Consumer Representatives Program Review: 2019 - 2023

December 2023

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About HCCA

The Health Care Consumers' Association (HCCA) is a health promotion agency and the peak consumer advocacy organisation in the Canberra region. HCCA provides a voice for consumers on local health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- consumer representation and consumer and community consultations
- training in health rights and navigating the health system
- community forums and information sessions about health services; and
- research into consumer experience of human services.

HCCA is committed to consumer-centred care as a foundation principle in all its work and to promoting consumer-centred care across the health system, within government and across the ACT community. Consumer-cantered care meets the physical, emotional, and psychological needs of consumers, and is responsive to someone's unique circumstances and goals.[1]

Acknowledgements

The Health Care Consumers' Association (HCCA) thanks all the health service representatives and consumer representatives shared their insights on and experiences for this review.

Our work is collaborative and benefits from the contribution of our members and staff. We extend appreciation to those who continually contribute their experiences, concerns, and vision for the future of health services.

HCCA also thanks the members of the HCCA Consumer Participation Committee who provided valuable guidance and advice on this work. They are Sue Andrews, Alan Thomas, Linda Trompf, Lou Bannister, and Miram Pavic.

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Executive Summary

Overview

This Report shares findings from a 2023 internal review of the HCCA Consumer Representatives Program. It draws on a context scan, literature review, analysis of implementation of recommendations from past Program reviews, and interviews (n = 15) as well as surveys of consumer representatives (n = 24, a 66% response rate) and committee Chairs and Secretariats (n = 24, a 38% response rate).

The Report finds that at almost 25 years since establishment, the Consumer Representatives Program (CRP) is a mature, impactful, and well-regarded program.

Key strengths include:

- Consumer representatives report very high levels of satisfaction with the CRP.
- The CRP enjoys a reputation among health services and other requesting agencies for providing capable and knowledgeable consumer representatives.
- Consumer representatives, Chairs and Secretariats value the administrative and practical support the CRP provides.
- Consumer representatives, Chairs and Secretariats identify a range of tangible impacts that consumer representatives have on committee decisions and processes.
- The CRP supports consumers and health professionals to build relationships for consumer partnership, and to learn and gain skills and confidence in this area.

The CRP contributes to quality improvement and change in health care by delivering:

- *Process outcomes* (e.g. better design of health service initiatives and buildings)
- *Community outcomes* (e.g. audience-relevant consumer information resources, which in turn enable better community health literacy)
- *Partnership outcomes* (e.g. Chairs', Secretariats', and consumer representatives' satisfaction with the quality of consumer partnerships)
- *Empowerment outcomes* (e.g. for consumer representatives who develop knowledge and skills in consumer advocacy).[2]

These four areas are recognised as key impact measures for consumer participation programs. The CRP is making a positive difference in each of them.

The issues that limit participating consumer representatives' satisfaction with the CRP are related to the *variable quality of opportunities to participate* offered by health services and other requesting agencies. For consumer representatives, the issues include:

- Perceived tendency toward tokenistic engagement by some services, Chairs, and committees,
- Frustration with the slow pace of quality improvement and policy change, and
- The inherent limitations of committee processes.

These issues can lead to a sense of disillusionment for consumer representatives. Other challenges include:

- The difficulty of influencing health service processes and decisions as a sole consumer member of a committee.
- Variable quality administrative and secretariat support provided by health services and other requesting agencies.
- The shift to remote committee meetings during COVID-19, which has limited opportunities for committees to develop strong working relationships with consumer members.

Health services' and professionals' variable understandings and expectations of consumer representation presents additional challenges. In addition, requesting agencies appear to be seeking quite distinct consumer perspectives from the CRP, including:

- People with recent lived experience of specific services or health issues, and
- Highly skilled consumer representatives able to bring a broad understanding of consumer issues in health care along with negotiation and advocacy skills.

While this suggests a positive interest in diverse approaches to participation, the CRP may have a role to play in assisting health service personnel to clarify the aims of consumer participation in their specific areas, committees, and projects; and their expectations of the skills, knowledge, and contribution of consumer representatives.

There are also opportunities for the CRP to:

- Continue to deepen diversity in the pool of people taking on consumer representative roles, and
- Work with health service areas and leaders that want to implement good practice consumer participation, to identify and roll out models that are best suited to their specific needs – this should include considering how the CRP and consumers contributing to committees can connect with other approaches (for example time-limited consumer engagement opportunities) to ensure the strongest possible consumer contribution.

HCCA's recent experiences of partnering with health services to support project-specific consumer advisory groups (e.g. in the Canberra Health Expansion Project and Paediatric Liaison and Navigation Service) are a promising model for wider use within health services.

Finally, there may be opportunities for Consumer Representatives to learn more about some aspects of health service delivery, including through enhanced induction and/or training.

Recommendations

The Review's recommendations relate to three areas: CRP program development and promotion, CRP planning and risk management, and supporting health service capacity to work with consumer representatives.

2.1 CRP Development and Promotion

It is recommended that HCCA consider how best to:

Promote the CRP to health service personnel, including providing information about:

the HCCA nomination process

HCCA resources for consumer representatives, Chairs and Secretariats, and

the opportunity to partner with HCCA on a range of approaches and methods for consumer and community participation.

Support requesting agencies to develop their understanding of consumer representation and the role/s of consumer representatives. Capacity allowing, this could take the form of training or resources for professionals. This should include information about the distinction between consumers with recent or current lived experience, and consumer representatives with skills in consumer advocacy.

