up for me. Even though her efforts did not bring forth a resolution of my complaint, her caring attitude and tenacity in pursuit of a resolution was not only appreciated but was also very impressive. It's such a pity that the responsible government department does not possess the same qualities. All I can say is thank you.”

“We would not have been taken seriously with our concerns regarding my husband’s health and the communication between the Cardiologist Department and ourselves. It would have just been ‘swept under the carpet’ and forgotten about. However, with your support we were able to meet the Cardiologist, the Service Director and the Family & Liaison Manager and for that I sincerely thank you from the bottom of my heart.” Hopefully now in future the Hospital will listen to patients and families when symptoms persist, regardless of whether results are negative or not, so other families don't go through the trauma that we went through, when I nearly lost him on the operating table. Again, a huge thank you for all your effect and support throughout our case. It was very much appreciated.”

Consumer feedback obtained from HCC’s 2019/2020 Advocacy Service Outcome process;

Consumer was "very happy" with their advocate. They said "It's good there is somewhere people can go" for when they are unable to put forward their own case. The consumer said, "Thank goodness for the Health Consumers' Council'.

Consumer felt that the advocate was paramount in achieving the desired outcome. The consumer said having the advocate there to support them during appointments enabled them to communicate their point of view to health professionals. The consumer said having an advocate contributed to a more equal power structure and meant there was an extra witness.

Consumer said (their advocate) was wonderful, supportive and explained everything so they could understand it. The consumer said they found advocacy support so valuable and wishes they had come to HCC with their complaint in the first instance.

Consumer said they benefitted from having an advocate at their appointment as it made the clinician take them more seriously.

Consumer said (the advocate) did a 'marvellous job' and the HCC was more helpful than any other place he had been to.

Consumer Consultation- Advocacy Service Outcomes

An independent party recently undertook the “2019/2020 Advocacy Service Outcomes Report” (a copy of the report can be found in the “attachments” of this Contract Report. This Outcomes Report is reflective of “complex” advocacy cases closed to the Service in the last 12 months. Selected clients were presented with a set of 13 questions, with the aim of collecting feedback about their experience with the HCC’s Advocacy Service. The survey enquired about the following areas;

- How clients learned about the 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 the HCC’s online services
- Clients’ expectations about the HCC Advocacy Service and their experience using the Service
- Clients’ ability to access the HCC Advocacy Service
- Client suggestions for improvement
- General client feedback

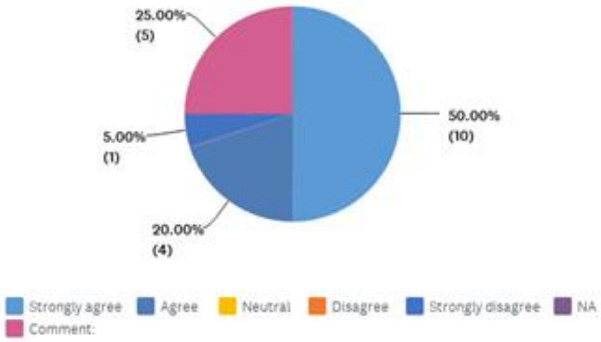
This report was compiled to identify areas where clients’ needs were not fully supported by the service, and to suggest methods for improving future services. It reflects the HCC’s continued commitment to working with consumers to meet their needs and is in keeping with our values of integrity and accountability. This report also supports the contractual reporting requirements of our funding body, The Western Australian Department of Health.

Upon reflection on consumer comments, it was realised that the current survey does more to collect quantitative information about consumers’ experiences with the health system and their own issues, rather than provide qualitative, constructive feedback about HCC’s advocacy service. As of May 2020, a review process of the survey questions and purpose behind the survey has begun, with the aim to improve the process moving forward. To assist us in this endeavour, we are receiving support and guidance from a research and insight specialist.

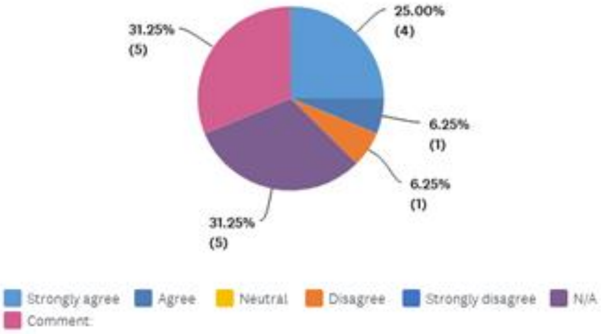
Non-Complex Advocacy Cases

Consumers provided with advocacy for non-complex health related issues are asked to provide feedback on their experience of the Service via a short Survey Monkey questionnaire, some of the feedback obtained via this process can be seen in the graphs below;

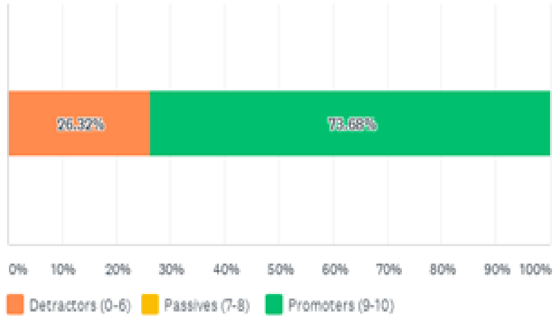
Q5 HCC provided me with the information I needed so I could progress my issue.

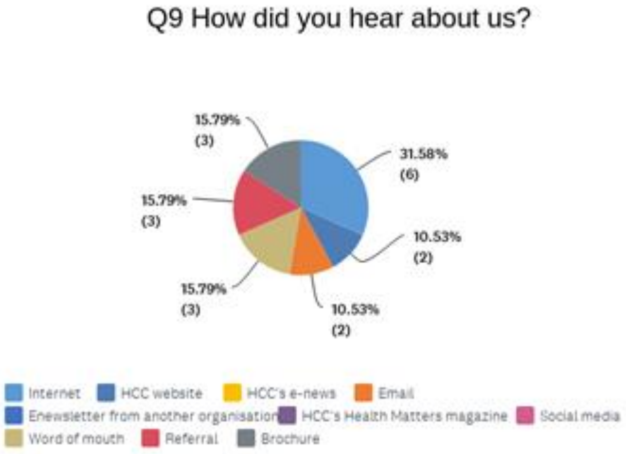


Q6 HCC referred me to another service to resolve my issue.



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





Consumer comments obtained via the short survey;

“The Advocate was perfectly what we needed at a very urgent time, providing support and information.”

“The Advocate gave us the information for the appropriate service, and also offered to call them and connect them to us.”

“I’m very very grateful to the Advocate for the way in which she helped me and was able to reassure me about things and what she could do to help me in which she did.”

Self-Advocacy

Self-advocacy remains an important element of HCC’s Advocacy Service; we recognise the value of the “strengths-based approach” in empowering consumers to have the tools and confidence to manage their own healthcare journeys. Enquires to the Service are often managed by way of information provision and active linkage to a range of agencies and resources.

The previous reporting period saw HCC engage in a process with the Western Australian Patient Safety Surveillance Unit that seeks to improve consumers’ ability to provide feedback on their health care experiences. This process, along with feedback provided by HCC’s Advocacy Service clients, has highlighted the need to further develop the advocacy resources and information on our website. We are currently working on the improvements that hopes to realise a more inclusive and informative consumer experience.

