



# **SERVICE DELIVERY DATA REPORT**

## **HEALTH CONSUMER SUPPORT SERVICE**

### **Reporting period:**

Year: **July – December 2020**

Organisation Name: Health Consumers' Council

Completed by: Pip Brennan

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## **SECTION 1: SERVICE DELIVERY DATA OUTPUT MEASURES**

### **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: 25
- 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:

Christmas Closure – 28-30 December 2020

## SERVICE ONE - HEALTH CONSUMER: INDIVIDUAL SUPPORT

### 2. DESCRIPTION OF SERVICE USERS

#### KEY ELEMENT 1 – Individual Support

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

Yes  No

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

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

a) Gender

Gender	Number
Female	137
Male	82
Unknown	1
<b>TOTAL</b> <i>(Total of all tables in 2.1 should be the same)</i>	<b>220</b>

b) Age

Age	Number
Under 20 years	13
20-29 years	20
30-39 years	36
40-49 years	47
50-59 years	53
60 years and over	46
Unknown	5
<b>TOTAL</b> <i>(Total of all tables in 2.1 should be the same)</i>	<b>220</b>

c) Ethnicity

Ethnicity	Number
Aboriginal/ Torres Strait Islander	22
Culturally and Linguistically Diverse Background	28
Other	153
Unknown	17
<b>TOTAL</b> <i>(Total of all tables in 2.1 should be the same)</i>	<b>220</b>

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	97
Private Health	31
Public Mental Health	78
Private Mental Health	13
Unknown	1
<b>TOTAL</b>	<b>220</b>

b) Geographical Location

Location	Number
Perth Metropolitan Area	193
Rural, Regional and Remote Western Australia	26
Unknown	1
<b>TOTAL</b>	<b>220</b>

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	11
Health – Rights	26
Health – Disputes Diagnosis/ Treatment	51
Health – Access	25
Health – Access to records	9
Other	7
Mental Health – Costs	2
Mental Health – Rights	28
Mental Health – Disputes Diagnosis/ Treatment	42
Mental Health – Access	15
Mental Health – Access to records	3
Other	1
<b>TOTAL</b>	<b>220</b>

**SERVICES PROVIDED**

**KEY ELEMENT 1 – Individual Support**

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

Yes  No

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

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

Occasions of Service - Type of Individual Support	Number
Telephone Support	1313
Home Visiting	0
Online Support – including email	1127
Face to Face	95
Formal Referral/Active Linkages	48
Formal Letters	119
Other Tasks (includes case research, case administration, provision of resources and travel time).	1244
<b>TOTAL</b>	<b>3946</b>

## KEY ELEMENT 2 – Information and Linkages

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

Yes  No

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

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

Type of Information and Linkages	Number
Information provision	198
Active linkages for non-users of the service	143
<b>TOTAL</b>	<b>341</b>

## KEY ELEMENT 3 – Community Education

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

Yes  No

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

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

Type of Community Education Activities	Number Provided	Total No Attending
<b>Workshops/Training</b>		
Introduction to consumer rep training	1	15
Advanced consumer rep training	1	13
Consumer rep network meeting	2	36
Preventive Health strategy consultation workshop	1	8
Healthy Weight Action Plan morning tea	1	10
<b>Seminars/Presentations</b>		
Fireside Chat with senior WA Health leaders - Director General WA Health, Joe Boyle Pathwest, Dr Andy Robertson	3	67
Community conversation on Sustainable Health Review	2	45
Presentation to Warren DHAC on Healthy Weight Action Plan	1	8
Presentation to DHAC Chairs	1	20
Community conversation on Healthy Weight Action Plan	1	9
<b>Community Activities (e.g. promotional stalls at fairs and festivals)</b>		
Mental Health Week stall at EMHS	2	50
Womens Health Day 2020 Ottey Centre	1	50
<b>Information Sessions</b>		
Presentation to General Medical Students at Curtin - Advocacy	1	40

ABC - comment on premium rises during COVID (listener estimate)	1	5,000
ABC Jessica Strutt - Intermittent Fasting (listener estimate)	1	5,000
<b>Cultural Engagement</b>		
Rights and Responsibilities/Choosing the Right Health Service/ Going to Hospital	5	90
<b>Other</b>		
Lived Experience Collective – initial meetings	3	5
Meetings with AHPRA and consumer re systemic issue	2	1
Online catch-up with mesh injured women	1	2
<b>TOTAL</b>	24	10,469

## **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

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
<b>Number of projects or partnerships worked on with other agencies</b>	
Chairs network	2
Weight Issues Network story telling training	1
Meeting with FSH CAC member re consumer engagement	1
Working with Consumer and Community Involvement program team	2
Meeting with Freo CAC member re CAC work	1
Meeting with DoH End of Life team about community education resources	1
Meeting Chair of FSH CAC re health literacy activities	1
Meeting with WA consumer rep re CHF Covid commission	3
Forum with Consumer Health Forum on social prescribing	1
Meeting with Weight Issues Network	1
Freo/FSH CAC strategic planning	3
Meeting with WACOSS re lived experience engagement framework	1
Meeting with WACHS re e-learning for consumer reps	2
Meeting with Down Syndrome WA	1
Meeting with Town Teams	1
Meeting with The Behaviour Change Collaborative	2
Meeting with Wangkiny Mart Aboriginal Leaders group re HWAP	1
WHO Forum on engaging people with lived experience of non-communicable diseases	2
Empowering Health Consumers with disability Advance Health Directives	1
Palliative Care WA / People with Disabilities WA – Advance Care Planning	1
<b>Number of relevant interagency forums or networks participated with</b>	
Social Inclusion Mirrabooka meeting	1
South East Multicultural Network forum	1
Multicultural Futures' Community Ambassador network	1
East Metro Multicultural Network Meeting	1
CHF COVID Commission	1
<b>TOTAL</b>	<b>34</b>

## **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
<b>Workshops/Training</b>		
<b>Seminars/Presentations</b>		
Diversity Dialogue – Telehealth for CaLD communities	1	650
Diversity Dialogue – CaLD youth and mental health	1	76
Presentation to Obesity Collective Emerging Leaders group	1	20
Presentation to DoH Policy Essential course	1	25
Obstetric Malpractice Conference Panel Discussion	1	58
Demand Driven Research Panel Discussion - Curtin	1	70
<b>Community Activities (e.g. promotional stalls at fairs etc.)</b>		
<b>Cultural Engagement</b>		
Cultural Diversity in Healthcare training	1	19
<b>Other</b>		
<b>TOTAL</b>	<b>6</b>	<b>918</b>



## 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

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
<b>Number of projects or partnerships worked on with other agencies</b>	
Meeting with Laura Depczynski, DoH Leadership Institute	1
Healthy Weight Action Plan (HWAP) – Obesity Collaborative, Stewards Meeting, Steering Committee, Strategic Planning	15
EMHS re Shift media guide on overweight and obesity	1
Meeting with Diabetes WA re Total Meal Replacement project – HWAP	3
Meeting with WAPHA re consumer engagement	1
Meeting with Connect Groups WA re Healthy Weight Action Plan	1
Meeting with CAHS re consumer engagement on HWAP	1
WA Palliative Care summit	1
Palliative Care WA sector consultation	1
Meeting DoH re using HCC Teams for Connect Share Collaborate group	2
Traditional Healing Working Group with SMHS	1
Meeting with Simon Towler re shared decision making	1
Meeting with EMHS re consumer engagement during COVID-19 period	1
Meeting with Director of SHR Implementation Unit	1
Meeting with Bethesda re CAC evaluation	1
Meeting with WACHS re regional consumer engagement	1
Meeting with Multicultural Futures Australia re CaLD engagement	1
Health Consumers Queensland about engagement frameworks	1
CCI Program stakeholder morning tea, ED and Manager catch-ups	3
State-wide Cancer issues meeting	1
WAPHA Better Together forum, Strategic Plan Launch, regular CEO Catch-up	5
Health Networks Unit re consumer engagement framework	3
Health Networks Unit and Mental Health Commission re consumer engagement framework	1
Mental Health Commission, Mental Health Matters 2, Consumers of Mental Health WA, WA Association of Mental Health re consumer engagement framework	1
Consumers of Mental Health WA briefing re: Lived Experience Framework	1
Meeting with Health Futures Australia and DoH	1
Health Networks Unit and Mental Health Commission re consumer engagement framework	1
Health Consumer Peaks across Australia meetings	9
People With disabilities WA and Consumers of Mental Health WA briefings and catch-ups regarding individual advocacy	2
Pop Health Genomics re rare diseases engagement	1
Launch of Buurtzorg Neighbourhood Care model – Midland	1

Type of Activity Working Towards Interagency Collaboration and Strategic Planning	Number
Care Opinion Community of Practice	1
Aboriginal Health Council WA <ul style="list-style-type: none"> <li>• Traditional healing</li> <li>• National Justice Project</li> <li>• Health information during COVID-19</li> <li>• Mappa Launch</li> </ul>	6
WACHS – Aboriginal Prisoner Health	1
Department of Communities (Child Protection) Health Rights Advice	1
Aboriginal Traditional Healing Project – South Metropolitan Health Service	4
Derbarl Yerrigan meeting	1
Otley Centre Yarning Circle	1
Community Skills WA – Aboriginal Health workforce	1
Climate and Health Community of Practice	1
Wangkiny Mart – initial contact	1
Digital Cooperative Research Centre re telehealth panel discussion webinar)	1
Consumers of Mental Health WA (Diversity Dialogue CaLD youth mental health panel discussion webinar)	1
Ethnic Communities Council of WA (Group discussion with community leaders about COVID-19 messaging and the CaLD community)	1
Department of Health Advance Care Planning/Advance Health Directive Project (CaLD consumer feedback session on the draft new Advance Health Directive form)	1
Meeting with NDIS/Wanslea Community Capacity Building Officer - To discuss working with CaLD community and possible overlap / working together.	1
Meeting with Community Development Officer City of Gosnells - to discuss working with CaLD community and possible opportunities in City of Gosnells.	1
Meeting with Girrawheen librarian - to discuss community conversations / Rights and Responsibilities sessions in Girrawheen library.	1
Meeting with chair of Fiona Stanley hospital CAG - to discuss health literacy.	1
Meeting with the maternity leadership at KEMH - to discuss health literacy / Rights and Responsibilities sessions.	1
Meeting with Project Coordinator at CoMHWA - to discuss working together and CaLD mental health.	1
Meeting with Headspace Armadale to discuss working together and CaLD youth mental health.	1
Meeting with Multicultural Futures - to discuss COVID-19 communications and Community Ambassadors model.	1
SHR Partnership Group Peak Catch-up	2
Telehealth Awareness Week	1
St John Ambulance – contribution to Value for Money consultation, follow-up meetings with CEO	3
<b>Number of relevant interagency forums or networks participated with</b>	
Connect Share Collaborate group with DoH, HSPs and WAPHA	4
National Obesity Collective	3
WA State-wide Goals of Care implementation group, Steering Group	5
WA Palliative Care Summit planning group	3
WA Obesity Collaborative	2
Curtin HWAP Deliberative planning meeting and Forum on quality indicators	2
Telethon Kids – WA Child Ear Health Strategy Speech and Language	1
WA Aboriginal Child Health Survey Data Linkage Study	1
Youth Health Forum WA	1
<b>TOTAL</b>	<b>120</b>

### 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
Consumer consultation on Total Meal Replacement project – Diabetes WA under HWAP	1	3
Palliative Care WA workshop on AHD	1	1
Feedback on WACHS consumer engagement strategy	1	1
DoH End of Life team re consumer engagement	1	2
Men's Health policy implementation	1	1
EMHS Multi-cultural Plan	1	2
Feedback on MHC Consumer Engagement Paid Participation policy	1	1
AHD Register consultation	1	1
Feedback on Advance Care Planning and end of life from a CaLD perspective.	1	2
Participation in Sexual health CaLD Resource Steering Group.	1	1
Participation in "Reimagining the Patient e-Health Experience" with WA Health and WA Innovation Hub	1	1
Participation in consultations at Nous Group for the Mental Health Commission on mental health and AOD services for CaLD communities.	2	2
Feedback to consulting firm re St John's Ambulance Value for Money Assessment	1	1
Feedback to Joondalup Health campus re community engagement on spiritual requirements in hospital	1	1
CaLD community needs in response to COVID-19	1	2
Cancer Forum – Election Asks	2	4
<b>TOTAL</b>	<b>18</b>	<b>26</b>

### 3.8 Mechanism for Provision of Advice and Information

<b>Mechanism for Provision of Advice and Information (through)</b>	<b>Number of Activities</b>	<b>Number of Instances</b>
<b>Consumer Representation* (HCC appointed) participation on Department committee or forum</b>		
Sustainable Health Review Program Board meetings	1	4
Sustainable Health Review Recommendation Four Working Group	1	14
Sustainable Health Review Partnership Group	1	2
Sustainable Health Review Transformational Change Workshop	1	2
Sustainable Health Review Recommendation 16 Working Group	1	1
Sustainable Health Review Recommendation 22- Electronic Medical Record meetings and consultations	1	4
Meeting with SHR Implementation Unit about SHR outcomes	1	2
Sexual Health and Blood Borne Virus Advisory Group	1	2
Sexual Health and Blood Borne Virus Case Management Advisory Panel	1	2
Clinical Senate Executive Advisory Group and Debate Senator	2	5
Advanced Health Directive Register Working Group	1	3
Reviewing Palliative Care in WA	1	1
WA Health ICT Consumer Reference Group	1	3
WA Health ICT Governance Review	1	2
<b>Consumer Advisory- participation on Department Committee or Forum – where HCC provides general support</b>		
Pharmacy Registration Board – nomination of potential reps	1	1
<b>Participation on (other) committees or forums whose purpose is aligned with the Department's strategic priorities</b>		
First People's Disability Network (WA)	1	1
Prison Health - Catch up - J Wallam Office of the Inspector of Custodial Services	1	1
Speech Pathology Information, Linkages and Capability Grant Project Advisory Committee	1	4
Speech Pathology Australia ATSI Committee	1	2
Consumer Health Forum Digital Health Special Interest Group	1	4
Consumer Health Forum Consumer Commission	1	1
Australian Commission on Safety and Quality in Health Care Partnering with Consumers Committee	1	1
WA Health Translation Network – Board meetings	1	3
Australian Health Research Alliance – MRI Feasibility study, Research Collective	1	2
<b>Formal or documented responses to policy issues aligned with the Department's strategic priorities</b>		
Submission to Parliamentary Enquiry on implementation of Our Life Our Choice enquiry	1	2
<b>Meetings with (Department's) Minister, Ministerial staff and/or Department staff</b>		
Chief of Staff – Minister for Health meetings	1	1
Attendance of Minister for Health, Shadow Minister for Health, WA Senator for the Greens at HCC AGM November 2020	1	1
<b>TOTAL</b>	<b>28</b>	<b>71</b>