Continue to attract people drawn from diverse backgrounds, and with a diverse range of health experiences, to participate in the CRP, through promotion and engagement with diverse communities and consumers.

Respond to the interest from some health service areas in securing participation from people with recent lived experiences of specific services. This may require a decision from HCCA about whether it is appropriate to work with health services to meet this demand in some circumstances, for example a service might advertise and/or recruit and HCCCA then train and/ or support participants – noting these roles may be mutually exclusive in an approach that aims to recognise and minimise risks to participants.[3]

Communicate to requesting agencies (in particular health service partners) HCCA's approach to supporting renewal in consumer representative nominations, while recognising and promoting the benefits of working with experienced consumer representatives.

Provide informal face-to-face networking opportunities for consumer representatives, and opportunities to discuss specific issues and challenges in consumer representation.

2.2 CRP Quality Improvement and Risk Management

The Review identifies some issues for consideration in CRP planning, quality improvement, and risk management. These include the need for:

a) Regular meetings with key personnel in all requesting agencies to understand and, where possible, influence requesting organisations' future planning in relation to committees, and consumer participation and representation.
b) Identification of any requesting agencies, and/or areas within agencies, where the CRP and HCCA would like to increase participation of consumer representatives on committees.
c) In light of increasing requests for consumer participation in infrastructure projects and university research projects, consider whether these new foci

require bespoke approaches to consumer representation – and if so, whether the CRP has capacity to provide these.

2.3 Health service capacity

The Review also identifies a continued need for the CRP to work with health service partners to build their capacity to provide:

d) Consistently high-quality secretariat support, including clear reimbursement processes.
e) High-quality induction for consumer representatives, and committee-specific training (e.g. in models of care, roles in interdisciplinary team care and budget development).

Capacity allowing, the CRP could provide resources, advice, or training in this area, including working collaboratively with health services to provide training on the specific matters at recommendation **K**).

Consumer Representatives Program Review

1. Introduction

This report shares learning from an internal review of the Health Care Consumers' Association's Consumer Representatives Program (CRP), conducted between June and November 2023. This is the first full review of the CRP since 2012. The review's overarching aim is to identify strengths and areas for improvement for this long-standing program, which will reach a landmark 25 years since establishment in 2024. Subsidiary aims of the Review include ensuring that the CRP:

- Continues to reflect contemporary good practice in consumer participation and representation; and
- Is well-placed to support consumer participation in health decision-making in the ACT into the future.

The Health Care Consumers' Association (HCCA) is the peak health consumer organisation in the ACT. HCCA has supported consumer participation in health policy, planning and service decision-making for over 40 years, and is among the longest continuously operating health consumer organisations in Australia.[4] The Consumer Representatives Program (CRP) is a cornerstone of HCCA's approach to community and consumer participation. Through the CRP, HCCA recruits, trains, and supports Consumer Representatives participating in health-related committees and other consultative fora.

A Consumer Representative is a community member who is endorsed by HCCA to represent the views and interests of health consumers, as a member of a committee or similar group.[5] Consumer Representatives have experience as consumers of health services, and they commit to being well-informed about relevant health issues and representing a broad range of consumer views by ensuring they are accountable to HCCA or other community groups to which they are connected.[6]

This report includes key information about:

- The context in which the CRP Review takes place
- Methodology
- Findings
- Recommendations

The Attachments to this Summary provide more information about each of these areas. The Attachments are:

- Attachment 1: Methodology
- Attachment 2: Context
- Attachment 3: Implementation of Recommendations from Past Reviews
- Attachment 4: Findings from interviews and surveys

2. Methodology

2.1. Aims

This Review aims to identify strengths, and areas for improvement, for the Consumer Representatives Program. This includes:

- Documenting the experience of consumer representatives in working with health services, and identifying examples of good practice and aspects for improvement.
- Documenting examples of how consumer representatives influence policy, service design and the ongoing delivery of care.
- Assessing the extent to which HCCA members and consumer representatives feel the Consumer Representatives Program is meeting its objectives.
- Determining the level of satisfaction of health services and policy makers with HCCA consumer representation.
- Reviewing consumer representation in the context of contemporary approaches to consumer engagement.

2.2. Methods

The methods for the review included:

- A literature and practice scan to identify relevant emerging trends in consumer representation and participation.
- Reviewing achievement against the recommendations of the 2012 review of the Consumer Representatives Program, and 2017 Review of Consumer Representatives Training.
- Surveys of HCCA-nominated Consumer Representatives, and committee Chairs and Secretariat service providers.
- Semi-structured interviews with consumer representatives and health service representatives (Chairs and Secretariats)
- Incorporation of findings from a current HCCA project exploring consumer experiences of contributing to the Canberra Hospital Expansion Program (CHEP).
- Advice and feedback from the HCCA Consumer Participation Committee (CPP) on emerging findings and a draft of the report. The CPP provides consumer oversight of the Consumer Representation Program.

See **Attachment 1** for more detail about the Review methodology.

3. Context

3.1. Health service context

The context in which the Program operates has changed significantly since past reviews of the Program, particularly since the last full Program review in 2012. There have been substantial changes in the ACT health system, including the separation of the ACT Health Directorate and Canberra Health Services in 2018. The National

Quality and Safety Health Service Standards (NQSHSS) *Standard 2 – Partnering with Consumers* was introduced in 2013, requiring all public and private hospitals and many other health services to report how they involve consumers in service-level decision-making and governance for safety and quality, as a condition of accreditation. Professional standards and codes of conduct for many health professions – medical, nursing, and allied health – position consumer partnership as core professional competencies. It is fair to say that consumer participation is now an accepted feature of health service governance and decision-making – though not without continued contention about how best to approach this work or measure its impact (see 3.2 and 3.3).