Website

The outcomes survey identified some consumer dissatisfaction with the Advocacy Service’s area on the HCC Website, and as already mentioned, we are working to make this an easier to navigate, more informative and inclusive space for our online visitors.

Partnering

This reporting period has seen the Advocacy Service continue in their partnerships with a myriad of NGO's and statutory agencies in our endeavours to achieve successful health related outcomes for our advocacy clients.

Research methods

We have and continue to partner with a research expert who has generously offered their time, and knowledge pro-bono, as we work to develop a better consumer service feedback process.

Systemic advocacy

We recently met with representatives from The Mental Health Advocacy Service, Consumers of Mental Health WA, HelpingMinds, Ethnic Disability Advocacy Council, People with Disabilities WA and Developmental Disability WA met to discuss the true extent and impact of the lack of funded individual advocacy for the most vulnerable West Australians across the mental health and human services sectors.

We know first-hand the impact that individual advocacy has for consumers who otherwise cannot access services or redress to the same degree that other West Australians can. We believe a coordinated response across mental health and disability sectors is essential to address this inequity.

As an initial step in addressing the gap in such advocacy, The HCC, and those agencies mentioned above, formulated and co-signed a letter to the Mental Health Commission that raised the collective concern, and invited them to join the conversation. We are awaiting their response.

Social Work student placement

During this period, the Advocacy Service has continued its relationship with Curtin University's Social Work Faculty. We welcomed our third student to undertake the three-month fulltime fieldwork placement. The student placement is of benefit to all, having the extra individual to take on advocacy-based tasks is a huge help to the advocacy team.

Clinical review of medical records

Advocacy cases often benefit from clinical reviews and deciphering of medical records to better understand the nuances of individual health care journeys. Our staff are not qualified to undertake this task, given we are not clinically trained. Previously, we had some capacity to fund a suitably qualified health practitioner to undertake such reviews however, our budget is no longer able to sustain this, and it is with a heavy heart that we have ceased this service.

HCC's Legal Information Sessions

The sessions provide opportunity for consumers to have a one to one meeting with a medical negligence lawyer to ascertain whether their issue has the merit to proceed to litigation. During this reporting period, 14 individuals attended the Legal Information Session that is held each month. Since the implementation of restrictions due to the

COVID19 Pandemic, these sessions have taken place via telephone consultation, which has worked well.

Sustainability

The HCC Advocacy Service continues to see increase in the complexity of advocacy cases. Consumer issues often relate to highly convoluted subject matter, which demand a significant investment of advocacy effort. The Service currently operates with a team of just 3.5 FTE, which is significantly less than desirable. We continue to have a waitlist system that can result in individuals waiting for up to 5 weeks until an advocate has capacity to take on their case.

Again, we note our inability meet the contract agreement to contact consumers within 48hours of their enquiry. However, the Service continues to work to ensure those most vulnerable consumers' (live advocacy need) are expedited on the waitlist and are usually contacted within 48 hours of their enquiry to the Service.

As we have previously advised, there is 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.

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 our Advocacy Service.

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 continue to acknowledge 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). It is now time that we must retract our scope to advocating for health-related issues only.

You will be aware, that in 2019, in attempt to go some way to mitigate our capacity issues, we submitted an unsolicited funding application to the Mental Health Commission (MHC). Unfortunately, the application was unsuccessful. Now, with a very heavy heart, in the absence of funding from the MHC, we will cease our provision of mental health related advocacy from 1 August 2020.

Health Rights Information for Consumers

During this period, we developed the Self-Advocacy edition of our Health Matters publication in this period, which is also circulated via social media.

https://www.hconc.org.au/consumer/being-involved-in-your-own-health/self-advocacy-resources/

Health Rights and Responsibilities Presentations and Information

During this period, we had a change of staff in the Cultural Diversity Engagement position. This has required the new staff member to invest time in establishing productive relationships with a range of community partners.

We plan to resume our partnership with Red Cross to deliver health literacy information as part of their orientation program to people who are newly arrived in WA as refugees and asylum seekers. However, due to Covid-19, the Red Cross program is on hold with staff seconded elsewhere until (at this stage) September 2020. Topics include health rights and responsibilities, choosing the right health service at the right time, and providing feedback.

We have made contact with a number of local government areas – targeting those areas with high numbers of immigrants and people from culturally and linguistically diverse communities such as Canning, Gosnells, Bayswater and Stirling, and those with established multicultural networks such as Wanneroo and Belmont). We have been able to offer information, connections and support and Health Rights and Responsibilities Presentations and Information sessions. A number of sessions were planned prior to COVID-19 but were deferred in light of social distancing restrictions.

Information about health rights during COVID-19

As COVID-19 hit in WA, we created a specific page on the HCC website to provide a focus about information.

On this page, we referred people to Government sources of information about public health measures and restrictions.

HCC website information and resources for consumers

Over this reporting period, website content relating to advocacy, healthcare rights, making a complaint, patient opinion, and self-advocacy have been accessed by approximately 2,960 unique visitors. This brings the total for the calendar year to almost 5,568. The most accessed pages after the home page are “how to make a complaint” and “rights under the Mental Health Act, patients of a psychiatrist”.

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 1908 people (increase of 9% since Jan 2020)
- Total page reach Jan-Jun 20 is 119,026 (decrease of 14% on previous 6 month period)
- Total post engagements Jan-Jun 20 is 18,422 (increase of 57% on previous 6 month period)
- Instagram
- 500 followers (28% increase since Dec 2019)
- Total reach for Jan-Jun 20 of 4,156 (decrease of 75% on previous 6 month period)

- Total impressions for Jan-Jul 20 of 7828 (decrease of 74% on previous 6 month period)
- Twitter
- 1349 followers
- Total impressions Jan-Jun 20 of 52,241 impressions (increase of 71% on previous 6 month period)
- 58 retweets (decrease of 3% on previous 6 month period)

HCC's electronic newsletter is sent monthly to approximately 800 subscribers, as well as HCC's individual and organisational members. It is also promoted via our social media channels.

Black Lives Matter and social media

In this reporting period, HCC posted information on our main Facebook page relating to health advice for people who may have been considering their plans to attend the Black Lives Matter march in June. The post contained links to information from the Department of Health, as well as a link to an online event that was hosted by Jordon Steele-John for people with disability.

This post reached over 25,000 people with over 7,000 engagements – which is by far and away the most popular post by HCC.

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 – membership in this period has increased by 61% 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 - membership in this period has increased by 11% https://www.facebook.com/groups/248123835784261/
- Aboriginal Health – we started this group in this period. As of 30 June 2020, it has 42 members.

Traditional Media

We continue to respond to requests for consumer comment.

SERVICE TWO – SECTOR SUPPORT

Health Consumer Council Consumer and Community Engagement Program

Building capacity in the consumer engagement community

This section covers these areas:

- Liaison with community advisory councils (CACs)
- The Consumer Representative Network
- Training and workshops for consumer representatives
- E-news and Health Matters

Liaison with Community Advisory Councils (CACs) and District Health Advisory Councils (DHACs)

During this reporting period, in light of the drop in consumer engagement by many WA Health services, we increased our communication with CAC Chairs, and extended our regular contact to include Chairs of the regional District Health Advisory Councils.