### 3.9 Source and Number of Request for Policy Advice and Information

<b>Source of Request for Policy Advice and Information</b>	<b>Number of Activities</b>
<b>Department of Health – Royal Street</b>	
Advance Health Directives Consumer Workshops (1xdisability 2x Aboriginal 1x general)	4
Research Development Unit – consumer engagement discussion	2
Ambulance Policy meeting	1
<b>East Metropolitan Area Health Service</b>	
Consumer briefing meeting – Sandra Miller	1
<b>North Metropolitan Area Health Service</b>	
<b>South Metro Area Health Service</b>	
Partnership on EY Innovation Workshops, advice on Recommendation 11 consumer involvement	
<b>Child and Adolescent Health Service</b>	
Midland Community Hub Consultation	
CAHS Director Aboriginal Health meeting	1
<b>WA Country Health Service</b>	
Palliative Care Program Project Control Group	1
<b>State Government (other agency)</b>	
Department of Premier and Cabinet - Budget Briefing	1
Department of Premier and Cabinet – consultation re digital inclusion in WA project	1
Department of Corrections - Clinical Governance Advisory Group – Prison Health	2
Department Communities (Disability) State Disability Strategy Workshop	1
Office of the Chief Psychiatrist Update meeting	1
<b>Service (self-initiated)</b>	
<b>TOTAL</b>	<b>16</b>

## **SERVICE ONE- INDIVIDUAL SUPPORT - OUTPUTS**

### **Advocacy Activities- Outputs**

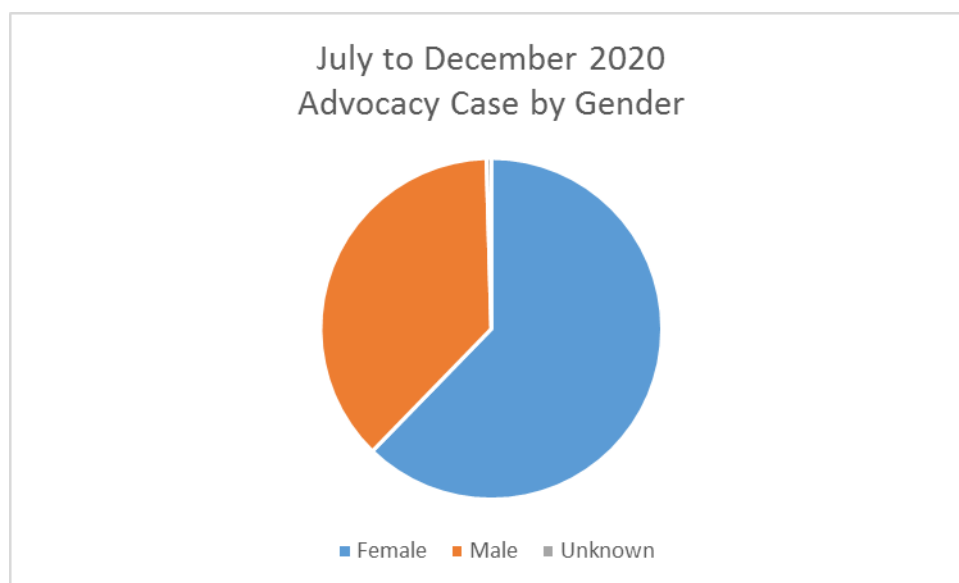
The HCC provides a flexible and Individual Advocacy Service for West Australians seeking assistance with access to health service and/or complaint resolution processes. In this reporting period, there were 220 advocacy cases.

Our reception staff have provided information and active linkage to 341 individuals during this period. Such provision includes information and linkage support to 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 numerous advocacy cases over from the previous period(s). The advocates resolved/closed 284 advocacy cases during this period.

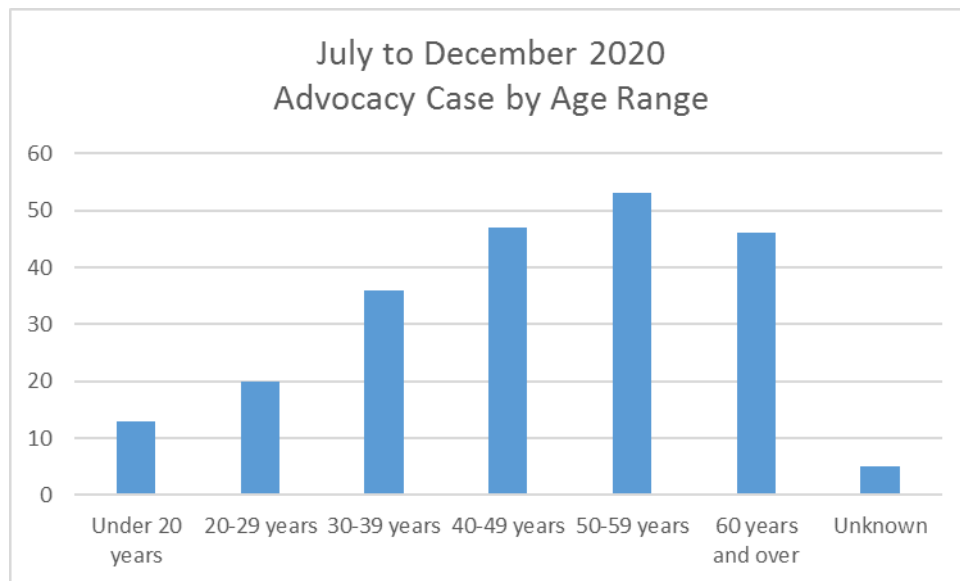
### **Advocacy Cases- Gender**

Individuals identified as female in 137 cases, male in 82 cases and 1 consumer identified as unknown. This compares to 115 female, 56 male and 4 unknown from the previous reporting period.



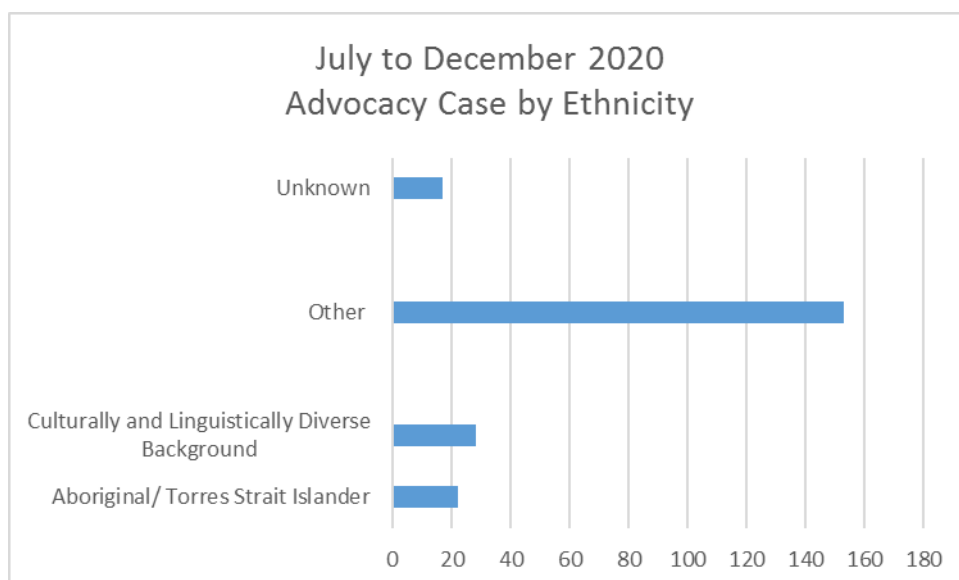
### Advocacy Cases by Age Range

This period and the previous period saw 6% advocacy clients belonging to the under 20 years cohort. 10% belonged to the 20 – 29 cohort compared to 8% for the previous period. 16% belonging to the 30 -39 cohort compared to 18% for the previous period. 21% were from the 40 – 49 cohort compared to 20% for the previous period. 24% from the 50 – 59 cohort compared to 18% for the previous period. 23% belonged to the 60 and over cohort compared to 30% for the previous period.



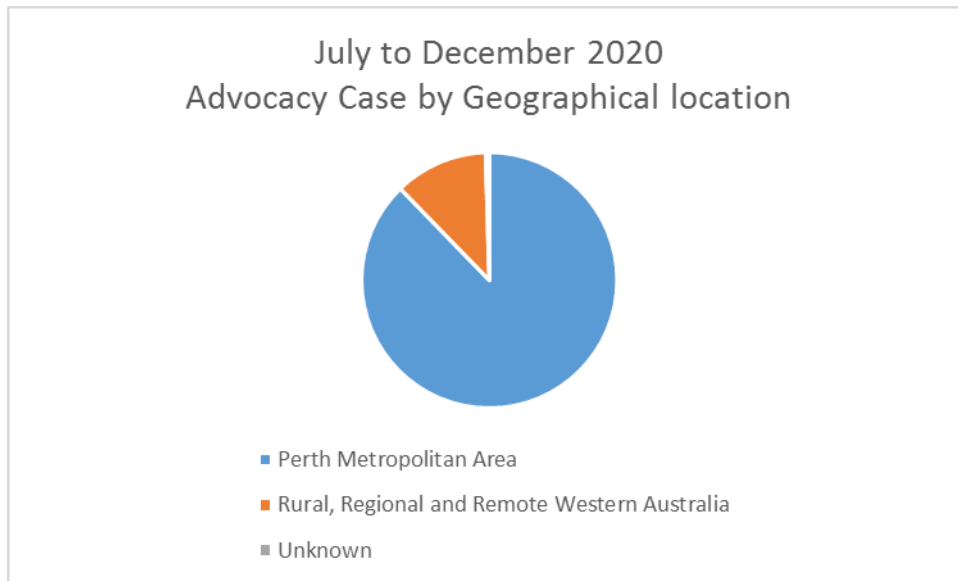
### Advocacy Cases by Ethnicity

This period saw an increase in advocacy clients from the Aboriginal/ Torres Strait Islander cohort at 10% compared to 4% for the previous period. Culturally and Linguistically Diverse Background clients remained fairly similar at 13% compared to 14% for the previous period. The “Other” cohort slightly decreased at 69% compared to 75% For the previous period. Unknown ethnicity was at 8% compared to 7% for the previous period.



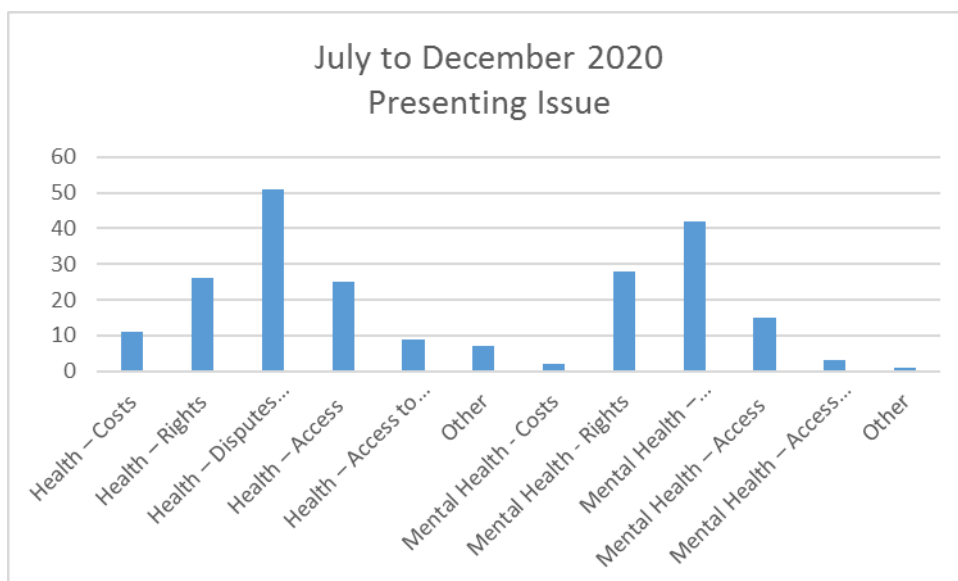
### Advocacy Cases by Location

This period saw 86% of advocacy clients from the Perth Metropolitan Area compared to 94% in the previous period. We are encouraged to see a slight increase in clients accessing the service from Rural, Regional and Remote Western Australia at 11% compared to 7% for the previous period.