The COVID-19 pandemic has also altered the context in which the CRP operates. Among the impacts of COVID-19 that affect committee work, as reported by Consumer Representatives who participated in this Review:

- Some health service committees not directly related to the pandemic entered an extended hiatus, as health system resources were diverted to the COVID-19 response at its peak in 2020-21.
- The shift toward remote/online committee meetings (introduced from necessity in response to social distancing requirements) has become standard practice – with positive and negative impacts (which are explored at Section 3.1 in **Attachment 4**).
- High turnover among health service personnel involved in committees and provision of secretariat services may have been amplified by workforce and health system resourcing challenges associated with COVID-19.

3.2. Contemporary approaches to consumer participation

Approaches to consumer representation and participation continue to evolve, though core principles and practices remain consistent. Recent trends in consumer participation, which shape the context in which the CRP operates, include:

- An increasing expectation (including from accrediting and funding agencies) that consumer partnership is core business for health services, and for organisations conducting health research.[7]
- Increasing consumer expectations of non-tokenistic and authentic approaches to participation.[8]
- Growing diversity in the approaches and methods for consumer participation available to agencies.
- Recognition in mental health, aged care, and welfare policy (among other areas) that elevating consumers' and carers' lived experiences can assist in re-orienting services and systems toward rights-based and consumer-centred approaches.[9]
- Criticism that representational models of consumer participation are limited in the extent to which they can meaningfully reflect diverse consumer experiences and perspectives.[10]

In this context it is important to consider whether the CRP's approach continues to reflect good practice, and what changes may be required to ensure the CRP remains

well-placed to influence health services and policy in the ACT in coming years. The findings outlined below speak directly to these issues.

3.3. The CRP and HCCA's approach to consumer participation

Reflecting wider changes in approaches to consumer participation described at 3.2 above, HCCA's approach to consumer and community participation has also continued to evolve since past reviews of the CRP. Consistent with the principles outlined in the HCCA Consumer and Community Participation Framework,[11] the CRP sits at the centre of a program that also includes:

- Community consultations and forums on health matters.
- Training in health rights and navigating the health system.
- Information sessions about health services, and
- Advocating on issues of concern to consumers.[12]

Of particular note for this Review, in recent years HCCA has increasingly worked with health service partners to support consumer participation in Consumer Advisory Groups for specific time-limited projects. In this model, HCCA leverages its relationships with consumers and community groups to assemble an advisory group that may comprise HCCA members or non-members, with members bringing lived experience and/or expertise developed through involvement in community organisations (as staff or members). HCCA's role is to lead and support the group and the health service project team intensively and over the life of the project, to deliver consumer expertise to complex multi-year projects. In this role HCCA will:

- advise the health service partner about appropriate participation mechanisms and provide genuine, meaningful participation opportunities.
- follow up any issues, both practical matters such as reimbursement, and advocacy actions resulting from consumer input.
- ensure that advice from the consumer group is accurately recorded, tracked and actioned.

This model has been used in two recent projects:

- the Canberra Hospital Expansion Project, led by Major Projects Canberra – where consumer advice has had tangible impacts on decisions about the design of new health facilities.
- The co-design of the CHS Paediatric Liaison and Navigation Service – where the consumer advisory group jointly participated in the design of this new service together with health service staff.

HCCA monitoring and evaluation of these projects indicates positive experiences for participating consumers and health service personnel, and identifiable, positive consumer-led impacts on the projects.

There is more information about the issues covered in this section in **Attachment 2**. Review Recommendations about **Quality Improvement and Risk Management** relate to the issues covered in this section.

The positive experience of the Canberra Hospital Expansion Project and Paediatric Liaison and Navigation Service co-design project inform the Recommendations related to potential development of future CRP offerings (including Recommendations **A** and **D**).

4. Findings

5. Recommendations

This section lists the Review's recommendations. These are organised into three areas:

- CRP program development and promotion opportunities.
- Issues for consideration through CRP processes for risk management and reporting.
- Recommendations for agencies that request consumer representatives.

5.1. CRP Development and Promotion

It is recommended that HCCA consider how best to:

a) Promote the CRP to health service personnel, including providing information about:
   i) the HCCA nomination process,
   ii) HCCA resources for consumer representatives, Chairs and Secretariats,
   iii) the opportunity to partner with HCCA on a range of approaches and methods for consumer and community participation.

The Review identified these as areas where health service personnel have varied levels of knowledge. Efforts to increase awareness in these areas are particularly important given the turn-over of staff in key roles responsible for consumer participation, both at strategic/leadership level and roles responsible for secretariat services.

It is also recommended that HCCA consider how best to:

b) Support requesting agencies to develop their understanding of consumer representation and the role/s of consumer representatives. Capacity allowing, this could take the form of training or resources for professionals. This should include information about the distinction between consumers with recent or current lived experience, and consumer representatives with skills in consumer advocacy.
c) Continue to attract people drawn from diverse backgrounds, and with a diverse range of health experiences, to participate in the CRP, through promotion and engagement with diverse communities and consumers.
d) Respond to the interest from some health service areas in securing participation from people with recent lived experiences of specific services. This may require a decision from HCCA about whether it is appropriate to work with health services to meet this demand in some circumstances. For

example, a service might advertise and/or recruit and HCCA then train and/ or support participants – noting these roles may be mutually exclusive in an approach that aims to recognise and minimise risks to participants.[16]

e) Communicate to requesting agencies (in particular, to health service partners) HCCA's approach to supporting renewal in consumer representative nominations, while recognising and promoting the benefits of working with experienced consumer representatives.
f) Provide informal face-to-face networking opportunities for consumer representatives, and opportunities to discuss specific issues and challenges in consumer representation.