In January, we extended an invitation to our quarterly Chairs meeting in Perth to the Chairs of Aboriginal Community Advisory Groups (ACAGs) – three Chairs from EMHS were able to attend in person. The EMHS Aboriginal Health Strategy group advised that they generally organise transport for Chairs from the ACAGs to attend meetings, due to the fact that they don’t have access to a private car and they face some challenges using public transport. We were able to accommodate this cost to enable participation by this group, but this is not something that is included in the HCC budget on an on-going basis. We believe this cost is an important enabler to participation in these groups, and we believe extending participation in this group by Chairs of Aboriginal groups is important. We will flag this cost in our discussions regarding any future contract with the Department of Health in this area.

At this meeting, the metro based Chairs expressed an interest in having the opportunity to connect with the DHAC Chairs.

On 25 March, we held a special meeting of the Chairs group, extending an invitation to the DHAC Chairs to discuss the emerging situation with COVID-19. From that meeting we were able to pass on information to the WA Country Health Service engagement team that many regional consumer leaders felt there was a lack of localised information in their area. We also learned that most health services had suspended their consumer and community engagement activities as they responded to the emerging situation. Other feedback related to the value of people staying connected to community activities, as well as an interest in receiving information about COVID-19 from reliable and trusted organisations. See elsewhere for our reflection on the lessons learned for consumer engagement from this period.

We held another Chairs quarterly meeting in early April, again, including the DHAC Chairs. At that meeting, we discussed the situation regarding COVID-19, as well as a range of other issues. One topic was how metro-based CACs ensure that they understand the needs and interests of consumers who live outside Perth. Anecdotally, from the discussion at the time, it seems that these perspectives may be missing from CAC discussions. There have been early discussions at FSH about how to better understand this perspective and this will be discussed in more detail at the meeting in early July.

Going forward, it is likely that we will continue to host Chairs meetings virtually to enable the interaction between Chairs based regionally and in metro areas to continue.

HCC staff also presented to the DHAC group in February 2020 about upcoming issues.

Consumer engagement forum

We had been planning to hold a consumer engagement forum when DHAC Chairs were going to be in Perth in August. Early discussions with WACHS had suggested there was support for this, including WACHS' willingness to fund an extra day of attendance. However, it was subsequently confirmed this was not the case.

HCC believes there is a strong value in bringing together consumers and staff with an interest in consumer and community engagement across WA and will continue to seek opportunities to bring this about.

Consumer Representative Network

We provide a range of opportunities for people in consumer, carer, family and community representative roles to connect with each other and get support from Health Consumers' Council. These include:

- Networking events – general and for Chairs
    - New – Consumer Rep Drop-ins – during COVID-19
- New – Fireside Chats with senior WA Health staff
- Hosting a private Facebook page
- Maintaining a targeted mailing list

Networking events

In this reporting period, we ran two general consumer, carer, family and community representative networking sessions – in March and June. We also introduced Consumer Rep Networking sessions to respond to the need to increase community connections during the time of social distancing.

The aims of these sessions are 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

March 2020 – quarter 3 – Bunuru/autumn

This session focused on increasing people's understanding of the Australian Safety and Quality Health Service Standards with a focus on Standard 2. Carolyn Ngan, a health service professional who is an assessor for the national Standards gave an overview of the standards and Standard 2. In light of the COVID-19 situation, this session was held online. See next section for feedback from this session.

We also ran a supplementary session with Carolyn for anyone with an interest in being a consumer assessor in early April.

Session for staff on Standard 2

We have had early discussions with Carolyn about providing a workshop for Health Service staff on Standard 2 on a fee for service basis. Plans were deferred in light of COVID-19.

June 2020 – quarter 4 – Makuru/winter

This session focused on national consumer representative opportunities. We heard from Ghislaine Martin from the national consumer peak body Consumers' Health Forum Australia. It also included an opportunity for participants to practise using one of the online engagement tools – Jamboard.

Ghislaine's notes from this session are online at https://www.hconc.org.au/wp-content/uploads/2020/07/200630-Info-on-CHF-and-Consumer-Program.pdf

Consumer rep drop-in sessions

As physical distancing restrictions hit, and many HSPs cancelled their engagement activities, we identified the need to provide opportunities for the consumer representative community to stay connected with the health system and with each other.

We introduced fortnightly drop-in sessions, each with a theme, which were promoted to our consumer rep network and people who have registered for other consumer events. Each session ran for 90 minutes with time for introductions, an overview of the topic and questions and discussion on the topic.

We ran five sessions between over two months. The themes were:

- Consumer involvement in COVID-19 research
- Consumer engagement in primary care
- Consumer engagement in palliative care
- Choosing Wisely
- Consumer engagement in the WA Healthy Weight Action Plan

120 people participated in these five sessions and we received positive feedback including:

- "Excellent - I'm just loving Zoom - it so much more efficient than having to travel there & back to a meeting. Gives me back my day"
- "Great, loved it. You could see who you were talking to. I think this form of meeting should be almost the default setting."
- "I am loving the zoom sessions. You can see who is sharing info and just be part of it"
- "Fantastic to meet all the consumer reps."
- "I feel needed"

Fireside Chats with senior WA Health staff

As well as these informal drop-in sessions, we also worked with DoH staff to run fortnightly Fireside Chats with senior WA Health staff. The first of these was on 14 May with the Director General. In this reporting period we held four sessions – the other speakers were Dr James Williamson, Denise Sullivan, and Wendy Casey.

We had over 120 registrations for these four session. A fifth, with the DG, is planned for 23 July.

Private Facebook page – Source: Connect – Learn - Share

Membership of this group grew by 61% during 2019 – from 59 – 95 people. Content posted to the group includes information about upcoming training and networking events, as well as information about consumer rep opportunities that HCC are asked to promote.

Targeted mailing list

Membership of this mailing list grew by 45% during 2019 – from 98 – 142 people. Content posted is the same as is posted to the FB group.

During this period we have been sending out a weekly email to the targeted mailing list with information about consumer rep opportunities in WA and nationally.

This can be a time consuming activity – many opportunities are provided with insufficient information for us to publicise these roles effectively. We continue to look for ways to streamline and make this process more efficient while continuing to promote these opportunities to a diverse group of potential candidates.

Consumer Representative Network – responding to COVID-19

Consumer representative drop-in sessions

As COVID-19 hit and social distancing restrictions were introduced, we reached out to the consumer and community engagement network through the CAC and DHAC Chairs. We heard loud and clear that many consumer engagement activities had been suspended, and that many people felt the need to connect with others in the community.

We introduced fortnightly consumer representative drop-in sessions to provide people with opportunities for health consumer, carer, community and family representatives to connect with each other, with the health system and with HCC and other organisations.

We ran five sessions during this reporting period each session had a theme and included a presentation from an external partner:

- Consumer and community involvement in COVID-19 medical research – with the Consumer and Community Health Research Network
- Consumer, carer, family and community engagement in primary care – with the WA Primary Health Alliance
- Engaging community members in Advance Care Planning and National Palliative Care Week – with Palliative Care WA
- Engaging consumers in a conversation about reducing unnecessary tests, treatments and procedures – with Choosing Wisely

- How consumer input helped shape the WA Healthy Weight Action Plan and what comes next – with the WA Department of Health

These sessions all ran by Zoom. Over the five sessions there were 120 participants.