### Advocacy Cases by Presenting Issue

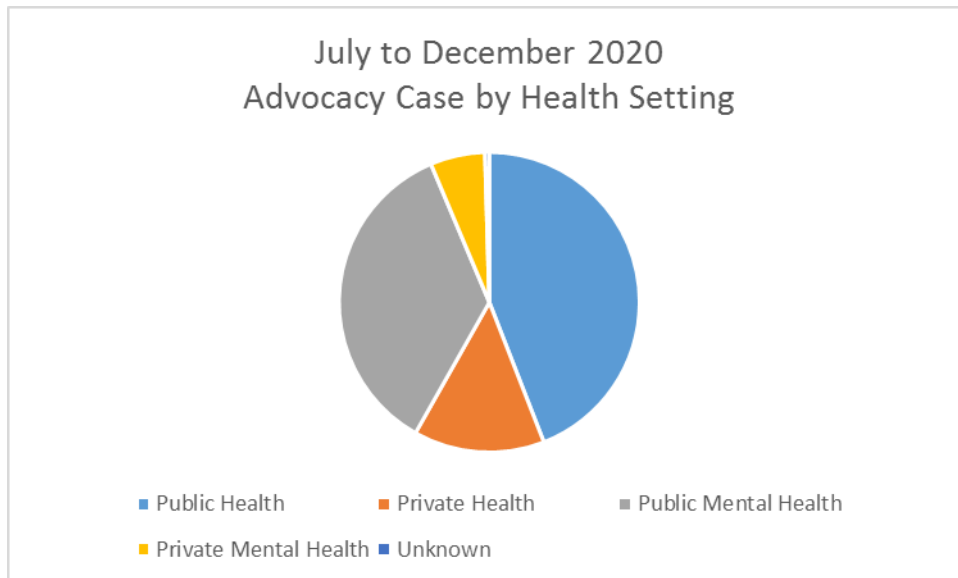
As in previous periods, the service saw the highest number of complaint categories emerging from issues around health rights and dispute of treatment/diagnosis.





### Advocacy Cases- Health Setting

This period has seen an increase of advocacy clients accessing the service from the private health setting. This period, 80% were from the public setting compared to 95% for the previous period. 20% of advocacy clients from the private setting compared to just 3% last period.



## **Advocacy Activities- Advocacy Case Stories**

### ***Case Story 1- Complex case- Avoidable Clinical Incident***

Parents presented their 3-week-old baby to Hospital. Baby was having issues with feeding and seemingly experiencing pain. The Hospital determined Baby had pyloric stenosis, and advised upon surgery (laparoscopic pyloromyotomy). The parents met with the allocated surgeon who explained that the surgery was low risk and what to expect in the hours and days post operation.

In the hours after surgery, the parents noted that Baby was not presenting in the way they had been told to expect. Baby was not feeding well and seemed to be in pain. They raised concern to staff and Baby's surgeon, but were told not to worry and that all seemed fine. The parents had a gut feeling that Baby was not fine.

The parent's concern continued, and they alerted a clinical nurse to their fears. The nurse contacted the surgical team and requested they review Baby. However, the nurse conveyed that the surgical team had declined to accept their "clinical recommendation." After several hours, the surgical team reviewed Baby and ordered a scan. The imaging revealed Baby's bowel was perforated. As this had gone undetected for an extended period, Baby had developed sepsis.

Baby was taken to surgery for a second time for laparoscopic and laparotomy repair of the perforation, correction of the pyloric and wash out. Baby was admitted to Neo Natal Intensive Care Unit experiencing E.coli bacteraemia and E.coli meningitis.

Over the next few days and weeks the parents raised further concerns for Baby's clinical situation, speculating to the treating team that Baby could be suffering from a bowel obstruction/adhesions. Staff dismissed this suggestion.

Days later, investigations revealed Baby was experiencing a bowel obstruction. The attending surgeon advised the parents that Baby would need to undergo surgery for adhesive obstruction. The surgeon explained that a Gel product would be used during surgery. The surgeon did not convey any associated risks of using such a Gel.

Days after surgery, extracellular blue/purple precipitant was noted on Baby's blood films. This was presumed to be the Gel product that had been used during surgery that had infiltrated his blood system. Global opinions confirmed that the clinical significance of this finding was unknown in humans, particularly in the neonatal setting. Baby's parents were told that there is no other case known globally and that they could not advise as to whether there will be negative impact to his long term health. The parents now felt very concerned.

The parents sought information from the manufacturers of the Gel product. This information revealed that the Gel is not evaluated in the use of children and that it is contraindicated in presence of infection. To this end, Baby's parents became very concerned as to why the Gel was used in the case of their child. They engaged with HCC's Advocacy Service.

Baby now requires regular and ongoing multi-disciplinary monitoring from a range of specialisms. Baby and the parents are significantly traumatised by the extended hospital

admission, and the many invasive, painful clinical events and interventions that took place. The parents feel let down by the clinical incidents but also by what they consider to be a poor complaint resolution process. They do not believe that the Hospital have invested enough effort to seek answers into Baby's case. The parents consider the Hospital have not sufficiently reflected upon their mistakes to identify learnings to ensure something similar never happens again.

The parents live in fear as to how the incident may impact their child's long term medical, sensory and psychological picture.

Advocacy has included;

- effort to ascertain whether the Hospital followed the "WA Health Clinical Incident Management Policy" correctly
- checks to ascertain that an adequate "Root Cause Analysis" was undertaken
- formulating letters of complaint
- attendance/support during complaint resolution meetings and medical consultations
- liaison with the Hospital Executive
- obtaining baby's medical records
- referral to medical negligence lawyer
- formulation of Baby's hospital admission timeline.

This case is still ongoing with much work to do and represents an example of the kind of complexity dealt with by HCC's advocacy service.

### ***Case Story 2- Unfair Costs***

Consumer "C" contacted HCC's advocacy service stating they had been charged for an appointment with their GP via Telehealth. C believed this to be wrong due to measures legislated in response to COVID-19 that state all vulnerable individuals, and individuals with a health care concession card should be bulk billed for such services. C explained that they had attended this GP for some time and were required to have consultations in order to be prescribed a specific medication for their child's epilepsy.

Following their most recent appointment, C was charged \$180. When they contested the amount, they were advised that the bulk bill only counts for one provider, and seeing as the child was receiving the service from other providers, the GP claimed they were unable to bulk bill on this occasion. When C requested the Medicare item number from the GP, they were told that there was no item number for the charge. C followed this up with Medicare who explained that this cannot be the case and that every service is required to have a Medicare number. C explained that their child has a range of vulnerabilities and as such were required to self-isolate until the specialists gave the "all clear" that they could return to normal.

The HCC advocate researched the information available on the websites for the Australian Medical Association and Department of Health and determined that GP's were required to bulk bill for such services.

With C's consent, the advocate contacted the GP to remind them of their obligations. After much "back and forth," a refund was issued to C and an agreement by the Service to bulk bill in the future.

### **Case Story 3 - Too Long Waiting for Surgery**

T engaged in with the advocacy service believing they had been left too long waiting for a total hip replacement. T had been deemed as requiring the surgery due to significant degeneration of the hip joints. T had initially waited for 14 months to see a surgeon and was then placed on the waitlist for surgery as “Category 3”. After a wait of several months, T was then booked for surgery, which was cancelled due to Covid-19. T received another surgery date for 8 months later, which was also cancelled due to a lack of beds and a Western Australia shortage of orthopaedic surgeons.

After waiting for a total period of 2.5 years for surgery, T presented to the Emergency Department due to worsening pain and decreased mobility only to be given more pain analgesia. She was advised that her surgery would take up to another year.

T explained to the advocate that they were in a great deal of pain, could not mobilise without crutches and not able to perform usual day-to-day tasks. T reported that the left hip was now much worse than it was at the time of referral, meaning it was no longer the stabilising joint it was once. Despite this, T had to shower whilst standing on one leg, which placed them at significant risk of falling. T was also experiencing significant fluid retention in their ankles and feet. T’s pain medication was causing incontinence, which was understandably very distressing to them. T could not go shopping, drive a car or undertake domestic activities.

The advocate invested vigorous effort in this case by engaging the GP to also advocate for T. The advocate along with the GP wrote to the Hospital’s Admissions Manager and the Surgeon. The advocate argued that that T being waitlisted as Category 3 was no longer appropriate given the worsening symptoms and mobility deficits, and to that end, requested surgery be expedited as a matter of urgency.

To T’s relief, surgery took place three weeks later.

In T’s own words,

“I was really at the end of my tether, and you guided me through the advocacy process very skilfully. Now because of your professional approach and HCC, I have been re-assessed as to my priority and my surgery has been brought forward to this week. I cannot thank you enough. It has been a life changing experience to go through this process with HCC.”

## **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.

### **Website and Self Advocacy Resources**

This period has seen us doing significant work to improve the advocacy section on our website. We have developed the following online information and resources, which are drafted and due to go live in the coming weeks:

- Clear information on the definition of individual advocacy at HCC
- Clear explanation as to the role of a HCC advocate
- Clear guidance around how to make a complaint/provide feedback directly to a hospital or health service

### **Links to:**

- A step by step guide to writing a complaint
- How to access your medical records
- WA Hospital consumer/patient liaison departments
- Care Opinion
- Health and Disability Services Complaints Office
- Australian Health Practitioner Regulation Agency
- Community Support Services Directory produced by RUAH
- Australian Charter of Healthcare Rights
- Mental Health Rights
- Information on informed Consent
- Guardianship and Administration- info sheet
- Questions to ask your doctor- question builder tool
- Medical procedure specific information sheets
- Understand your pathology tests info sheet
- Going to Hospital info sheet

### **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.

### **Social Work Student Placement**

During this period, the Advocacy Service has continued its relationship with Curtin University's Social Work Faculty. We welcomed our fourth 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 review and deciphering of medical records as to better understand the nuances of individual health care journeys. Our staff are not clinically trained, therefore not qualified to undertake this task. Previously, we had some capacity to fund a suitably qualified health practitioner to undertake such reviews however, as we previously reported, we had been forced to cease this service in early 2020. On reflection, no longer having the service is a significant loss to the work we do, and means we cannot always reach optimal insight into complex cases.

### **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, 17 individuals attended the Legal Information Session.

## **Service One – Individual Support – Outcomes - Consumer Feedback**

“Advocacy for me was about helping me in navigating the health system. I was hitting brick walls and advocacy helped me to break through the walls and help my child. I wouldn’t have gotten anywhere on my own. My advocate laid the groundwork so that my child could get the supports and procedures he needed within the health system. Thank you so much, I wish I had known about you nine years ago.”

“We’re very grateful for your attendance at the clinic appointment and are so impressed with how thoroughly you captured all the information. They are excellent notes and invaluable for us to refer to as well as to recount to our GP and others.”

“You have been such a help and so efficient & professional. I am wondering, how did you actually get through to them [health service]? Is it ever possible for a patient to make contact? This has brightened my day considerably. Thank you again”

“Of course I am disappointed that I have come to the end of your involvement as I have felt that you were so much more professional and responsive than HaDSCO. It has always been a joy to me to witness a skilled communicator. I wish to thank you for all your time and effort. I do appreciate all that you have done.”

“I have nothing bad to say about the help you have given me. You never gave up on me. I appreciate your support”

“Thank you for trying so hard to resolve my issue (with the service provider). Thank you for being so supportive of me and persisting, it means a lot to me, I am so grateful.”

“Thank you so much for your help with my issue, I felt supported and it was much appreciated. You calmed me down and I was able to have a different perspective of my issue.”

## **Service One - Advocacy – Reflections on Sustainability**

The HCC Advocacy Service continues to see increase in the complexity of advocacy cases. Consumer issues often relate to highly convoluted subject matter and/or consumers who require extended time to discuss their issue.

HCC does not currently have a designated administrator nor intake/triage role. All administration and intake work is undertaken by our receptionist. Ideally, we would have one position to provide the administration support of our busy organisation, and another dedicated to the intake, referral and information provision.

From July 1<sup>st</sup> 2020, the Mental Health Commission granted 12 month interim funding for 1 FTE advocate. Although this has marginally helped with capacity, we are currently operating with a team of just 4.5 FTE advocates, which is significantly less than desirable. The Service is certainly operating at a deficit, which significantly impacts the workload and wellbeing of our staff. Further, we continue to acknowledge the negative impact this issue is having on the quality of service we are able to offer to consumers. For further context, this reporting period saw 41% cases pertaining to issues around mental health. 1 FTE provision to fund mental health advocacy is too little to resource such work.

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. Should HCC not receive further and suitable funding from the Mental Health Commission, it will be forced cease mental health advocacy in 2021.

In 2020, the HCC Advocacy Service Manager undertook a comparison to an advocacy service in the disability space who deal with comparable numbers of intake and advocacy cases compared to the HCC. The other agency operate at 12.5 FTE and close their waitlist at 20 due to being unable to meet demand. This comparison solidifies our resolve that the HCC are operating at a deficit, which cannot be sustained beyond the existing contract agreement.

HCC continue to have a waitlist that can result in individuals waiting for up to 5 weeks until an advocate has capacity to take on their case. Although considerable effort is invested to ensure those with a “live advocacy need” are expedited on the list. Given the Service does not have the capacity to respond to consumers in a timely manner, and as we run the risk of providing a deficit quality of advocacy, HCC may soon need to make a decision to reduce the scope of the Service and/or close the waitlist at a specific number.

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 unable to access our independent specialised advocacy for their health issues.



## **Service One - Health Rights Information for Consumers**

For the second year we produced a Self-Advocacy edition of our Health Matters magazine. It has articles and information on self-advocacy and peer support, and can be used as an ongoing resource for consumers. The magazine is available on our website and circulated via email and social media.

The self-advocacy resources page on our website continued to be one of the most viewed during this period.

### **Health Rights and Responsibilities Presentations and Information**

During this period, we conducted a number of health literacy sessions on Health Rights and Responsibilities, Choosing the Right Health Service and Going to Hospital. These were conducted at English conversation classes, arranged through local government contacts. Sessions were well received with much appreciation from participants as well as the English language teacher hosts. A surprising number of participants seemed to be totally unaware of basic rights prior to the sessions such as the right to an interpreter.

As English conversation classes are of mixed ability, there were some challenges with the very beginner / basic English speakers and in 2021 we plan to work with the Australian English Migration programme and see if attending specific advanced English classes might be an even more successful addition/alternative.

### **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. We also provided links to translated resources.

Our new Cultural Diversity Coordinator Nadeen Laljee-Curran continued to build her network during the second part of the year. Nadeen made new connections with City of Gosnells, Consumers' of Mental Health WA, Red Cross Migration Support to name a few and also strengthened relationships with existing key stakeholders in the CaLD space, for example Ishar Multicultural Women's Health, Multicultural Futures and the Ethnic Communities Council of WA which allowed for collaboration on community conversations and diversity dialogue discussions.