5.2. CRP Quality Improvement and Risk Management

The Review identifies some issues for consideration in CRP planning, quality improvement, and risk management. These include the need for:

g) Regular meetings with key personnel in all requesting agencies to understand and, where possible, influence requesting organisations' future planning in relation to committees, and consumer participation and representation.
h) Identification of any requesting agencies, and/or areas within agencies, where the CRP and HCCA would like to increase participation of consumer representatives on committees.
i) In light of increasing requests for consumer participation in infrastructure projects and university research projects, consideration of whether these new foci require bespoke approaches to consumer representation – and if so, whether the CRP has capacity to provide these.

5.3. Health service capacity

The Review also identifies a continued need for the CRP to work with health service partners to build their capacity to provide:

j) Consistently high-quality secretariat support, including clear reimbursement processes.
k) High-quality induction for consumer representatives, and committee-specific training (e.g. in models of care, roles in interdisciplinary team care and budget development).

Capacity allowing, the CRP could provide resources, advice or training in this area, including working collaboratively with health services to provide training on the specific matters regarding Recommendation **K**.

Attachment 1: Methodology

This document provides information about the approach taken to the 2023 internal review of the HCCA Consumer Representatives Program.

1. Aims

The aim of the review is to assess strengths and weaknesses and identify areas of improvement for the Program. This includes:

- Reviewing achievement against the recommendations of the 2012 external review of the Consumer Representatives Program, and 2017 internal review of Consumer Representatives Training.
- Documenting the experience of consumer representatives in working with health services and identifying examples of good practice and aspects for improvement.
- Documenting examples of how consumer representatives influence policy, service design and ongoing delivery of care.
- Assessing the extent to which HCCA members and consumer representatives feel the Consumer Representatives Program is meeting its objectives.
- Determining the level of satisfaction of health services and policy makers with HCCA consumer representation.
- Reviewing consumer representation in the context of contemporary approaches to consumer engagement

Areas which are explicitly out of scope are:

- The performance of HCCA staff.
- Challenges in recruitment to volunteer roles.

2. Method

This is a multi-method project. The stages of work were:

- A literature and practice scan to identify relevant emerging trends in consumer representation and participation.
- Reviewing achievement against the recommendations of the 2012 external review of the Consumer Representatives Program, and 2017 internal review of Consumer Representatives Training
- Surveys of HCCA-nominated consumer representatives, and committee Chairs and Secretariat service providers, currently working with consumer representatives.
- Semi-structured interviews with consumer representatives and health service representatives (Chairs and Secretariats)

- Inclusion of findings from current HCCA research exploring consumer experiences of contributing to the Canberra Hospital Expansion Program (CHEP).
- Advice and feedback from the HCCA Consumer Participation Committee (CPC) on emerging findings and a draft of the report. The CPC provides consumer oversight of the Consumer Representation Program.

3. Literature and practice scan

The literature and practice scan at Attachment 2 reports on findings of a rapid review of academic literature; and an environmental scan of practice-related resources produced by consumer organisations, health services, research agencies and others.

The search strategy involved a search of the PLOS One and MedLine online databases to identify publications with the following criteria:

- Systematic reviews and reviews of the state of practice/theory OR examples of innovative practice.
- Published since 2012 (the date of the most recent full external review of the CRP), and preferably within the last five years.
- Published in or about an Australian setting, or directly relevant to the Australian context.

Additional relevant articles were identified through review of citations in publications meeting these criteria.

The following search terms were used: Consumer/Community Participation (in) Health*; Consumer Representation (in) Health*; Community/Consumer Involvement (in) Health*; Public Participation (in) Health*; Consumer Engagement (in) Health; Consumer Representatives; Lived Experience (in) Health*; Lived Experience; Living Experience.

Examples of practice frameworks, policies and procedures related to consumer participation and representation were sourced through a targeted internet search of Australian health consumer organisations, state and territory government health departments, and key agencies with well-established consumer representation and participation programs, including the West Australian Health Translation Network which curates a comprehensive resource bank related to Consumer and Community Involvement[17].

4. Surveys

Two surveys were circulated in August 2023, one for consumer representatives and one for Committee Chairs and Secretariat members. The surveys were developed with advice from the HCCA Consumer Participation Committee and the HCCA Consumer and Community Participation (CCP) staff team, who provided feedback on draft of the surveys. The surveys covered the following topics:

- overall satisfaction with the CRP
- satisfaction with the support provided by the CRP.
- satisfaction with the contribution, knowledge, and skills of Consumer Representatives (for Chairs and Secretariat providers)
- satisfaction with the support provided by Chairs and Secretariats (for Consumer Representatives)
- impact and influence of consumer representatives
- perceived extent to which the CRP is meeting its goals.

The HCCA CCP team provided a list of current Chairs and Secretariats, and consumer representatives, with which the survey was shared.

The survey for consumers achieved a 66% response rate (24 individuals), while the survey for health professionals and researchers (Chairs and committee Secretariats) achieved a 38% response rate (24 individuals). This is within expected tolerance for survey response rates. While the overall numbers of respondents are low, there were clear trends in responses and strong congruence with interview findings and with key themes identified in the literature and practice scan. Therefore, while findings can be interpreted with confidence it is important to note that the discussion in this report may overemphasise the importance of some views which were expressed by a small number of respondents (particularly where these views depart from the majority experience). This is noted, where applicable, in the Report.