Recordings of these sessions are available on the HCC website at https://www.hconc.org.au/what-we-do/workshops/

E-news and Health Matters

We produced 2 editions of Health Matters in this period. Each edition had a theme:

- Patient Experience
- Self-Advocacy and Peer Support

We will be maintaining similar themes from year to year – this enables us to plan ahead and encourage a diverse range of articles.

In this period we also carried out a Marketing and Communications survey to seek input to help us shape the way we communicate with our stakeholders and members.

Many responses indicated that HCC is a trusted source of health information. 70% of respondents told us they prefer to hear from us via email, and 44% said they prefer e-news. So we'll be dedicating time to tidying up our mailing lists, simplifying our e-news templates, and ensuring they look just as good on mobile phones so no one misses out on important information. Facebook was the third most popular option for staying up-to-date with HCC news, so we'll be focusing our social media efforts there.

We heard what issues are most important to our stakeholders, so we'll make sure these stay top of mind for us in our communications and engagement.

Workshops

Consumer Representative Training 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, 24 people registered to attend, we received 7 apologies in advance, and 16 people attended on the day.

At the Advanced session in February, 27 people registered to attend, we received 5 apologies in advance, and 20 attended on the day.

We are seeing increasing interest in attending these sessions. We held the “advanced” session in the HCC training room, but received some feedback that the space was a bit cramped for the numbers that attended. Prior to COVID-19, we had booked an external venue for the October sessions to enable us to accommodate more people.

However, in light of the changes to delivery that we have made to other sessions due to COVID-19 we are exploring the possibility of delivering these sessions virtually – at least once/year. This would enable participation by people who are unable or prefer not to attend in person. This will be reviewed during the next reporting period.

We continue to want to create a suite of training materials, based on the content from these sessions that can be posted on the HCC website. We have begun this work, but have been unable to progress it further due to the volume of other work.

We would like to do this to enable the content of these sessions to be available on demand and accessible to people who are outside of Perth.

Cultural Diversity Program

Overview

As highlighted previously, this portfolio has the potential to be very wide-reaching in its scope. The risk is that our efforts and resources (currently 0.6 FTE for the whole health system) are spread across a very diverse range of activities and therefore the impact is reduced.

As this portfolio aims to impact on the experience, participation and health outcomes of people who are “hardly reached”[1], it requires the investment of time in building and fostering positive relationships with individuals and organisations – so that we can work in partnership to develop activities that maximise impact and reach.

As flagged in our last report, a new staff member – Nadeen Laljee-Curran joined the team at the start of January. During this period, Nadeen has connected with a wide range of stakeholders in this portfolio. These include the Ethnic Communities Council of Western Australia, the Multicultural Youth Advisory Network, the City of Bayswater and Ishar Multicultural Women’s Health Service.

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[1] https://www.semanticscholar.org/paper/Peer-Support-for-the-Hardly-Reached%3A-A-Systematic-Sokol-Fisher/090d48f14a6d67de8c631e6676fecd0f93efd3a8 accessed 04/02/20

Staff changes – COVID-19 impacts

As reported elsewhere during this reporting period HCC's team pivoted and began working from home from mid-March due to COVID-19. Nadeen, due to personal circumstances arising from the pandemic, reduced her hours from 0.6FTE to 0.4FTE. The impact on the workload was mitigated in part by the fact that a number of the activities which had been planned for this reporting period – such as presentations to community groups and some meetings – were deferred in light of social distancing restrictions.

Objective: building capacity and understanding amongst staff

- Diversity Dialogues Forum
- Supporting Cultural Diversity in Healthcare Workshops

Diversity Dialogues Forum

Diversity Dialogues (DD) 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, or staff with extensive experience in working with people from CaLD backgrounds who provide insights from their practice, to assist providers develop understanding and improve service provision to this cohort.

During this reporting period, we began to develop plans for a DD forum on the experience of people from CaLD backgrounds when using telehealth. This session is planned to be held in September. We are in discussion with the Digital Health CRC team about delivering this session in partnership with them. This has the potential to extend the reach of this session significantly. We will report further on this session in the next reporting period.

Supporting Cultural Diversity in Healthcare Workshops

This three-hour workshop is designed to assist health care staff 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

Previously, when we've advertised this session, we have been quickly over-subscribed. During this reporting period, we planned to trial a fee for service offering, as a way of extending the reach of this content.

We advertised a free workshop for 30 April. This was promoted through the Department of Health's Health Happenings update and the Health Networks bulletin and was quickly over-subscribed. As this session is funded by the Department of Health, we prioritised applications from WA Health staff and maintained a waiting list for other participants.

As social distancing restrictions were in place, we ran this session virtually via Zoom. Participants were appreciative of the opportunity to participate but a number of people commented that they would value the opportunity to attend in person when that was possible.

This session was attended by 26 people 7 of which were regional / remote. It is worth nothing that we had a much lower no show rate than our face to face sessions (29 registered and 26 attended on the day). See below for feedback from this session.

We also promoted a fee for service workshop, on the same content, for late June. The session was promoted at a cost of $160 per person. Promotion of this session was planned to start just as social distancing restrictions were put in place. We have opted to defer the fee for service (FFS) workshop until it is possible to hold in-person workshops again. The marketing and promotion of a FFS workshop requires considerably more staff time than the free workshop.

The next free workshop is scheduled for 3 December 2020.

Objective: building capacity and understanding amongst community members

- Community conversations and health rights
- Culturally and linguistically diverse consumer panel

Community conversations and health rights

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.

It is also important that community members understand what they can expect from the health system, and the rights they have when using health services.

The way we aim to address these issues is by organising community conversations with community members, to discuss “what matters to you?” with regards to health services. For many community members – particularly those who are newly arrived in Australia, or who may not yet know much English – the first step is to help people learn about the Australian health system. Our community conversations and Rights and Responsibilities sessions conducted in the last reporting period indicated there is lack awareness of the different health services available and how to access them and anecdotally suggested a lack of resources in this space.

During this period, we have begun to scope a health literacy resource aimed at people from CaLD communities, to increase knowledge and awareness of the WA health system. This includes a survey that has been circulated to HCC stakeholders and key organisations working with people from CaLD communities, to identify what resources currently exist, to what extent they are utilised and if those working with refugee, migrant and CaLD communities see a gap in this space

In the next reporting period, we will review this feedback and if required, develop a scope to create a resource. Based on what’s required, this may require us to seek external funding to enable us to create that.

Culturally and linguistically diverse consumer panel

During this period, we have continued to explore the potential for creating a way to target communications about events, training and consumer representative opportunities to people from CaLD backgrounds. The aim of this is to increase the participation and involvement from CaLD backgrounds in these activities.

In light of the importance of circulating links to trusted sources of information relating to COVID-19 and associated public health measures, we circulated information to this group from the WA Department of Health, as well as links to information in a range of community languages https://www.hconc.org.au/covid-19-multicultural-resources/

At the time of reporting, this group has 47 members.

Opportunity to increase capacity in this area through volunteers
As reported previously, we believe this is another area where we could increase our capacity to reach more people (and also leverage on the trusting relationship and language connection people have with members of their own community) if we had resources to recruit, train and support volunteers to work in this area. For example, we could train volunteers to deliver basic health rights information and host local community conversations with small groups of people. This would be an opportunity both to share information as well as gather feedback from this group.