Due to WA's border policy and success in eliminating community transmission of COVID-19, Nadeen, who had reduced her hours from 0.6FTE to 0.4FTE during the early part of the pandemic due to personal circumstances and family commitments was able to return to her normal hours from 15 June.

## **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 12,840 unique visitors. This brings the total for the calendar year to 22,262 unique visitors. In total, the website had 16,497 sessions during the 6 month period, and 28,854 for the full calendar year.

The most accessed pages after the home page were 'how to make a complaint', 'donate now', 'what we do – advocacy', 'who we are', 'self-advocacy resources', 'upcoming events', 'workshops' 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. It is also useful for collecting feedback via surveys, promoting HCC events and workshops, and providing links to other health services. HCC is active on Facebook, Instagram, LinkedIn and Twitter. Our current social media stats are:

### **Facebook**

- Page likes of 1979 people as of Dec 20 (increase of 13% since Dec 2019)
- Total page reach July-Dec is 29,943 (a 74% decrease on the previous 6 month period)
- Total post engagements July-Dec is 2664 (a decrease of 85% on the previous 6 month period)
- Total page views July-Dec is 2661 (an increase of 17% on the previous 6 month period)

### **Instagram**

- 596 followers as of Dec 20 (52% increase since Dec 2019)
- Total reach for July-Dec of 1,945 (decrease of 53% on previous 6 month period)

### **Twitter**

- 1357 as of Dec 20 (3% increase since Dec 2019)
- Total impressions of 25108 (a 52% decrease on the previous 6 month period)
- 35 retweets (a decrease of 39% on the previous 6 month period)

### **LinkedIn**

- 878 connections as of Dec 20 (a 78% increase since Dec 2019)
- Total post views of 7283 (an increase of 60% on the previous 6 month period)

\* There has been much reporting around the huge decreases in organic Facebook and Instagram reach in 2020<sup>1</sup>, with posts from businesses being deprioritised. This was compounded by periods of time when posting was limited due to staff resources. During the height of the pandemic (first half 2020) we were posting up to 4 times per day, creating more opportunities for reach and engagement but skewing the result for the remainder of the year when posting returned to normal levels. We also experienced unprecedented engagement with our post on the Black Lives Matter protest in the previous reporting period.

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<sup>1</sup> <http://korayodabasi.com/decline-in-instagram-reach-and-engagement/>

YOU						
8		Health Consumers' Cou...	2K	▲0.1%	12	345
Keep up with the Pages you watch. <a href="#">Get More Likes</a>						
9		Health Consumers Quee...	1.2K	▲0.2%	6	221
10		Consumers Health Foru...	1K	▲1.3%	4	169
11		Health Care Consumers'...	779	▲0.3%	8	76
12		Health Consumers NSW	681	0%	7	47
13		Health Issues Centre	625	▲0.6%	1	3

**As a matter of interest, the Health Consumers' Council in WA has the largest number of Facebook followers at 2K. Considering our population, this is an achievement we want to continue to build on.**

### Social media groups for peer support 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 22%  
<https://www.facebook.com/groups/hccsource/about/>
- Partners in Change – Healthy Life for Longer – a group for people interested in the topic of obesity and weight management - membership in this period has increased by 40%. This is likely to be due to the fact that for some of this time we have had a dedicated staff member working on this project.  
<https://www.facebook.com/groups/248123835784261/>
- Aboriginal Health – we started this group in March. During this period, membership has grown by 30%.

### Traditional Media

We continue to respond to requests for consumer comment. During this period we had media mentions on 720 Drive Time, 6PR Mornings, and ABC News website and radio.

## **SERVICE TWO – SECTOR SUPPORT - OUTPUTS**

### **Health Consumers' Council 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
- Cultural Diversity Program
- Aboriginal Engagement
- E-news and Health Matters

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

During this reporting period, we continued to provide our events for consumer reps and Chairs of consumer groups virtually. This enables participation by members of the regional District Health Advisory Councils.

We held two Chairs network sessions. HCC staff also presented to the DHAC group in December 2020 about upcoming issues, as well as a targeted presentation on Recommendation 4 of the SHR.

#### **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
- Continued – 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 September and December.

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

### September 2020 – quarter 1 – Djilba/Spring

This session focused on increasing people's awareness of the mechanisms for giving feedback or making complaints in the WA Health system. This was prompted by the discussions at workshops we held in February with the PSSU at DoH when many people said a major barrier to giving feedback was that they didn't know they could or how to.

The session included a presentation from HCC's Advocacy Manager as well as an overview of Care Opinion from the CEO.

### December 2020 – quarter 2 – Birak/Summer

This session focused on the Sustainable Health Review. The slides are online at <https://www.hconc.org.au/what-we-do/policy-development/sustainable-health-review-consumer-view/>

### **Fireside Chats with senior WA Health staff**

We worked with DoH staff to run Fireside Chats with senior WA Health staff. In this reporting period we held three sessions: Pathwest's Joe Boyle, the Director General of WA Health and Chief Health Officer Dr Andy Robertson.

We had almost 80 registrations for these three sessions.

### **Private Facebook page – Source: Connect – Learn - Share**

Membership of this group grew by 50% during 2020 – from 77 to 116 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 – consumer representative opportunities**

Membership of this mailing list grew by 75% during 2020 – from 98 to 172 people. Content posted is similar to that 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.

### **E-news and Health Matters**

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

- Engagement - looking at the many and varied ways health service providers and consumers can engage to create authentic, productive partnerships in healthcare. This edition includes lots of resources for anyone interested in becoming a consumer, carer or community representative.
- Year in review - takes a look back at the year that was, exploring some key projects and progress for 2020. Even before the global pandemic hit this was always going to be a busy year for HCC, so in this edition we also look at some of the impacts of COVID-19 on our team and our communities.

This year we trialled producing only digital versions of the magazine as a result of the uncertainty around in-person events. The PDF of the magazine is available on our website, and cross promoted across our social media channels and emails. The Health Matters page on our website was visited 738 times in calendar year 2020. Articles from Health Matters are also repurposed as blog posts, which were visited 188 times in the calendar year.

Pulling the content into a formatted publication each month is a significant investment of staff time, in a role that we only have for 2 days/week. Each publication is being viewed by approximately 180 people. While this is valuable, we are continually looking for how we can extend our message to more health consumers.

For this reason, we would like to explore the opportunity of using this time to promote specific content to partner health organisations – such as the Health Foundation, the Stroke Foundation, and Cystic Fibrosis WA etc. – as an avenue to reach people who may not be aware of our work. We propose not publishing a specific Health Matters publication in the next period, but instead will invest that time into developing a database of potential channels and building relationships to enable us to extend our reach with consumer-focused content through relevant health publications.

HCC's electronic newsletter (E-news) is sent monthly to approximately 800 subscribers, as well as HCC's individual and organisational members. It cross promoted via our social media channels and all previous E-news are available on our website to view.

### **Training and Workshops for Consumer Representatives**

In this six month period, one of each workshop – the Introductory and Advanced Consumer Representative Workshops – were scheduled for open invitation.

We considered running these virtually, even though WA was out of lockdown, but were unable to allocate the time to adapt the program for a virtual setting.

At the Introductory session in October 15 people attended on the day.

At the Advanced session in October, 13 attended on the day.

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.

In this period, we were approached by WACHS to see if we could work together on creating online learning materials for DHAC members. We have provided the workshop materials we use for the Intro workshop and will work with WACHS in 2021 to progress this.

We continue to receive requests to make these sessions accessible to people who are outside of Perth. This will require the allocation of staff time to adapt the materials for

virtual delivery. We would like to explore opportunities for online delivery as part of the contract renewal discussions.

## **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”<sup>2</sup>, 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.

Our Cultural Diversity Coordinator Nadeen Laljee-Curran continued to build her network during the second part of the year. Nadeen made new connections with City of Gosnells, Consumers’ of Mental Health WA, Red Cross Migration Support to name a few and also strengthened relationships with existing key stakeholders in the CaLD space, for example Ishar Multicultural Women’s Health, Multicultural Futures and the Ethnic Communities Council of WA which allowed for collaboration on community conversations and diversity dialogue discussions.

### **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 and health service staff. Panel members are people from CaLD backgrounds who provide cultural and traditional insights and lived experience accounts of dealing with particular health issues or parts of the health system, or staff with extensive experience in working with people from CaLD backgrounds who provide insights from their practice. The purpose is to assist providers develop understanding and improve service provision to this cohort. Traditionally our DD forums were conducted in person and also provided networking opportunities. During this reporting period COVID-19 forced us to consider an online webinar format which had some limitations in terms of networking but was able to far extend the reach of our discussions. As such they were considered very successful and we are likely to keep at least one of our DD forums as online beyond the pandemic.

During this reporting period, the first DD forum was held on the experience of people from CaLD backgrounds when using telehealth. This session was delivered in partnership with the Digital Health Collaborative Research Centre. Following that the

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<sup>2</sup> <https://www.semanticscholar.org/paper/Peer-Support-for-the-Hardly-Reached%3A-A-Systematic-Sokol-Fisher/090d48f14a6d67de8c631e6676fec0f93efd3a8> accessed 04/02/20

second DD forum was delivered in partnership with Consumers of Mental Health WA on the topic of CaLD, youth mental health.

### 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.

We held our second annual Supporting Cultural Diversity in Healthcare workshop in this period. As previously, we were quickly over-subscribed but had to cap registrants at 25.

There is always high demand for this training with sessions filling up quickly when advertised.

### **Objective: building capacity and understanding amongst community members**

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

### Community conversations and health rights

We have previously reported a seeming lack of awareness about the West Australian Health system, services available, how to access them and rights and responsibilities in health from people from a culturally and linguistically diverse background, particularly newer migrants. However, during the last reporting period we were unable to get out into community to run any of our health literacy sessions due to COVID-19. We scheduled a number of sessions for the later part of the year and luckily were able to hold these. We held a total of five sessions on Choosing the Right Health Service, Rights and Responsibilities in Healthcare and Going to Hospital with community groups, one Mother's Group and four English conversation classes. As people quite often do not know what they do not know, the idea is to meet a group where they are and when they regularly meet. Sessions were well received and again highlighted the lack of understanding about the health system, lack of resources in this space but also a lack of awareness of existing resources. The lack of awareness around the right to request an interpreter was also a little alarming.

During the last reporting period, we circulated a survey around understanding and resources about the Australian/West Australian health system. We had 40 respondents, approximately half of which were consumers from CaLD backgrounds and half of which were people working with and supporting CaLD community. There was an almost unanimous thinking that there is a lack of resources explaining the WA health system with one person commenting that there are some resources available but that what is needed is one source of truth or a library which contains all the available information.

What was less clear from the survey is what resource(s) are needed. Some suggested printed brochures or flyers and other commented that literacy (even in first language) can be a problem. Some suggested audio or video and others felt a presentation from an organisation like HCC would be useful. Thirteen respondents stated they are keen to participate in further discussions or working groups to establish what a resource should



be like. What was clear is that more work is needed to fully understand what is needed and we plan to apply for a grant in 2021 which will allow us to develop a resource, including being able to offer consumer participation payments to recognise the contribution of consumers who give us their more detailed views and test prototypes when the time comes.

#### Culturally and linguistically diverse consumer panel

During this period, we have continued to engage with our CaLD consumer panel with 88 members at the time of reporting. We continued to circulate links to trusted sources of information relating to COVID-19 and associated public health measures as well as opportunities for giving feedback about / to the health system or being involved on consumer committees. Although 27% - 43% of subscribers open the mail circulars we would like to engage more with the panel in person and hope to get them together face to face with an appropriate topic of discussion (perhaps health literacy) in 2021 if funding permits.

#### Aboriginal Engagement

HCC remains committed to ensuring Aboriginal health is a core part of HCC's focus and services. Our Aboriginal staff member has continued to focus on ongoing communication and relationship building with community and consumers through informal and opportunistic engagement. Through the development and maintenance of an ever growing contact register of Aboriginal consumers, we have been able to quickly source consumers for various forums and feedback, and to share widely relevant and consumer focused health information quickly.

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) Panel**

This panel has met twice during this reporting period. The panel considers the management of complex patients from the perspectives of the clinical, legal, rights and cultural perspectives. Many of the clients on this program are Aboriginal and so the cultural and consumer rights perspectives are important to the balance of the advice given to the CHO. This is an ongoing appointment.

#### **National Clinical & Community Advisory Group / Child Digital Health Checks 5-14 Advisory Group (National Children's Digital Health Collaborative)**

The Collaborative has now wound up its work. The involvement of our Aboriginal staff member on these groups was important for raising the awareness of the WA context to an Eastern States based and experienced Collaborative. It has also meant that we were able to share the work and contact details of the Collaborative project team with the Child and Adolescent Health Service, Community Health staff who are currently looking at developing a digitalised version of the baby book, which is what the Collaborative produced.

#### **Feedback to WA Health on Advance Health Directives**

We were able to quickly provide two workshops to assist the project team to get feedback from Aboriginal consumers on the template for a new Advance Health Directive form. This was especially important as we were able to involve a group from the Kimberley to give their valuable perspectives on this topic.

### **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 has been progress on updated and refreshing the training material and developing a timeline for finalisation of the resource. We recognise that AHCWA has had a very busy 2020 and competing priorities, and we look forward to this work being completed in 2021.

### **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 are continuing to build our relationship with the Office of the Inspector of Custodial Services and have requested information on complaints from HADSCO in order to better understand the nature of issues in our prison system.

### **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. This review didn't happen in 2020 due to COVID, however we remain in contact with the Aboriginal Health team at NMHS and regularly share and promote resources at mutual request.

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 continued to be suspended due to COVID-19.

### **Traditional healing**

HCC staff continue to work with the Aboriginal Strategy team at SMHS in order to progress this long term initiative. It is a complex and multilayered issue with significant cultural and practical considerations. We remain committed to speaking with consumers and community in order to ensure their voices are heard and this conversation continues, and to understanding more clearly the role Traditional healing currently plays within our health system.