5. Interviews

Interviews were conducted using a semi-structured interview guide, developed with advice from the HCCA Consumer Participation Committee and HCCA Consumer and Community Participation team. The guide covered:

- overall experience of the CRP,
- impact of consumer representatives
- challenges
- reflections on possible changes or future opportunities for consumer representation and participation.

The issues covered, and prompting questions, were similar for consumer representatives and for Chairs and Secretariat service providers.

The HCCA Consumer and Community Participation team provided a list of consumer representatives, and Chairs and Secretariat providers, to invite to participate in interview. Most interviews took around 30 minutes; some lasting up to one hour. Fifteen interviews were conducted: 8 with consumer representatives and 7 with Chairs (5) and Secretariat providers (2). Interview and survey data were thematically analysed, with a focus on identifying issues that were consistent across both datasets.

6. Consumer Participation Committee (CPC) review

The HCCA CPC provided advice on initial findings from surveys and interviews in August 2023. This advice assisted in refining key themes presented in this report and developing the recommendations. The CPC considered a draft report in October 2023, and a final draft in November 2023, to assist in finalising this Report and its recommendations.

Attachment 2: Context

1. Introduction

This document describes the context in which the HCCA Consumer Representatives Program (CRP) operates. It was produced as part of the 2023 internal review of the CRP. It provides information about:

- The Health Care Consumers' Association, and the Consumer Representatives Program.
- The status of implementation of recommendations from past reviews of the Program.
- The broader context for consumer and community participation, including evidence for the impact of consumer representation programs and emerging issues in consumer representation.

2. Context

This section provides a brief background on the Health Care Consumers' Association, and the Consumer Representatives Program.

2.1 HCCA and Consumer Participation

The Health Care Consumers' is the ACT peak organisation for health care consumers. It is one of Australia's longest continually operating organisations of health care consumers, first incorporated in 1978. Like most health consumer organisations, HCCA emerged from an activist tradition of collective action for health care reform, founded in the view that access to affordable, timely, appropriate health care is a right of all people.[18]

The Consumer Representatives Program is a core component of HCCA's approach to consumer and community participation. It sits at the centre of a program of work that also includes:

- Community consultations and forums on health matters
- Training in health rights and navigating the health system.
- Information sessions about health services and
- Advocating on issues of concern to consumers.

HCCA also involves consumers in policy development, and provides health literacy education and training for consumers, health professionals and community sector workers. In addition, HCCA supports consumer participation in co-design and quality improvement projects, evaluation and research projects undertaken under contract, and training and education activities for future health professionals. HCCA takes a community development approach to consumer empowerment and community participation, with the aim of reducing health inequities.[19] The connection between the CRP and other approaches to consumer participation supported by HCCA is set out in the HCCA Consumer and Community Participation Framework.[20]

Of particular note for this Review, in recent years HCCA has increasingly worked with health service partners to support consumer participation in Consumer Advisory Groups for specific time-limited projects. In this model, HCCA leverages its relationships with consumers and community groups to assemble an advisory group that may comprise HCCA members or non-members, with members bringing lived experience and/or expertise developed through involvement in community organisations (as staff or members). HCCA's role is to lead and support the group and the health service project team intensively, to bring consumer expertise to complex multi-year projects. In this role HCCA will:

- advise the health service partner about best practice consumer participation.
- follow up any issues, both practical matters such as reimbursement, and advocacy actions.
- ensure that advice from the consumer group is accurately recorded, tracked and actioned.

This model has been used in two recent projects:

- the Canberra Hospital Expansion Project, led by Major Projects Canberra – where consumer advice has had practical impacts on decisions about the design of new facilities.
- The co-design of the CHS Paediatric Liaison and Navigation Service – where the consumer advisory group participated jointly with health service staff in the design of this new service.

HCCA internal monitoring and evaluation of these approaches indicates positive experiences for participating consumers and health service personnel, and positive impacts on outcomes of these projects. Benefits of this approach include:

- The impact of consumer participation in the project is able to be tracked, and particularly in the case of infrastructure, is easily identifiable.
- Because the group composition is largely consumer representatives and consumer organisation representatives, the subject matter and culture supports the sharing of consumer experiences and advice, with health service partners in the minority as the advised group. This tends to remove tokenism and feelings from consumer participants that their input may not be appropriate or at the right time.
- The less formal nature of committee work, which focuses on consumer experience tends to give people the confidence that they could contribute, and therefore makes them more likely to nominate, and for similar reasons, encourages people with a more diverse range of backgrounds and experiences to participate.

At the time of writing, HCCA is towards the end of two such projects, and starting another with the ACT Health Directorate's new Health Infrastructure Consumer Reference Group. The model, while not in itself groundbreaking, is relatively new for HCCA, CHS and Major Projects Canberra. It combines the expertise and capacity of HCCA, with the needs of health services for meaningful, actionable consumer input and a recognition of the value this provides. It also gives HCCA a defined stewardship role throughout the course of a specific project. It is a promising model

for consideration in relation to Recommendations related to future development of CRP offerings, including Recommendations **B** and **E**.