Aboriginal Engagement

HCC is committed to ensuring Aboriginal health is a core part of HCC's focus and services. With the one very valuable Aboriginal staff member (0.7 FTE) we have, we have opted to focus on consumer engagement rather than individual advocacy, as this provides the best way to leverage here time. However, it is worth noting that this staff member is often approached directly by Aboriginal community members who have advocacy-like enquiries. We believe they contact her directly because of her positive reputation in the community and because this is a culturally safe way for them to get support.

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.

HIV Integrated Case Management Program (ICMP) Guidelines Reference Group

This group has been meeting regularly to discuss the updating of the guidelines for people under the ICMP. The majority of the consumers in this program are Aboriginal, so it is important HCC stay engaged with this process.

National Clinical & Community Advisory Group (National Children's Digital Health Collaborative)

The Collaborative has been continuing to meet remotely since the onset of COVID. They are trialling the Pregnancy record in NSW and QLD currently, and providing feedback at each meeting. The harmonisation of data for the Child 5-14 record is a focus of that project, as well as consumer and stakeholder engagement to develop their user personas. No further changes to the staff or direction of the Collaborative has been reported. They are working closely with the ACCHO's in the trail area and the Aboriginal Liaison staff in the trial hospitals to ensure Aboriginal mums are included in the trail.

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

Outreach at WA health services

During this reporting period, the outreach visits to Fiona Stanley Hospital to meet directly with Aboriginal community members to hear about the concerns and issues they are experiencing when accessing health services were suspended in light of COVID-19. These will be resumed when there is more certainty about the likelihood of the return of social distancing restrictions.

Increasing awareness and knowledge about end of life/palliative care options

We have had early discussions with Relationships WA and Advocare about running information sessions for Aboriginal community members. These discussions have been put on hold in light of COVID-19.

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 partnered with the Aboriginal Health Council of WA (AHCWA) to develop and deliver the training, and it is envisaged that the training will 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, there have been staff changes at AHCWA. This has led to a change in their involvement in the project. While AHCWA remain committed to the project aims, they are unable to commit to delivering this training. The next steps are to develop a communications plan to promote this training on a fee for service basis. This will be progressed once there is certainty about the likelihood of a return to social distancing restrictions.

Prison Health

HCC has been working for the past two years to better understand the health concerns of WA Prisons and specifically that experience for Aboriginal prisoners. We participated in a series of Prisoner Consultations at 4 Perth prisons with Prison Health, HaDSCO and the Mental Health Commission in 2018. Since then we have continued to build our existing relationship with the Office of the Inspector of Custodial Services, delivered information sessions to the Official Visitor Scheme staff, and have met with Russell Simpson from WACHS on this topic. We are currently speaking with OICS regarding the Independent Visitor Service and how we might participate. Pip remains highly engaged with the Prison Health Clinical Governance Advisory Committee, which meets monthly.

Liaison with other Aboriginal Reference Groups

Tania Harris presents and meets regularly with the North Metropolitan Health Service Aboriginal Peer Review Group, with around 50 attendees.

Tania is also a member of a number of other reference and advisory groups including:

- the Langford Aboriginal Association (LAA) Aboriginal Aged Care and Community Hub (AACCH), Community Reference Group (CRG)
- the Murdoch University College of SHEE, Nursing Aboriginal and Torres Strait Islander Health Care Bachelor of Nursing Curriculum Content Reference Group, which looks at the new course curriculum and provides an Aboriginal perspective to the course coordinators.
- The EMHS Aboriginal Patient Journey Working Group
- The EMHS Aboriginal Reference Group (RPH)
- Speech Pathology Australia – Aboriginal and Torres Strait Islander Advisory Group

Aboriginal Community Conversations

During this reporting period, all community conversations were suspended due to COVID-19.

Traditional healing

HCC staff continue to coordinate meetings with staff from WA health to map what traditional healing services are currently available to the WA community, and to explore opportunities for extending this access to more people. Access to traditional healing in WA health services is currently unclear and there is no consistent approach across Health Service Providers.

During this reporting period, plans have been firmed up for a forum for community members where people can find out more and discuss traditional healing as an option – this is scheduled for 21 September at Fiona Stanley Hospital. HCC is working with staff from SMHS on this initiative.

HCC were fortunate to be joined by an intern from the McCusker Centre. She carried out a review of the literature on traditional healing across Australia which has been a very valuable exercise.

Mental Health Week community event “Drumming & Yarning in the Park” – October

There was no activity on this project in this reporting period. We will be seeking funding to support another community event in 2020.

Looking to improve the experience and journey of patients from outside Perth

There has been no activity on this project in this reporting period.

Other activity

Tania provided input to tailored resources for Aboriginal community members on the Care Opinion platform.

Patient Experience Week 2020

During this reporting period, we marked Patient Experience Week 2020 (PXW 2020).

HCC opted not to organise a separate PXW event in 2020. This was because of the initial feedback from LotteryWest about HCC's idea. It's also because we believe now is a good time for HCC to focus our energies on different activities and support WA health service providers (HSPs) to run local Patient Experience Week activities.

To support HSPs, we hosted a number of planning sessions to support them to exchange ideas and collaborate on planning local activity. We also distributed the PXW postcards for HSPs to use in their local activities.

While a number of HSPs had activities planned, these were all suspended in light of COVID-19.

It has been planned to mark PXW in WA in late March – based on feedback from HSPs that using the same date as the global week clashes with school holidays etc. However, in light of all activities being suspended, we were able to post information about PXW twice – in March as we'd planned, and the following month when it is marked around the world. Our posts included sharing videos and posts about last year's event, as well as encouraging people to provide feedback on their experience through Care Opinion.

Consumer Excellence Awards

In the past, we have held these Awards during PXW. In 2020, we decided to host these in line with our AGM which will take place in November 2020. In this reporting period we have reviewed the Awards and their criteria. The ceremony will take place on Monday 23 November 2020 with the Minister for Health in attendance.

Patient Experience Week 2021

We have had early discussions internally about possible activities to mark PXW 2021. From those early discussions, we would like to explore holding an event focused on the patient experience of people travelling from outside Perth to Perth for healthcare.

It is likely to come down to what is possible to be funded. We have previously been successful in securing LotteryWest funding for these activities, however with the change of focus for LW funding, this may not be possible.

Consumer Representation – State Level

Sexual Health and Blood Bourne Virus Advisory Committee (SHaBBVAC)

Work has progressed with the three consumer members of the SHaBBVAC to train and prepare them for meetings, and debrief them afterwards. There have been a range of forums held with NGOs and consumers to build the consensus to undertake a consumer led evaluation of sexual health and blood borne virus services. This work is being done with some extra financial support of the Sexual Health and Blood Borne Virus Program in WA Health. HCC has continued to host Positive Organisation WA Board meetings, and attended the International AIDS Candlelight Memorial in Perth on May 17.

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 continues to advocate 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 continued to update 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 held a consultation session on 31 July which staff from HCC attended. This work is continuing through the Sexual Health and Blood Borne Virus Committee, and liaison with community groups. There is a strong push to develop a de-criminalisation of HIV which would negate the need for this Committee at all.

The Advisory Committee has meetings booked which HCC will continue to participate fully in.

WA Women's Health and Wellbeing Policy

Since the launch of the Women's Health and Wellbeing Policy in September 2019 there has been little activity or opportunity to ensure the policy is implemented.