### **Patient Experience Week 2021**

We have been unable to progress activities in this area due to other workload. We will look at this again in early 2021.

## **Consumer Representation – State Level**

### **Sexual Health and Blood Borne Virus Advisory Committee (SHaBBVAC)**

The work commenced last year to enhance consumer involvement in the sexual health and blood borne virus sector has progressed well. An initial meeting with key NGOs in the sector showed the need to focus on developing a Consumer, Carer and Community

### **The Integrated Case Management Program (ICMP)**

See above for an update on this program.

### **Palliative Care**

HCC continues to advocate for a strong consumer voice in the work on palliative care. Our work in this period included making a written submission to the Parliamentary Enquiry into the implementation of the Our Life Our Choice recommendations. HCC staff were also invited to attend as witnesses.

HCC staff were on the planning committee for the Palliative Care Summit and attended this event. We also spoke at the Palliative Care WA sector consultation session to inform their submission to the Parliamentary Enquiry.

## **Interagency collaboration and policy advice**

HCC worked with key advocacy agencies during this period to raise awareness of the many gaps in mental health and disability, and the need for independent advocacy to be prioritised. A meeting was sought with the collective and the Mental Health Commission and DG of Communities, and while this did not take place until January 2021, there are very positive early discussions being had.

HCC has also become the lead organisation on a Lotterywest project to develop training for independent, individual advocates right across the health and human services sector. This training will be developed in 2021, and there will be limited capacity through this grant to enhance the feasibility of the group meeting and working together on key policy areas.

## **Supporting the WA consumer voice at a national level**

### **National Digital Health Reference Group**

This newly formed group is one of the Consumer Health Forum's Special Interest Groups. HCC sits on this and provides updates from a state level.

**Input to national digital health activities**

*NT/ WA Child Digital Health Checks Initiative Committee*

See above for an update on this program.

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

See above for an update on this program.

**WA Health Translation Network – Consumer and Community Involvement Program**

The HCC Executive Director has continued to work closely with the Head of the CCI Program at the WA Health Translation Network 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.

During this period, HCC were approached by WA Health about the possibility of formalising the relationship with CCI and aligning funding mechanisms as part of the contract renewal discussions. Further clarity will be sought and this will be progressed early in 2021.

**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 Care Opinion.

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

**Health Engagement Network**

This Network was established in 2018 with seed funding from the WA Primary Health Alliance. There are current 351 members registered with the online platform – [www.healthengagement.org.au](http://www.healthengagement.org.au) – and a number of other people who have expressed interest but have not joined up online.

We have not undertaken any activities during this reporting period. We believe there is great potential to use this platform to provide a virtual space for consumer reps to connect with each other as well as other staff groups. With our current resourcing it is not possible for us to be more active in this space.

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.

We would like to explore opportunities for leveraging more impact through networks and communities of practice as part of the contract renewal discussions.

### **Clinical Senate**

There were two Clinical Senate Debates that HCC participated in- the Future of the Workforce which trialled the new format of dinner the night before, and the End of Life debate. HCC continues to serve on the Executive Advisory Group for Clinical Senate.

### **Empowering health consumers with disabilities**

As a result of a project with the Australian Digital Health Agency, we identified that there is very little/no tailored information about Goals of Care or Advance Care Planning 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.

We approached People With disability WA and Palliative Care WA and started work with them to run a small project which will involve the people from the previous Empowering Health Consumers project who discussed possible changes to PCWA's existing materials and approach to community training on Advance Care Planning. This project was predominantly funded by PWdWA, with some input from PCWA to fund consumer participation payments. Staff from the WA Cancer and Palliative Care Network also participated in some meetings.

As a result of this project, PCWA are exploring the possibility of a Lotterywest application to develop a train the trainer model for community education on ACP for people with disability.

### **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 (SHR)**

From September 2020, nearly 18 months after the launch of the SHR Final Report, there was (finally) real progress made towards implementation of the Recommendations outside the walls of WA Health. HCC has been taking a keen interest in the Implementation, as all during the development of the SHR Final Report, the Consumer and Carer Reference group stressed the importance of having a transparent, ongoing reporting of how the Recommendations are being implemented. HCC has therefore developed a page on our website that tracks all the different moving parts of the Implementation:

<https://www.hconc.org.au/what-we-do/policy-development/sustainable-health-review-consumer-view/>

This web page includes the presentations for community on the SHR, including both PowerPoint and recordings, as we have attempted to bring awareness of the opportunities of the SHR implementation to a wider community. We are constantly updating it and over time aim to reflect the progress against the Enduring Strategies.

The Executive Director sits on the Program Board as a Recommendation Co-Lead and also on the Partnership Group which brings together Co-Leads, consumer and community peaks and people with lived experience.

### **Recommendation 4 - Commit to new approaches to support citizen and community partnership.**

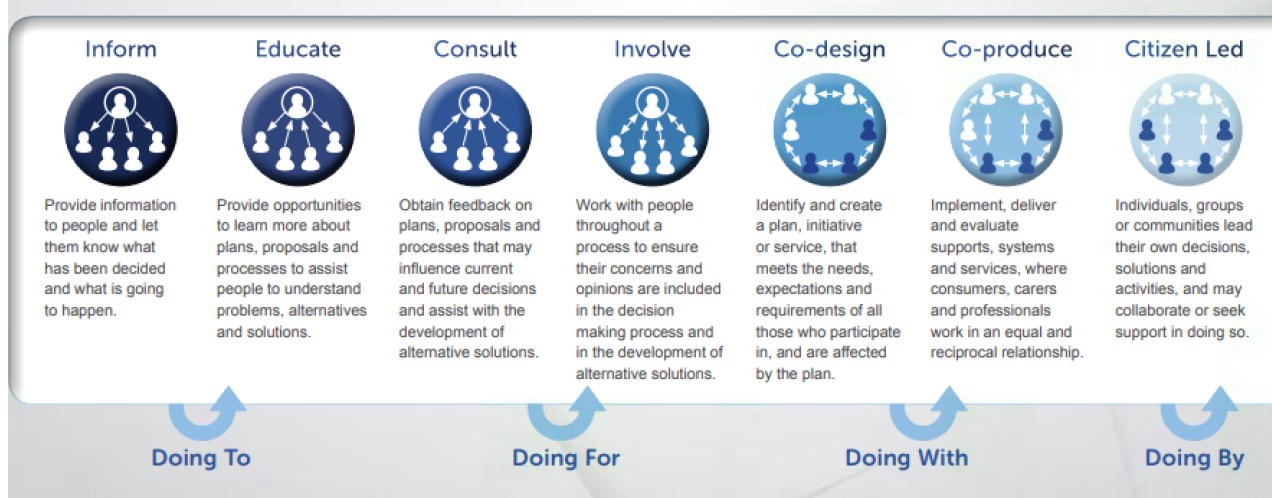
As noted in the last six month's report, Ryan Sengara was Co-Lead with Pip Brennan, the Executive Director of the Health Consumers' Council on Recommendation 4. After he moved to another government department, Ryan was replaced by Dr Theresa Marshall from North Metropolitan Health Service. Initially supported by the Sustainable Health Review Implementation Support Unit, fortnightly meetings were convened with a Working Group. Theresa and Pip Brennan met weekly as Co-Leads as we were keen to see some forward momentum. The Working Group includes membership from NGOs, consumer peaks, carers, Aboriginal health, and peer support groups among others. There has been little extra resourcing for this to date, but it is seen as a key priority for HCC. Every single Recommendation is impacted by Recommendation 4, although the actual lived experience involvement is still in development across all of them.

The initial focus of the Working Group was to ensure the Recommendation on a Page was presented to the SHR Steering Committee for adoption as part of the first 15 Recommendations (known as "Tranche 1"). This has at times seemed to be a somewhat bureaucratic process – a cutting and pasting of what is in the final report into the right template so it can be processed through the Steering Committee and follows a very lengthy period of "internal alignment" which has not appeared to include any

stakeholders outside the health system. A presentation of the Recommendation to the Independent Oversight Committee was undertaken on 24<sup>th</sup> November 2021, with Dr James Williamson, Dr Theresa Marshall and Pip Brennan presenting.

It was noted at this meeting that all Recommendation Leads need a way of reporting on how they are including the lived experience voice in implementing their recommendation. This work will likely sit across both Recommendation Four and Recommendation 30 (Implementation of SHR) – all of this is still being worked through, and a meeting to plan next steps will be held on 17<sup>th</sup> February.

DIAGRAM 5: Types of Engagement Approaches<sup>14</sup>



A short survey was sent out to Recommendation Leads in September 2020, and a summary of the results are attached in full as an Appendix. We asked a question about what resources Recommendation Leads might find useful and received these comments:

- It would be good to see how you are developing your framework / methodology to see what we might learn and change accordingly.
- We will be reaching out to understand what/where existing/future opportunities are to inform and support the work we are undertaking
- It would be great to have more support to discuss involving consumers in the next phase of activity for Rec 8.
- Advice around how to ensure broad, representative, diverse representatives (and how to reach and engage with hard-to-reach or under-represented groups), support with running consumer forums and tools available to run surveys or reach large audiences.
- Yes but this still needs to be worked through. I'm currently in discussions with the CCI team.
- Yes, thank you. I would welcome the opportunity to discuss this with you as it relates to Recommendations 1, 2a, 2b, 3b, 3c and 5.
- Perhaps a guide /ready reckoner as to how to identify the most appropriate consumers for proactive engagement. A standardised approach/framework.
- We have developed a Consumer Engagement Framework with resources for our staff; advice on working with vulnerable and hard to reach communities always welcomed
- finances for consumer participation payment; guidance for consumers and education/support for participation

Another key focus has been to progress discussions on measuring outcomes of engagement, both from the perspective of the lived experience representative and

health service staff. The Mental Health Commission's resource, Working Together has been an important starting point, and work has progressed on digitising a survey to measure engagement process outcomes which appears in the Mental Health Commission Working Together Toolkit <https://www.mhc.wa.gov.au/media/2531/170877-menheac-toolkit-web.pdf>

A copy of these surveys is included in the appendix for reference.

We have also worked with WACOSS to develop a community resource to ensure people are more up to speed with outcomes measurement to assist them in feeling confident that they can provide a lived experience voice confidently in the many discussions that are being had in relation to outcomes measurement.

See the URL for the video here: <https://youtu.be/6lVuz85O-j8> and the PowerPoint is included in the appendix for reference.

### **Recommendation 22 – Digital Health**

As well as Recommendation Four, HCC has been providing support to the Digital Health Recommendation. This has included providing small test groups to review key concepts developed by the Recommendation Lead Judith Stewart, providing a lived experience voice at the ICT Governance workshops and providing general advice about how to ensure the community voice is part of this important project. Negotiations progressed at the end of 2020 for HCC to develop a consumer charter for an Electronic Medical Record, using the Queensland model document as a starting point. Negotiations continued over into the New Year and the project commenced in January 2021.

### **Recommendation 11 – Outpatients**

Recommendation Leads from this well-advanced Recommendation reached out towards the end of 2020 to discuss consumer, carer and community engagement to supplement the work they had done to date. We debriefed the forum that had been convened by EY last year and noted that we would have liked to have seen more impact from this. As 2021 progresses, HCC will continue to be solicited for advice and support as part of the SHR, and also will continue to reach out to all Recommendation Leads to ensure the consumer, carer and community engagement being undertaken is continuing to develop up the rungs of involvement, aiming towards co-design where possible, but at least collaboration (rather than informing or consulting)

## **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:

- WA Department of Health
- Patient Safety Surveillance Unit – consumer feedback about consumer feedback and complaints process
- Sexual Health and Blood Borne Viruses – consumer involvement
- End of Life team – consultations on the Advance Health Directive form with Aboriginal people, people from culturally and linguistically diverse communities, and people with disability
- Health Support Services and WA Department of Health
- National Goals of Care Collaborative
- WACHS and Womens and Newborn Network - My Baby WA app



During this period we also spent time discussing and preparing proposals for the Health Networks Unit relating to their request for HCC support to develop a consumer engagement framework. At the time of writing this project has not been confirmed.

#### Lessons learned from fee for service work

##### *Consumer feedback and complaints*

As mentioned in the last report, 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 was attached last time.

Based on that work, as part of the contract renewal discussions, we would like to propose that Health Consumers' Council host a number of meetings a year and invite the Aboriginal members of community advisory groups and committees to attend. The aim of these sessions would be 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, funding staff time, and funding for venues and catering. We would welcome the involvement of senior staff from the Department of Health in these sessions.

## SECTION 2: OUTCOME PROGRESS REPORT QUALITATIVE FEEDBACK ON OUTCOME MEASURES

### **SERVICE TWO - HEALTH CONSUMER: SECTOR SUPPORT - OUTCOMES**

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

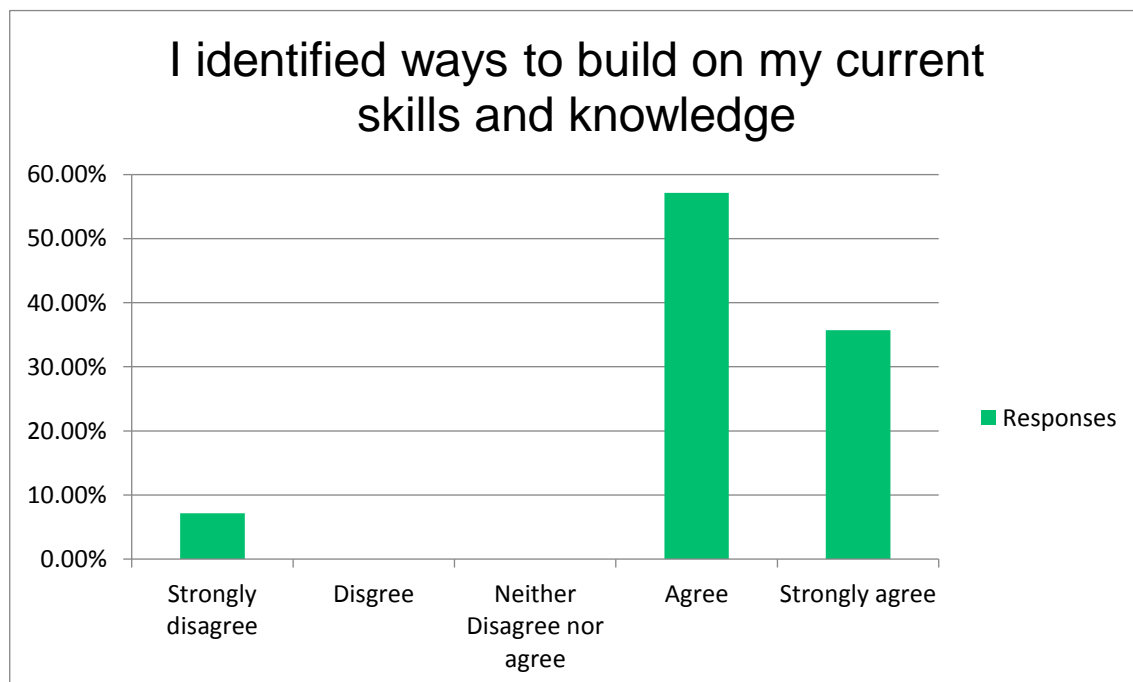
7.1 The extent to which health consumers have the opportunity to be supported and linked to health consumer networks and partnerships in the Western Australian health system.