2.2 HCCA's Consumer Representatives Program

Commencing in 1999, the CRP recruits, trains and supports Consumer Representatives participating in health-related committees and other consultative fora. A Consumer Representative is a member of the community who is endorsed by HCCA to represent the views and interests of health consumers, as a member of a committee or other consultative forum.[21] Consumer Representatives have experience as consumers of health services, and they commit to being well-informed about relevant health issues and representing a broad range of consumer views by ensuring they are accountable to HCCA or other community groups to which they are connected.[22]

In December 2022, the CRP had 123 active consumer representatives. Collectively, in the six months between July and December 20222, they spent a total of 675 hours preparing for committee meetings and participated in 624 meeting hours. The Program supports Consumer Reps contributing to committees established by the ACT Health Directorate, Canberra Health Services (CHS), universities in the ACT and region (primarily UC and ANU), the Capital Health Network (which is the ACT's Primary Health Network), and other community services, health services and ACT Government organisations. A majority of HCCA-endorsed consumer representatives participate in CHS committees, reflecting its role as the largest single provider of ACT public health services (and, since the August 2023 acquisition of Calvary Public Hospital Bruce by the ACT Government, the single provider of public hospital services in the ACT).

Figure 1 (next page) shows the diverse areas in which Consumer Representatives participate across CHS (current at April 2023). This includes areas in which consumer representatives are more concentrated. These areas of stronger representation include Quality, Safety, Innovation, and Improvement; Rehabilitation, Aged, and Community Services; and Cancer and Ambulatory Support. The image also indicates areas of lower concentration, in which consumer representatives could potentially have a stronger presence. This includes in the Office of Research and Education, and Policy and Strategy.

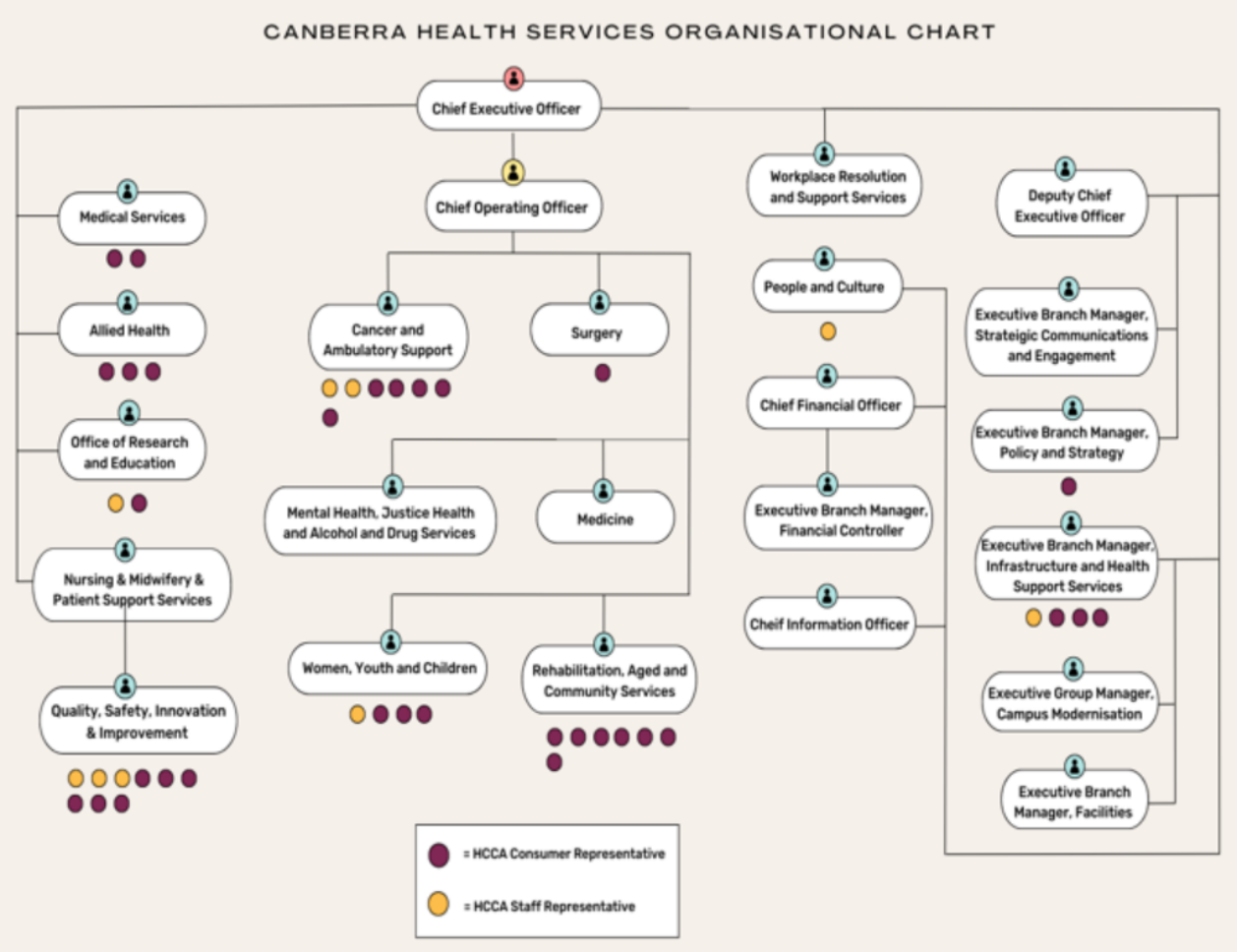

Figure 1 – Consumer representative participation, Canberra Health Services (at April 2023)

As this image only captures participation in CHS committees, it does not reflect areas of concentration or lower activity for the CRP in other services. A new area of significant activity for HCCA-nominated consumer representatives is in health infrastructure projects including those managed by Major Projects Canberra. This includes the Canberra Hospital Expansion Project, a major infrastructure development at the Canberra Hospital.