Palliative Care
HCC continues to advocate for a strong consumer voice in the work on palliative care. Our work in this period has included meeting with a new community-led group that would like to establish a hospice in the northern suburbs of Perth – LJM Memorial Hospice – and preparing HCC's response to the Joint Select Committee into Palliative Care.

Staff also participated in online meetings held by Palliative Care WA on a new community telephone support line and extending the compassionate communities approach.

WA Health Translation Network Data Linkage project
This project is funded by the WA Health Translation Network and is led by the WA Primary Health Alliance. It aims to test how data linkage between primary care providers can identify opportunities for improvements in service provision which could lead to a reduction in unnecessary hospitalisations for consumers with chronic disease. HCC staff are involved in the working group which has met once to date.

In this reporting period, the group worked on an ad for consumer reps to be involved in the working group.

Interagency collaboration and policy advice

Community link booth at Fiona Stanley Hospital
While the Community Link Booth was starting to show promising signs of adoption at Fiona Stanley Hospital with greater referrals from clinical staff, COVID-19 meant the end of this progress. The Community Link Booth has now been de-commissioned and the final meeting was held 9th June. There will still be a final report produced by Connect Groups, including key learnings, such as the importance of working with a hospital's existing volunteer group rather than developing a new team of volunteers. This will hopefully inform future similar models in other hospitals, given that this initiative is mentioned in the Sustainable Health Review under Recommendation 4, New Ways of Engaging with Consumers.

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. There was a change in direction for the project in 2019, with the project now focusing on defining the scope of the 5-14 year old records, what information it should contain (the National Data Model). The project is looking into what health checks are currently 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.

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 Collaborative's 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

Advanced Health Research Alliance (AHRA)
Work on the Involving Consumers in Research project, specifically developing a Best Practice Framework for involving consumers in research in Australia is progressing. As well as attending a workshop on this, HCC has met with the consultant working on this project. It is a partnership project with Monash Partners, Melbourne Academic Centre for Health (MACH), Sydney Health Partners (SHP), NSW Regional Health Partners (NSWRHP), and Sydney Partnership for Health, Education, Research and Enterprise (SPHERE), WA Health Translation Network (WAHTN) and Health Translation South Australia (HTSA). WA is leading this project.

WA Health Translation Network - Consumer and Community Health Research Network (CCHRN) – Consumer and Community Involvement Program
During this period, the CCHRN team have changed their name to the Consumer and Community Involvement Program (CCI).

The HCC Executive Director has continued to work closely with the Head of the Consumer and Community Health Research Network (CCHRN) to support the Network achieve their aims. We believe it is essential to ensuring active consumer and community participation at all stage of the health and medical research process. The HCC Engagement Team and the CCI team have started to maintain a shared calendar using MS Teams. The HCC Engagement Manager also meets monthly with CCI staff.

HCC staff attended a national workshop looking at what is best practice in consumer and community involvement in January 2020 and look forward to continuing to support this work going forward.

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 (now Care Opinion) and Patient Experience Week

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.

Care Opinion

During this reporting period, Patient Opinion changed its name to Care Opinion. We held a meeting of the Care Opinion Community of practice to discuss the practicalities of the name change.

It has been planned to hold an event for community members and for health service staff involving senior staff from the UK – including a Ministerial breakfast – in May, but this was cancelled in light of COVID-19.

A site visit was held in Brisbane in February in 2020 and since then HCC staff have met virtually with Care Opinion staff to discuss how the Care Opinion team seek consumer input into their processes. Care Opinion are considering establishing a consumer advisory group.

Health Engagement Network

This Network was established in 2018 with seed funding from the WA Primary Health Alliance. There are current 335 members registered with the online platform – www.healthengagement.org.au – and a number of other people who have expressed interest but have not joined up online.

In this reporting period, we hosted a learning event on virtual engagement techniques, to build capacity amongst staff and other members to support virtual engagement activities. There were 32 registrations for this event. This was delivered on a pro-bono basis by Joel Levin of Aha! Consulting.

Membership of the network continues to grow without any proactive promotion from HCC staff, which suggests that there is demand and interest for practical information about consumer and community engagement. We believe there is an opportunity to impact positively on how consumer engagement activities are implemented across health services through this avenue. However, this continues to be 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).

Consumer engagement competency framework

During this period, HCC staff had preliminary discussions with staff at WAPHA and the CCI Program, about the opportunity to create a framework outlining the different types of consumer engagement roles. This was prompted by the fact that many requests from health services don’t always make clear the types input that is sought – sometimes, this is based on a misunderstanding of the type of input that is available.

It is planned to run a small engagement process to involve consumer reps and consumer engagement staff in developing this matrix. This work was suspended in light of COVID-19.

Clinical Senate – moving online
HCC staff were involved in working with the Clinical Senate team to support them to move their activities to a virtual environment. A session was held on 16 June where Pip presented results of a small survey seeking consumer views on what they have started and stopped due to COVID-19 and what they would like to continue, or continue without.

Future of e-health – working with the WA Innovation Hub
Due to HCC's participation in the COVID-19 Research Group, we participated in the planning and organisation of a series of events looking at the future of e-health, specifically with regards to outpatients. These were joint events facilitated by EY, championed by the Innovation Hub and South Metropolitan Heath Service. HCC and the CCHRN collaborated to ensure there was a 50/50 split between consumers and other stakeholders at the sessions. We are awaiting a briefing from EY about next steps with the feedback.

Empowering health consumers with disabilities
During this reporting period, HCC received advice that we were not successful in our grant application to build capacity in health services to improve engagement with people with disability. This remains a piece of work we believe has value to the system and the WA community.

Also during this reporting period, HCC was involved with a DoH and Australian Digital Health Agency (ADHA) project relating to increasing the number of Goals of Care (GoC) and Advance Care Planning (ACP) documents that are captured on My Health Record (MHR).

During this project, it became clear that there is very little/no tailored information about GoC or ACP for people with disability. This is despite the fact that due to ableism in the health system, many health service staff make assumptions about the goals of care or advance care plans that people with disability may have. This was flagged as a lesson learned for the DoH/GoC project.

We have approached People With disability WA and Palliative Care WA to work with them to run a small project which will involve the people from the previous EHC project who will review and advise on changes to PCWA's existing materials on Advance Care Planning. This project is predominantly funded by PWdWA, with some input from PCWA to fund consumer participation payments. Staff from the WA Cancer and Palliative Care Network have also expressed an interest in being involved.

Promoting consumer representative opportunities to consumers
HCC continues to be 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, where time and resources permit we do promote these opportunities 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.

Sustainable Health Review

While the year began with some energy with the Co-Lead for Recommendation 4, Ryan Sengara working with the Executive Director on progressing implementation, only two meetings were held before COVID-19 stopped work. Ryan Sengara was co-opted to the COVID-19 response in WA Health, then Department of Premier and Cabinet. A forum had been planned to be held in April 2020, but this was deferred in light of COVID-19.

HCC staff have been approached to provide input to the SHR and Recovery Outcomes and Indicators Framework with a meeting planned for July 2020.

HCC staff were also involved earlier in the year as work on enduring strategy 2 relating to mental health services restarted. However, this was suspended in light of COVID-19.

Fee for Service work

During this reporting period, HCC was approached to submit quotes to work with a number of organisations in the public, private and non-government sectors to support them for their consumer engagement and partnership activities.