#### **Workshops for Consumer Representatives**

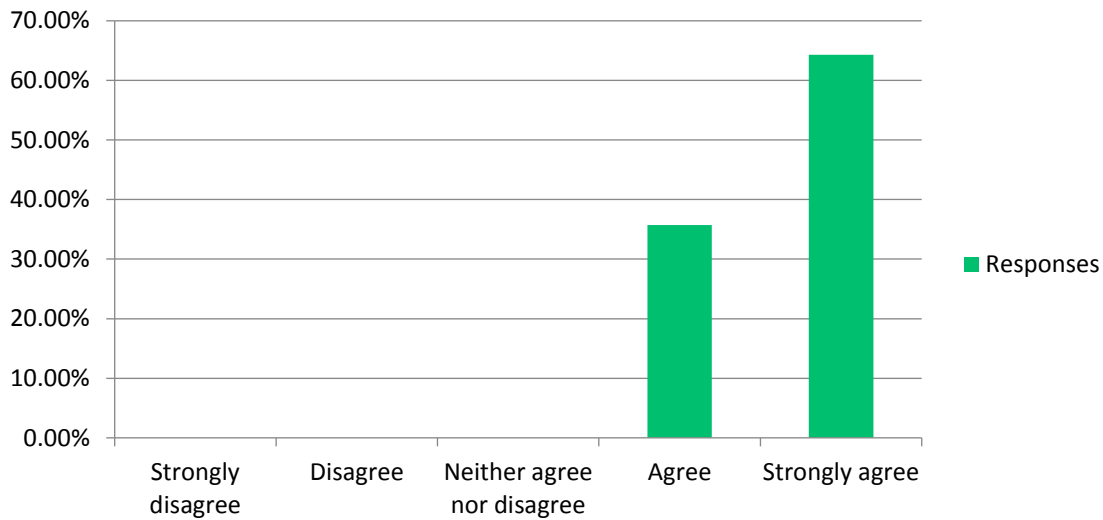
##### **Introduction to consumer representation**

In this period, we ran one Introductory Consumer Representative Training Workshop attended by 15 people, of whom 14 completed the evaluation form.

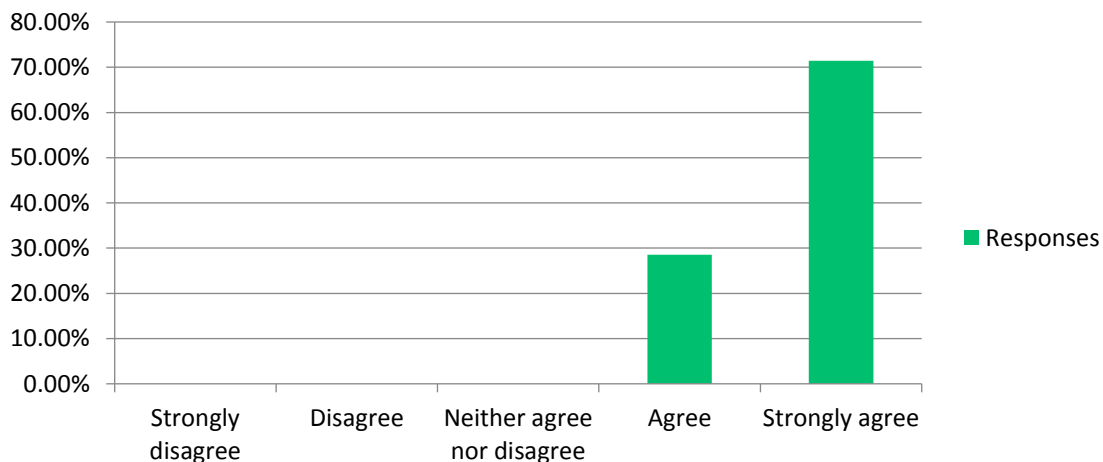
All but one agreed or strongly agreed that they had been supported to build their skills and knowledge by attending the session. All respondents indicated they would recommend this workshop to others and that they will be better able to engage and work effectively in their role.



## I would recommend this workshop to others



## After attending this workshop, I will be better able to engage and work effectively in my role



Some of the things people found most helpful were:

- “Understanding the role of Community Rep and how to be effective in the group.”
- “Interacting with the group throughout the day”
- “Every facet was important and informative”

Some suggestions for improvement or things to include in future courses:

- “Additional Team/Table interactive discussions on areas being explained.”
- “More interactive engagement with participants in the looking after yourself/self-care section”
- “upcoming opportunist [sic] assistance with application process”

Some of the things attendees planned to do differently were:

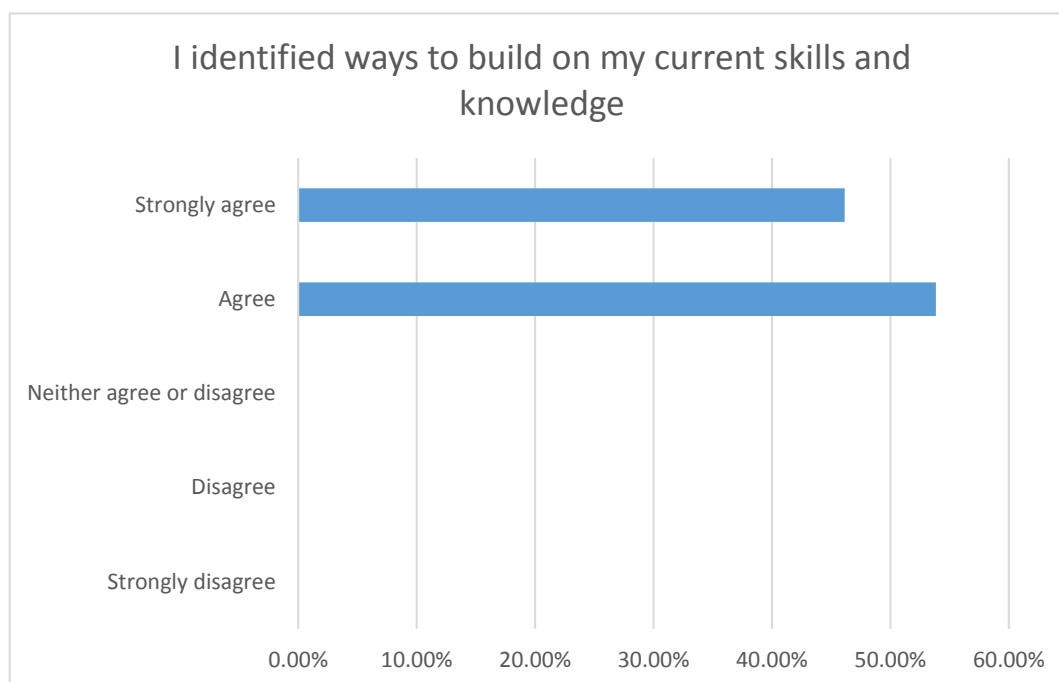
- “Own my lived-experiences more fully. I’ve felt imposter syndrome working in the health space without formal qualifications.”
- “Set boundaries before meeting with others”
- “Set up clear expectations for consumer reps.”

One other comment highlights an opportunity for further promotion of these programs: *“I wish I have been told about this earlier in my consumer rep experience. The health service should tell new consumer reps about the HCC and services available such as this workshop as part of induction and training and compensate people for attending. Thanks - very useful.”*

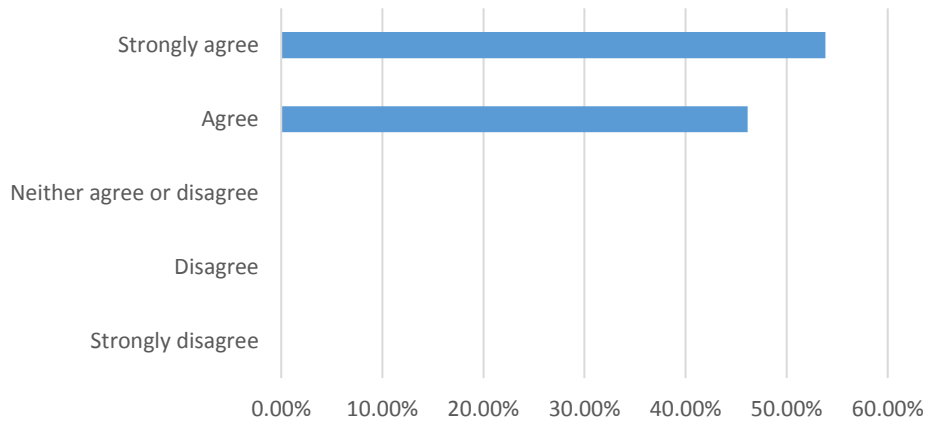
### Advanced Consumer Representation training

In this period, we ran one Advanced Consumer Representation training course attended by 13 people, all of whom completed the evaluation form.

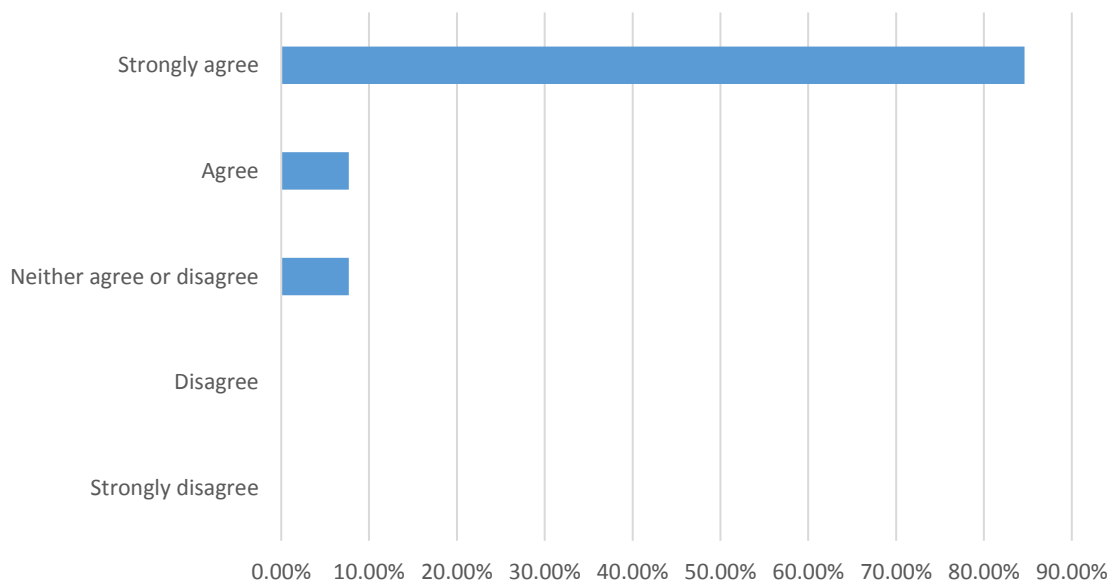
All respondents agreed or strongly agreed that they identified ways to build on their current skills and knowledge, and that that they are better able to engage and work effectively in their role as a result of attending. All but one would recommend this workshop to others.



After attending this workshop I will be better able to engage and work effectively in my role



I would recommend this workshop to others



Some of the things people found most helpful were:

- “meeting others and hearing their experiences”
- “I found a lot of useful resources e.g. definitions/differences between co-design and co-production. I've been after a reference for months!”
- “Levers for change in the WA System”

Suggestions for other content included:

- “I would have been interested in learning specific opportunities to apply for being a consumer rep”
- “Educate committees about how to improve r'ships with Consumer reps.”
- “How we relay information to others - external groups”

We also received one comment about the volume of paper that was used – we will consider how we can offer people the opportunity to access this information online in advance for future sessions, noting that all respondents found the handouts relevant and useful.