Between 2019 and 2023, there was a slight but steady decrease in the number of HCCA-nominated consumer representatives participating on committees. This amounted to a minimal reduction in overall numbers from 46 consumer representatives in 2019, to 38 in April 2023. The total number of committees on which consumer representatives participate also decreased over this time, from 172 overall to 139. However, the numbers of committees with consumer representatives participating at CHS reduced significantly, from 89 in 2020-21 to 51 in 2022-23. This drop may reflect a combination of the impacts of COVID-19 and a deliberate effort on the part of CHS to reduce the numbers of committees active across the organisation. This change indicates the importance of proactively managing relationships with requesting agencies, to understand (and where possible influence) their plans in relation to committees, consumer representation, and participation.

During this time (2019-23), numbers of committees remained constant at the ACT Health Directorate (38 in 2021, 37 in 2023). Numbers were similarly stable (though overall low) at Calvary Public Hospital Bruce, at an average of six consumer representative appointments per year from 2019-23 (noting that this will decrease to 0 following the transfer of Calvary-managed services to CHS). Numbers of committees with HCCA-nominated consumer representatives has grown most rapidly at the University of Canberra, though this remains a small proportion of consumer representatives overall (increasing from 3 in 2021 to 7 in 2023).

The Australian Commission on Safety and Quality in Health Care, Australian National University, Capital Heath Network and ACT Government Community Services Directorate have requested a consistent, though overall small, number of consumers to participate in committees between 2019 and 2023. National organisations, and other local organisations including community services, account for a small but fluctuating number of requests for which HCCA has endorsed a consumer representative over this timeframe. Figure 2 illustrates the breakdown in the proportion of consumer representatives participating on committees organised by these different agencies.

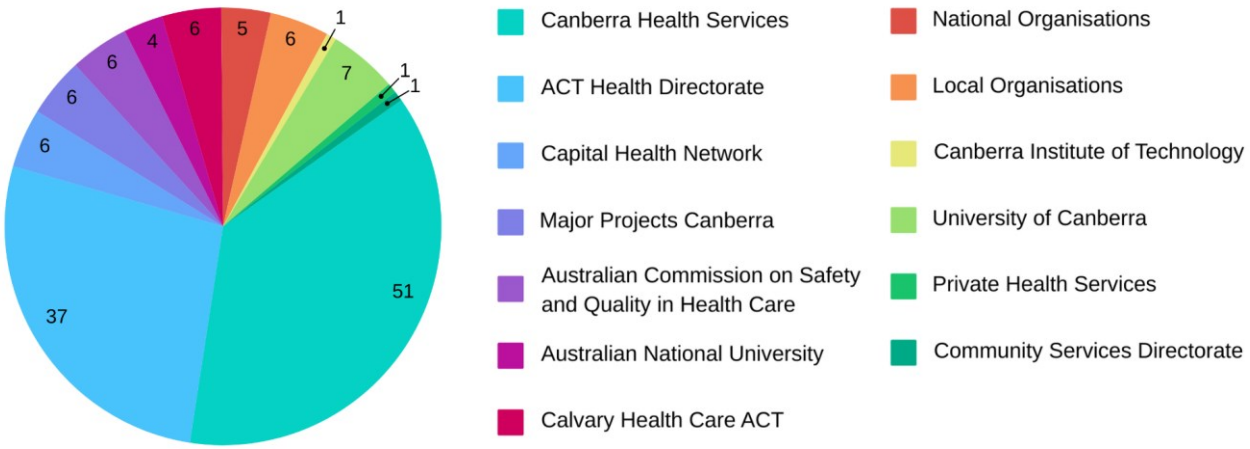

Figure 2 – Consumer representatives, distribution by requesting agencies, July 2022- April 2023.

While the overall number of committees with a HCCA-nominated consumer representative has decreased slightly since 2019, Consumer Representatives report a steady increase in the numbers of hours they spend participating in, and preparing for, committees. Meeting hours have increased from 497 in the first six months of 2019 to 624 in the last six months of 2022; with a similar trend in meeting preparation time (from 421 to 674 per six-month period in 2019 and 2022). The total hours Consumer Representatives spent on committees rose from 1,984 in 2019 to 2,381 in 2022. It's unclear what has driven this increase, but it may reflect increasing complexity, demand, and activity within key committees over that time, particularly within CHS as the major requesting agency.

2.3 Implementation of findings from past reviews

With very few exceptions, the findings from past reviews have been implemented. Recommendations which have not been implemented were considered by the CRP but not implemented either because they were not practical (e.g., too resource intensive or beyond program capacity), or because aims were achieved through other actions. A full list of implementation status of recommendations from past reviews is provided at Attachment 3. In short, the approach to consideration and implementation of findings from past reviews indicates the CRP is a mature program with sound processes for reflective learning, and quality improvement. Importantly, given oversight of this work rests with the HCCA Consumer and Community Participation Committee, there is a process in place for consumer governance of this work.

3. Trends in consumer representation and participation

This section presents findings from a review of literature and practice that aimed to identify emerging trends in good practice approaches to consumer representation and participation. The aim of the literature review is to help situate the CRP in the context of good practice approaches.