We did work for:

- Anglicare
- Foodbank
- WA Department of Health
  - Patient Safety Surveillance Unit – consumer feedback about consumer feedback and complaints process
  - Respiratory Health Network – consultation on community-based services to inform purchasing policy
  - Sexual Health and Blood Borne Viruses
  - Procurement team to inform the contract for Ambulance Services
- Health Support Services and WA Department of Health
  - National Goals of Care Collaborative
- WACHS and Womens and Newborn Network - My Baby WA app

Lessons learned from fee for service work

Consumer feedback and complaints
HCC was commissioned by the Department of Health to run consumer engagement activities to seek consumer feedback about the process of providing feedback or making a complaint to WA health services. We ran three consultation sessions and did telephone interviews with a number of Aboriginal consumers living regionally.

The report from that work is attached. We provide a summary of the key issues below.

Strengthening Aboriginal voices through collective impact
In particular, we would like to draw your attention to the feedback from Aboriginal people about the level of racism many people experience in the health system. We believe this is an urgent issue which would benefit from increased opportunities to bring Aboriginal consumer and community representatives together. We observed after these consultation sessions that while there are a number of Aboriginal community committees and groups at various hospitals and across Health Services, there are currently no

opportunities for the perspectives of Aboriginal consumers on system wide issues to be sought and heard by the system manager and health system senior leaders.

As a response, within the constrained resources available to HCC, we have established an Aboriginal Health Facebook page. This is our attempt to provide a channel for us to post on relevant issues, as well as providing a mechanism for some engagement on the topic. However, it is inadequate as a mechanism for raising Aboriginal community voices at a system level.

Racism in healthcare is understood to be a contributing factor to poor health outcomes[2]. We believe that if we are to see the type of change that is required, at the pace that is required to impact positively on health outcomes, it is essential to provide an avenue for the collective voices of Aboriginal consumers at a system wide level.

We propose that Health Consumers' Council will host two meetings a year and invite the Aboriginal members of community advisory groups and committees to attend. The aim of these sessions is to explore and understand system wide issues across WA Health that impact on the experience and outcomes of Aboriginal people. This will require additional resources including funding for consumer participation payments, funding for travel costs, and funding for venues and catering. We would welcome the involvement of senior staff from the Department of Health in these sessions.

In summary, these were the key issues:

- There are many barriers to giving feedback or making a complaint – most of which WA Health can influence
- Importantly, people from all groups described how difficult it was to find out how to give feedback or make a complaint.
- Feedback mechanisms don't match the complexity of the system
- Many people experience the responses received to feedback or complaints as impersonal and unhelpful
- Many Aboriginal people described experiences of racism in the health system which impacted on the likelihood and way they give feedback or make a complaint. There is much more to do to embed feedback mechanisms that are experienced as culturally safe by Aboriginal people.
- Providing feedback is often an emotional experience – a trauma-informed response could help create an environment where staff are more able to receive feedback and consumers are more supported to provide it.

These were the barriers to giving feedback:

- A prominent reason for not giving feedback is simply that people were not asked. There was a strong theme in the workshops about providing consumers with opportunities to give feedback "in the moment". Suggestions included putting information next to hospital beds and making this known to people and having a visible presence – in the shape of a person – in a prominent place in a health service.
- Lack of time and energy on the part of the consumer – dealing with one's health (or that of their family) is already time consuming.

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[2] Commonwealth of Australia. (2013). National Aboriginal and Torres Strait Islander Health Plan 2013 –2023. Canberra: Commonwealth of Australia as cited in the WA Aboriginal Health and Wellbeing Strategy.

- Unsure of the process for giving feedback/making a complaint
- Have previously had a negative experience of giving feedback
- No confidence that investing the time and energy in giving feedback will result in positive change
- Fear of being treated less well as a result of making a complaint – this was particularly prominent from people living in regional areas
- Literacy and language issues

What consumers would like:

- A system where it is easy to give feedback.
- Information about giving feedback or making a complaint that is
    - more visible
    - clearer
    - proactively given – seek feedback throughout the process of care
- Ways to collect feedback that include
    - Culturally safe options for Aboriginal people
    - More face to face options
    - More options that don't require written feedback
    - More opportunity to give feedback in the moment
- A more personalised and caring response
- A streamlined consistent process that
    - Is simpler
    - Is consistent between health service sites
    - Is focused on the needs of the consumer not on the needs of the system
    - Includes a clearer and more effective process for complaints that are complex or that relate to multiple parts of the system
- More support to provide feedback
    - More independent support focused on the interests of the consumers
    - Focus on removing barriers to giving feedback
- Accountability
    - More external review of complaints and feedback process
    - Assurance that feedback leads to positive action and change.

SECTION 2: OUTCOME PROGRESS REPORT
QUALITATIVE FEEDBACK ON OUTCOME MEASURES

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

Introduction to consumer representation

In this period, we ran one Introductory Consumer Representative Training Workshop. We trialled using iPads to collect evaluation feedback on the day. Unfortunately, due to a technical glitch, only 6 responses were able to be collected. Of those responses, all but one agreed or strongly agreed that they had been supported to build their skills and knowledge by attending the session. All respondents indicated they would recommend this workshop to others.

Some of the things people found most helpful were:

- “Learning and hearing about the different consumer rep roles and what other people's experiences are.”
- “Interacting and hearing from others.”
- “All brilliant. Organised. Effective.”

Some of the things attendees planned to do differently were:

- “Listen more, persist, find a crew”
- “Challenge set up of current consumer committee”
- “Engage with other committee members”
- “Engage more with other consumer reps”

Advanced Consumer Representation training

In this period, we ran one Advanced Consumer Representation training course.

All respondents agreed or strongly agreed that they identified ways to build on their current skills and knowledge, would recommend this workshop to others, and all but one agreed or strongly agreed that they are better able to engage and work effectively in their role as a result of attending.

Some of the things people found most helpful were:

- “Group Discussions+ sharing knowledge learning from others experience”
- “Better understanding of WA health (structure)”
- “Fabulous overview and participant involvement”

Consumer representative networking session

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

March 2020
This session was held just as everyone was switching to social distancing. We had planned to hold the event in person, but switched two days before the event to virtual. 31 people registered to attend the event and 9 attended on the day. We had 11 apologies in advance of the session.

Of those who attended, only two completed the online evaluation form.

Comments from those two included:

- “Everything [was useful], especially presentation by the surveyor”
- “…all useful. Great to see younger people getting involved”
- “well done”

June 2020
We ran this session virtually. As well a presentation by a speaker from the national Consumers Health Forum, we also provided opportunities for people to meet in small virtual breakout rooms, and try out an online tool for gathering feedback.

Over 83% of respondents agreed that they had the opportunity to connect with other consumer, carer, family or community reps across the health system in WA and that they learned something they can apply in their role as a rep. The same proportion of people agreed that they had increased their understanding of national consumer representative opportunities, with over 91% agreeing that the session was a good use of their time.

We had mixed feedback from people about the opportunity to network with each other virtually. Comments included:

- “There was a lack of interaction and networking in the break out group I participated in and did not enjoy using jamboard. Hence I did not get to learn anything about the people I was participating with and/or nurture working relationships.”
- “This was my first opportunity to be involved with a networking meeting through HCC. It was very informative and was nice to see some friendly faces. I took away some valuable information and insight. I am now feeling very inspired to continue on this Journey as Consumer Rep with possible National options.”