Some of the actions people said they would be taking as a result:

- “Might change Committee”
- “Keep up to date with Care Opinion”
- “Run meetings differently”

## Consumer representative networking session

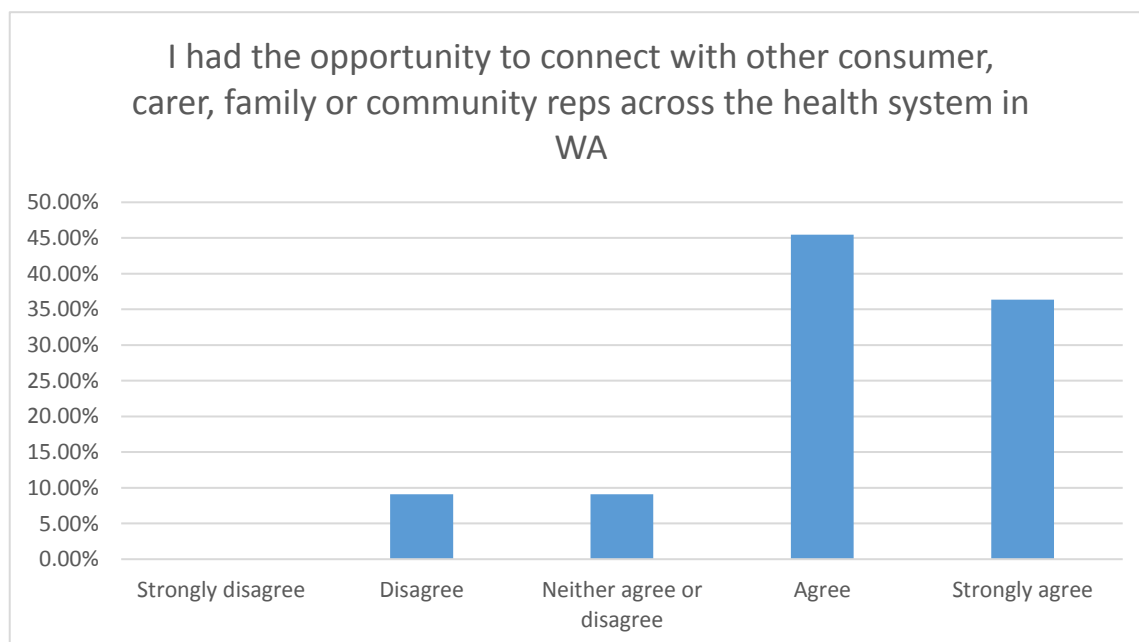
During this period we ran two networking sessions for consumer representatives.

### September 2020

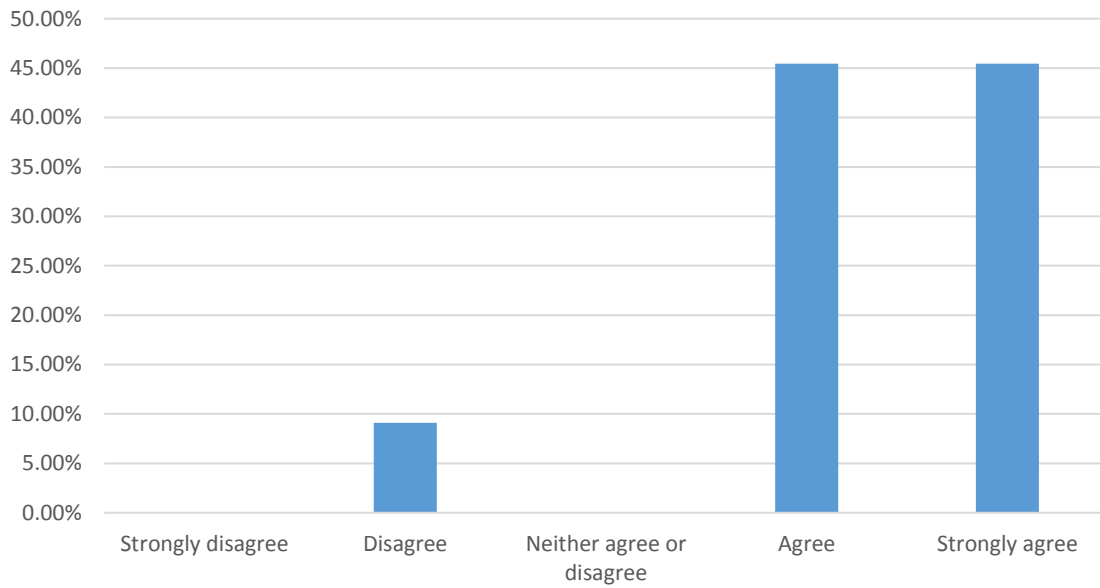
This session focused on the process for consumers giving feedback or making a complaint. This was in response to the feedback from the PSSU workshops that many people didn't give feedback or make a complaint because they were unaware of how to do so. The session was attended by 21 people, of whom 11 completed the evaluation form.

Responses:

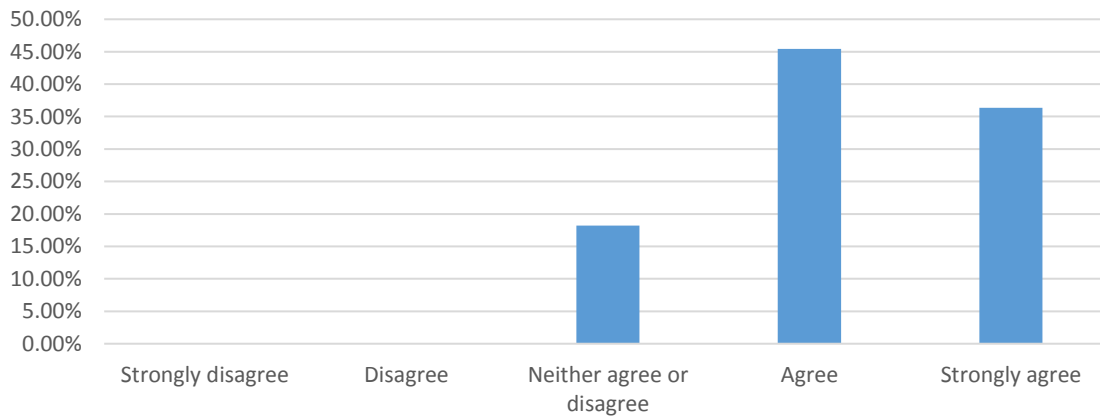
- 81% of respondents agreed or strongly agreed that they had the opportunity to connect with other consumer representatives
- 90% agreed or strongly agreed they learned something they can apply in their role as a rep
- 81% agreed or strongly agreed they had increased their understanding of how consumers can provide feedback or make a complaint
- 90% agreed or strongly agreed that the session was a good use of their time



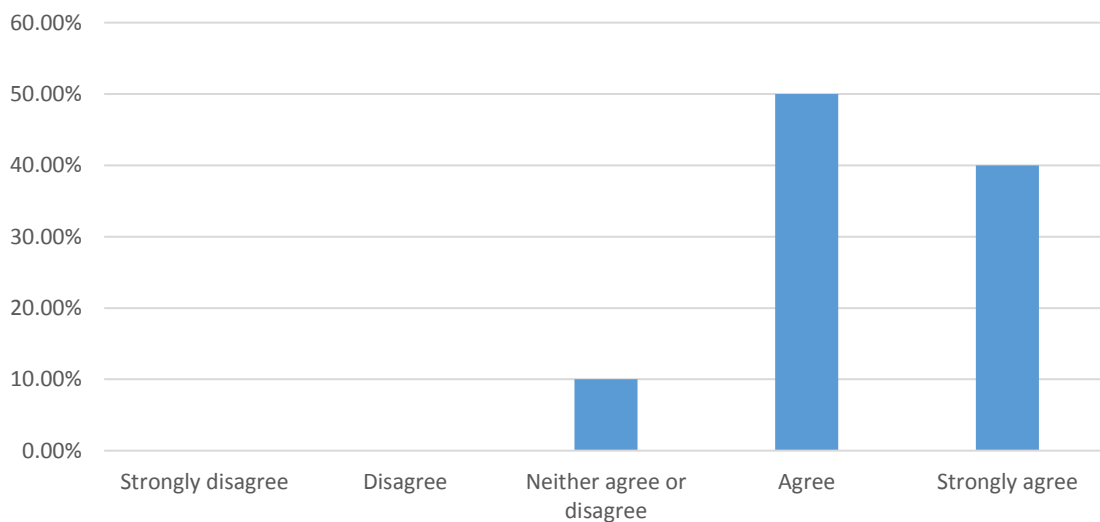
### I learned something I can apply in my role as a rep



### I have increased my understanding of how consumers can provide feedback or make a complaint



### Today's session was a valuable use of my time



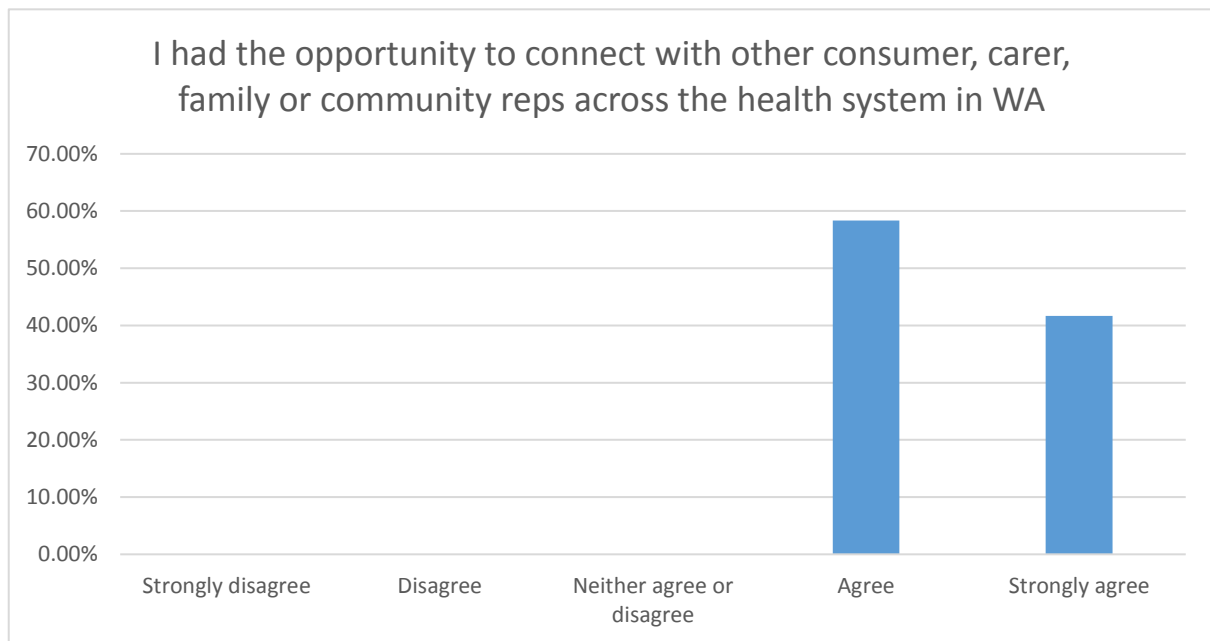
December 2020

For the first time, we offered this session as both an in-person event and a virtual event. One week prior to the event, we were expecting about half the people to attend in person and half virtually. When the event took place, we had 1 external attendee attend in person (alongside HCC staff), with 13 people attending virtually. 13 people completed the evaluation form.

The focus for this session was the Sustainable Health Review and Recommendation 4.

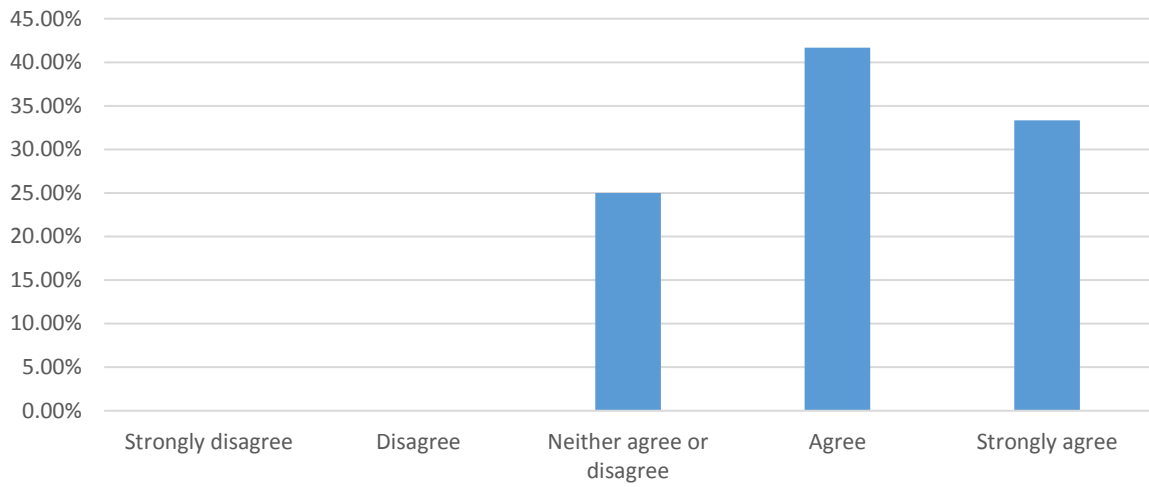
Responses:

- All respondents agreed or strongly agreed they had the opportunity to connect with other representatives
- 75% agreed or strongly agreed they learned something they can apply in their role
- All but one agreed they increased their understanding of the Sustainable Health Review.
- 100% said the session was a valuable use of their time

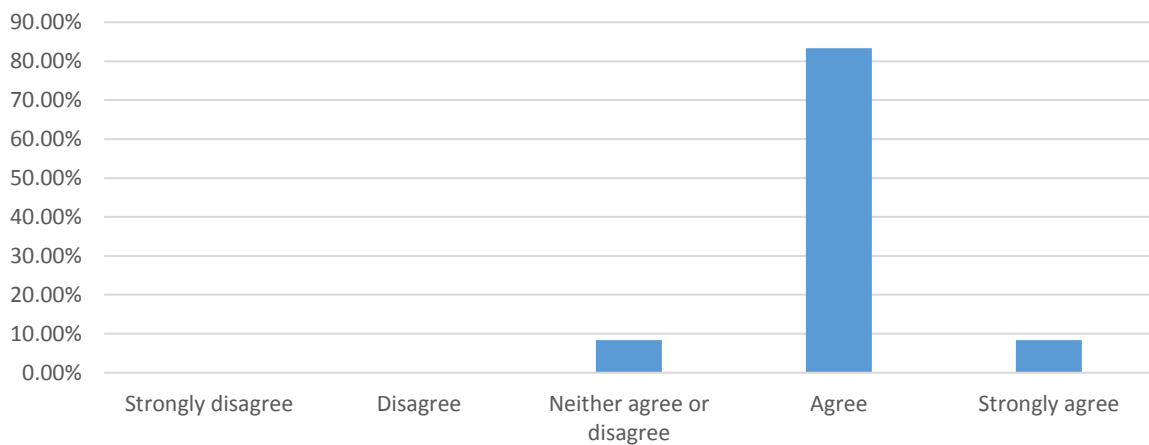




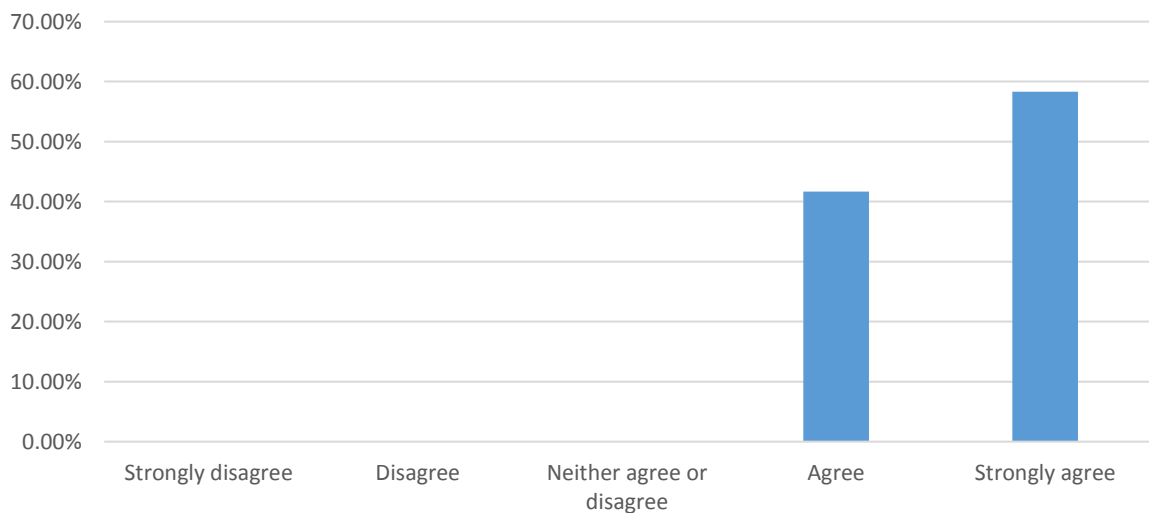
### I learned something I can apply in my role as a rep



### I have increased my understanding of the Sustainable Health Review



### Today's session was a valuable use of my time



## **Cultural Diversity program**

### **Supporting Cultural Diversity in Healthcare Workshops**

We ran this session in December 2020. It was oversubscribed with a waitlist. We took 24 confirmed registrations with 19 attending on the day. The scenarios and group activities were particularly commended in the feedback with very few negative comments but one person (who has a CaLD specific role and has been working in the space many years) found the workshop a little basic and another wanting more practical strategies about how to engage CaLD community.

- 88% agreed or strongly agreed that they had identified ways to build on their current skills and knowledge.
- 88% agreed or strongly agreed that the facilitator was knowledgeable and skilful
- 88% of people said they would recommend this workshop to others.
- 87% of people found the handouts relevant and useful
- 75% of people agreed or strongly agreed that they increased their knowledge and skills and feel more confident about supporting cultural diversity in their workplace.

### **Diversity Dialogues**

In September 2020 we held our first online (webinar format) Diversity Dialogues event on the topic of CaLD communities and telehealth. We partnered with the Digital Health Cooperative Research Centre (DHCRC), based in NSW. The focus was on delivering quality and culturally responsive telehealth services. HCC Executive Director chaired the panel which also consisted of CaLD advocates from the Ethnic Communities Council of WA and Multicultural Services Centre of Western Australia, the Health Services Manager of Ishar Multicultural Womens' Health (based in Mirrabooka), an interpreter and Managing Director of a WA Interpreters, a practising GP and national telehealth expert from NSW.

Over 1300 people registered for the webinar with 153 (11%) of these being from WA (DHCRC has a national reach and public online events in general are not restricted by geographic location). On the day over 650 people attended live (which is expected as many people will register so they get sent the link to the video recording to watch at a later date) with approximately 25% filling in the feedback survey (again the expected response rate). Feedback was 90% positive with the remaining 10% generally commenting around less discussion about interpreters in general and wanting more technical information on delivering telehealth. Some participants felt the conversation went off track, focusing heavily on interpreters and others felt this was relevant as it is a very real issue in dealing with CaLD and in particular there are new issues with the introduction of widespread telehealth. The currency of the topic seemed to be appreciated with respondents commenting the webinar helped them navigate current and real issues. A number of respondents said they would share the recording with their colleagues and more specifically we are aware that the WA Primary Health Alliance shared on their portal, the WA Country Health Service shared on their social media (as part of Telehealth Awareness Week) and Mater Refugee Health Services shared amongst their colleagues and networks (following clarification of discussion around Medicare billing when an interpreter is used).

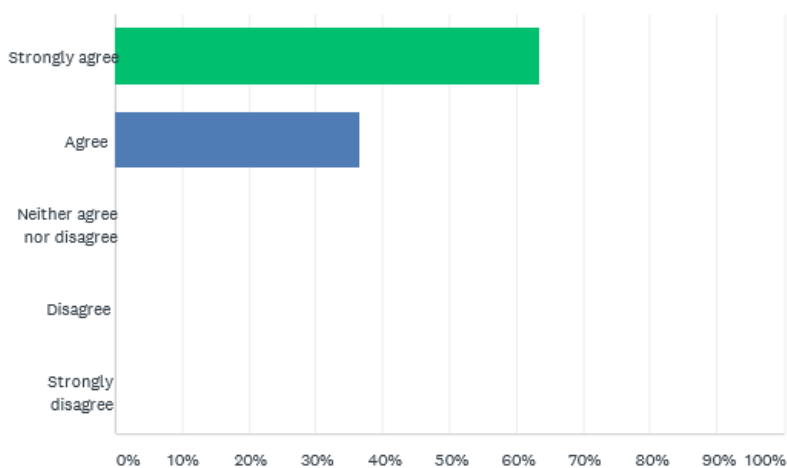
Our second Diversity Dialogue, held in November 2020 was on the topic of CaLD youth mental health. We partnered with Consumers' of Mental Health WA (CoMHWA) for this event and the event was co-chaired by our Cultural Diversity Engagement

Coordinator and a CoMHWA Project Coordinator who focuses on CaLD and is a CaLD young person herself. The panel also consisted of a representative from the Multicultural Youth Advisory Network WA (MYANWA), a CaLD youth mental health advocate and two young people with personal, lived experience of mental health diagnoses and treatment. Our panel discussed some of the complex and unique challenges faced by multicultural youth in Australia in regards to facing mental health issues and navigating diagnoses and treatment and some of the opportunities to overcome barriers were explored.

We had 162 registrations with 76 attendees on the day and 30 feedback survey responses. The survey response of 39% is higher than what we perceive to be normal for a webinar of this nature and it seems people took the time to respond because they wanted to give extremely positive feedback. Some people even emailed feedback directly. 100% of respondents found the webinar to be a valuable use of their time with 73% feeling that they had an increased understanding of the issues around CaLD youth mental health and 63% feeling the webinar would help them in their role.

### Q1 This webinar was a valuable use of my time.

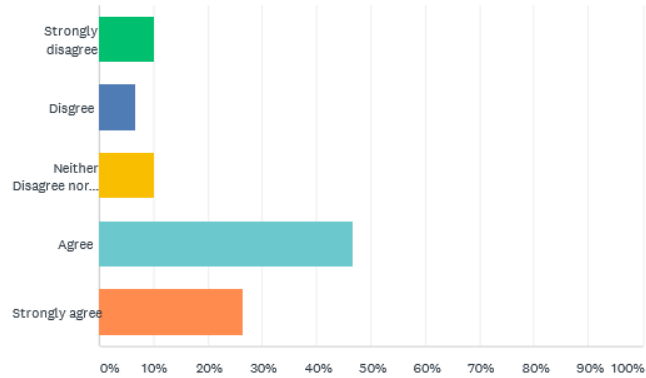
Answered: 30 Skipped: 0



ANSWER CHOICES	RESPONSES	
Strongly agree	63.33%	19
Agree	36.67%	11
Neither agree nor disagree	0.00%	0
Disagree	0.00%	0
Strongly disagree	0.00%	0
<b>TOTAL</b>		<b>30</b>

Q4 After the webinar, my knowledge and understanding of the issues in this space has improved.

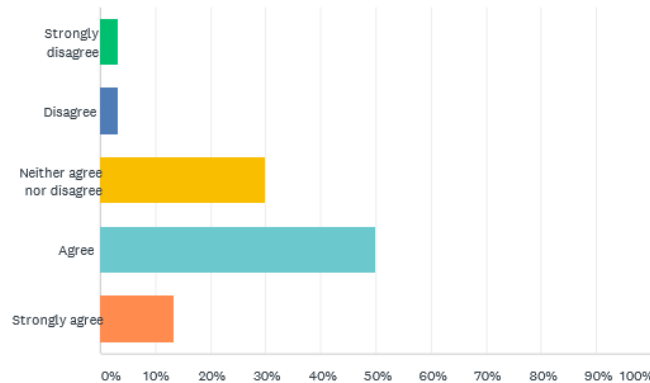
Answered: 30 Skipped: 0



ANSWER CHOICES	RESPONSES
Strongly disagree	10.00% 3
Disagree	6.67% 2
Neither disagree nor agree	10.00% 3
Agree	46.67% 14
Strongly agree	26.67% 8
TOTAL	30

Q8 After attending this webinar, I will be better able to engage and work effectively in my role.

Answered: 30 Skipped: 0



ANSWER CHOICES	RESPONSES
Strongly disagree	3.33% 1
Disagree	3.33% 1
Neither agree nor disagree	30.00% 9
Agree	50.00% 15
Strongly agree	13.33% 4
TOTAL	30

We did not record the event due to the sensitive nature of the discussion and the audience commented how powerful, impactful and useful the lived experience commentary was. 23 respondents (77%) took the time to write a comment about the strength of the panel.

**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.

**Presentations to DoH staff on consumer engagement**

HCC staff were invited to present to participants in the DoH Policy Essentials program

**Sustainable Health Review – New Ways of Engaging with Consumers**

From July 2020 to the end of the year there has been significant activity in the Sustainable Health Review. As noted earlier in the report, with the work we are doing on Recommendation Four we feel we are helping to supporting ongoing improvements in engagement with health consumers in our health policy implementation.

**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. See our separate report for more details of our work in this area as funded by DoH.

**Privacy and information sharing and guardianship**

Further work in this period to unpick the complexities of this area of privacy, information sharing and guardianship included providing input into a joint submission to the Legislation Committee Inquiry into the Guardianship And Administration (Medical Research) Bill 2020 as well as giving evidence to the Standing Committee.

**End of Life**

There is significant work occurring in this area, and an almost bewildering array of documents, forums and meetings to attend Work is

## 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)?

#### **Covid-19**

##### Impact on HCC operations

During this reporting period, we have moved to working in a hybrid model for most staff where people work between home and the office based on operational requirements. In most cases, this has involved staff using their own office and IT equipment at home and HCC's equipment when in the office. We continue to monitor the impact of this new approach.

One key impact is the need to ensure that staff are working safely (from an occupational health and safety point of view) and we were successful in securing a Lotterywest grant to enable us to undertake ergonomic assessments in the office and at home. It is possible that we will need to buy adaptive or new equipment to ensure people are set up to work safely.

##### Impact on engagement activities

We have been experimenting with a move towards a hybrid model of engagement activities – where we offer activities both in person, and virtually. One of our team identified the value of people attending in person using mobile devices to join the virtual meeting – meaning that those joining virtually can still see everyone who is attending in person (rather than the unsatisfying experience of a camera that takes in the whole table, but gives limited opportunity to connect directly with attendees). A couple of comments on this approach from a recent event shows that this is appreciated:

- “It was great. For the first time I didn’t feel only an observer to a large meeting going on.”
- “The experience of using zoom for a meeting with people online and in the room [was the most useful part of the session]. It was done really well and I hope will continue and that the practice will spread. Thanks for leading the way!”

This approach does require extra resource allocation from the organisation, but the benefits of enabling participation by people who may not otherwise be able to connect mean that investment is essential.

We will continue to experiment with this approach in the coming year.

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).

Our key focus as a health consumer body is to ensure that the intent of the Sustainable Health Review is implemented. In particular we will focus our efforts on **Enduring Strategy 1/Recommendation 4** relating to new models of citizen and community partnership. We believe this impact all Recommendations and are a key enabler for implementation success. As we move into 2021, discussions about resourcing to support implementation will provide greater clarity about HCC's actual role and real opportunity to influence positive change in our health system.

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 understand that there is an intention to combine the Consumer and Community Involvement Program (CCIP) with HCC's Engagement and Systemic Advocacy Activities from July 1 2021. CCIP has sat under WA Health Translation Network and it will take some time to ensure a smooth transition and an opportunity to leverage the synergies in what we both already do, and identify a cohesive strategy going forward. Given that our contract with WA Health goes until 31<sup>st</sup> December 2021, there is an opportunity to have a six month interim funding agreement in place to integrate CCIP and HCC activities over this period, and then include the agreed format in the new contract.

We would also like to explore alternative options to extend our reach and discontinue the quarterly publication of Health Matters. This is due to the relatively low levels of engagement with it and the fact that we are already doing a monthly e-news. Instead we would like to move to creating and distributing content in different ways, e.g. through blog posts (we could consider re-launching our blog as Health Matters and include posts in the e-news) and other opportunities such as Instagram stories, Op Ed pieces and stories (the West Australian and local newspapers, as well as other health consumer-focused publications, are a key opportunity) We believe we will be better able to get our content to the right audience and will be able to use our slim resources more effectively.

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. Depending on how much staff time could be allocated to this, this role could also provide support to enable us to host interns and students on placement. We would aim to include this in the new contract, and see if we can trial this in the interim period.