Things people found most useful:

- “jamboard playtime, reading and using chat-box”
- “The outline and background to CHF operations was informative”

- “I liked the Zoom meeting platform, it allows regions to interact with the metro areas”
- “Breakout rooms, [virtual] post it notes. Joint learning.”
- “The networking at the end”

Things people found least useful:

- “The session on Jamboard. Of new tools are being introduced should be wrapped around something more constructive.”
- “presentation by CHF - didn't learn anything new and reinforced my opinion that CHF is elitist and closed shop, and a barrier to representation not an enabler”
- “Lack of networking - this was a networking event.”

Workshop for WACHS Leadership Team on co-design

HCC were approached at short notice to provide input to a workshop on co-design being run by ACHSM for the WACHS Leadership Team. Pip took part in this session. It is noticeable that despite the session being on the subject of co-design, consumer input was not sought by the presenting team until the week of the event.

Consumer rep drop in sessions

We ran five additional sessions in this reporting period as a response to the drop in engagement activities by health services due to COVID-19.

- 96% of respondents agreed the session was a valuable use of their time
- 96% of respondents agreed they learned something of relevance to their roles as consumer reps
- 93% agreed they had the opportunity to engage with issues relating to the health system in WA

Cultural Diversity program

Supporting Cultural Diversity in Healthcare Workshops

We ran this session in April 2020. It was oversubscribed, but we had a number of people who did not attend on the day. It was attended by 26 healthcare workers. The session was originally planned to be a face to face event, but in light of COVID-19, we ran the session online. Of those who responded to the evaluation form:

- 73% agreed or strongly agreed that they had identified ways to build on their current skills and knowledge.
- 67% agreed or strongly agreed that the facilitator was knowledgeable and skilful
- 67% of people said they would recommend this workshop to others.
- 86% of people agreed or strongly agreed that they increased their knowledge and skills and feel more confident about supporting cultural diversity in their workplace.

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.

Health Engagement Network event – May 2020

HCC staff organised a session on virtual engagement for members of the Health Engagement Network. It was attended by approximately 20 people. This was provided on a pro-bono basis by Aha! Consulting. As it was done on a pro-bono basis, no evaluation information was collected.

Presentations to DoH staff on consumer engagement
HCC staff were invited to present to DoH staff on aspects of consumer engagement.

- To participants in the DoH Policy Essentials program – this session was deferred in light of COVID-19

COVID-19 Surveys
We provided senior health leaders across the system with feedback from consumers in relation to the lack of consumer engagement during COVID-19 and provided reports from our and other health consumer peak organisations to provide ideas about how to do this differently next time.

Sustainable Health Review – New Ways of Engaging with Consumers
We have had a limited opportunity to advise and drive innovations in the way WA Health engages with consumers and look forward to this increasing over the second half of 2020. We genuinely believe this to be an important driver of cultural change and innovation mapped out in the SHR Report.

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.

Obesity and weight management

HCC continues to work 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 hosted a consumer rep drop-in session where DoH staff had the opportunity to present on the Healthy Weight Action Plan and participate in discussions with consumers. HCC invested time in developing a proposal to DoH to enable the consumer and community voice to be promoted and supported during the implementation of the Plan that was launched in November 2019. HCC staff also participated in a number of meetings to discuss the transition from plan to implementation.

Privacy and information sharing and guardianship

HCC had been involved, alongside our partners at the CCI Program, in promoting opportunities to engage with community members on this topic. The need for rapid access to the latest medical treatments – some of which may still be being researched - led to the WA Government putting through a rapid amendment to the Guardianship Act which now makes it possible for people who may not be able to give consent themselves to access this kind of treatment.

COVID-19 Research

As well as sitting on the regular meetings to discuss the funding for COVID-19 Research, the HCC Executive Director sat on the judging panel for these grants.

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)?

From 23 March, HCC switched all our staff to working virtually in light of the information from the Department of Health relating to COVID-19. Although this was a significant change in how we work, many of our operations were able to continue uninterrupted, albeit differently.

Impact on HCC operations

As we already had tools like a remote desktop and Zoom in place, the transition to virtual working was relatively smooth. We did some internal capacity building to help people feel comfortable using Zoom for regular meetings. We also introduced a daily Zoom catch up for staff to touch base and stay connected. We also ran a weekly survey to enable us to give staff the opportunity to flag any concerns or issues they had as social distancing and working from home took place.

We have significantly increased our use of the MS Teams platform to enable staff to stay connected with each other while working remotely. We believe there are further opportunities to use MS Teams more which we will continue to explore.

Impact on engagement activities

Where possible, we switched all our engagement activities to virtual activities. To support this we ran three capacity building sessions to help people adapt to the new online environment, including a session that we ran completely by ‘phone, for anyone who was unsure about online meetings.

We also increased the number of activities we offered to consumer representatives in light of our observation of the need for people to remain connected with each other and with the health system at a time of physical distancing. This was also to counterbalance the fact that many health service engagement committees were suspended for up to three months.

Some of our activities – including community conversations where we might go to where groups area already gathering and group meetings – were deferred in light of COVID-19 restrictions.

In general, there have been benefits to our engagement activities from switching to virtual events. In particular, people who may not otherwise attend our events in Perth – either due to distance or inconvenience – have been able to participate in events they would not other have attended. It has also led to more discussions between metro and regionally based people.

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 believe the need to continue building on the health literacy capacity of the general population, as well as that of vulnerable communities is key. We would like the opportunity to trial working with a volunteer coordinator to recruit, train and manage a cohort of community-based volunteers that could undertake this work amongst their peers. This would require the funding of a dedicated position of at least 0.6FTE for an initial period of 12 months.

With regards to virtual engagement activities, we will be exploring what it will mean to us to move to a hybrid model of events – offering both in-person and virtual access. From our experience to date, this will lead to an increase in resources being required for these events – for an optimal experience for both sets of participants, you need to consider them as two events. For example, having one staff member dedicated to running the virtual discussions, while another staff member runs the discussions in the room. It also requires good quality AV equipment – for example, making sure that the microphone in the room is capable of picking up what all participants in the room are saying so that virtual participants can hear the discussion. We will continue to experiment and try new things.

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

☑ Yes ☐ No

We have just received notice that the Mental Health Commission will provide funding for 1.0 FTE for voluntary mental health advocacy services to continue. We will be adjusting our model in the coming weeks to ensure we can use this resource (half of what we asked for) to deliver a high quality service without putting staff under undue stress. We hope to be able to progress discussions with the designation policy area of WA Health to develop our next contract. We would also like to develop and refine the offerings and reporting for our contract post June 2021.

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	30/11/20	N/A
2. Professional Indemnity	Berkley Insurance Australia	93004727753	201612-0266 BIA	20 Mil any one claim 40 Mil in aggregate	30/11/20	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	30/11/20	
4. Personal Accident Insurance for Volunteers	AFA Pty Ltd	83067084333	5575005	1 Mil	30/11/20	
5. Motor Vehicle Third Party Liability.	RAC Insurance	59 094 685 882	MGP3259 30502	Agreed Value - $20,200	19/9/20	
6. Other Business Insurance	AIG Australia Limited	93004727753	9637274 CMB	Replacement Value	30/11/20	Management Liability, Loss or spoilage of stock, Outstanding accounts receivable, Building, Public & product liability

END OF REPORT