The benefits of consumer participation in health decision-making are well-established, and include:

- Health services are more responsive to community and consumer needs and preferences.
- Services have improved accountability and transparency to communities and the public.
- Patients, families, and carers report improved experiences of care.
- Staff report improved morale and workplace satisfaction.
- Care responds to demonstrated community needs – which potentially contributes to more cost-effective services.[23]

Additional benefits established in the context of health and medical research include:

- Enhanced trust between consumers and providers
- More relevant research questions and agendas
- A more ethical approach to research.[24]

Most health services and many health professionals are now expected and required to have processes and skills in community participation. All hospitals and many health services are accredited against National Safety and Quality Health Service Standards (NSQHSS) Standard 2, *Partnering with Consumers*, first introduced in 2013. Many professional standards – for example for General Practitioners and Registered Nurses – position consumer participation as a core competency.[25] The past 5 to 10 years has seen a significant shift toward consumer participation in health and medical research, driven in part by changes in national policy frameworks and the increasing expectations of funders in this area.[26] Most state and territory

health departments, key Commonwealth Government agencies (including the Department of Health and Aged Care and Mental Health Commission) and many national consumer and condition-specific organisations (for example Cancer Australia) have developed frameworks, guidelines and policies to support consumer engagement.[27] Many of these draw on the concept of "ladders of participation" – first articulated by Sherri Arnstein in the still-influential 1969 Ladder of Public Participation – to identify "levels" of participation from tokenism through informing, consulting, involving, working in equal partnership (for example through co-design) and consumer-led approaches.[28]

Consumer representation on health committees and decision-making forums, in which consumers are generally appointed as the single representative to a committee otherwise comprised of people participating in a professional capacity, is a long-standing approach to consumer participation. It is supported by health consumer organisations across Australia, and has been adopted by many health services as part of their approaches to consumer participation. Because it is well-established, and because it fits neatly into established models of health service governance and decision-making, it has been described as a "default" approach to consumer participation.[29]

In the last five to ten years, growing interest in – and expectations of – consumer participation has been accompanied by an increasing diversity of models and approaches to consumer participation. Newer approaches that are increasingly commonplace include: co-design (including of infrastructure, policies, and models of care), consumer advisory committees, online engagement, "kitchen-table" approaches to community consultation, and deliberative approaches including citizen's juries. In this context, consumer representation increasingly appears as one of many options available to consumer organisations and services. If it was once a "default" approach, this is no longer the case.

The last five to ten years have also seen increased interest in learning from "lived experience." Closely associated with consumer participation and representation, lived experience can be defined as "knowledge based on someone's perspective, personal identities, and history, beyond their professional or educational experience."[30] Efforts to learn from the lived experiences of people directly affected by policies and services have grown in importance in Australian mental health contexts, but also in welfare policy, human and community services and drug and alcohol policy.[31] Concepts, models, and practices of "lived experience" have significant overlap with consumer representation, as both are concerned with empowerment, human rights, and person-centred care.[32]

However, the two terms "co-design" and "lived experience" emerge from distinct though related histories and contexts. Consumer representation is closely tied to the health consumer movement which emerged in Australia in the 1970s and 1980s. "Lived experience" has gained specific traction in mental health reform efforts impelled by evidence of systemic failures in care. In the Australian context this has most recently been powerfully expressed in the findings of the Victorian Mental Health Royal Commission, which persuasively argued that people with lived

experience must be at the centre of leadership arrangements to restructure mental health service delivery.[33]

Efforts to strengthen the voices and influence of people with lived experience have led to the creation of new structures for governance and policy advice. One example is Victoria's Mental Health and Wellbeing Commission, which is explicitly responsible for supporting people with lived experience to "lead and partner in reform."[34] Efforts to strengthen peer and lived experience workforces are also related. Indeed, the Victorian Mental Health Royal Commission specifically identified the mental health lived experience workforce as an antidote to tokenistic approaches to consumer participation. Work is underway in different Australian jurisdictions to support the development of the lived experience workforce via improved career opportunities, appropriate remuneration, and better, support and supervision models.[35] Both Queensland and Victorian state health departments have developed new guidelines to support this work. There is also a growing acceptance for a role for "consumer leadership" in services, as distinct from participation.[36]

In 2023 it would be rare to hear dissent from the view that consumer participation (or the related terms of engagement and involvement) is important. However significant challenges remain in operationalising this concept. The vagueness of the terms contributes.[37] In addition, health professionals and decision-makers may assume they understand the value, and practices, of consumer participation without fully realising the challenges that exist to good practice. Chief among these are the fundamental imbalance in power between health professionals, who generally set the parameters for participation, select the methods and may oversee the appointment of consumers – and consumers themselves (who may continue to rely on access to services while participating).[38] Other recognised health service-side barriers to meaningful consumer engagement include lack of time, resources, organisational policies and organisational commitment to consumer engagement.[39] An "us and them" mentality can persist between participating consumers and professionals, and organisations do not always create opportunities for consumers to be "meaningfully included, supported and heard, with purposeful and relevant activities."[40] In addition, while it is common for services to have developed good policies and procedures related to consumer participation, this is often not matched by robust approaches to evaluation or monitoring.[41] As a result, the impact of consumer participation initiatives is unclear, with mixed evidence for practical outcomes.[42]

Consumer representation models face specific challenges inherent to committee processes in health care. This includes the challenge of "escalated indecision" within health services, the specific lack of value that decision-makers at different levels may place on consumer representation, and lack of staff support (including from Secretariat providers). In practice, the available evidence suggests that services do not consistently invest in the support necessary to make consumer representation work as intended.[43] For example, a small qualitative study of consumer representatives participating in committee work in a NSW public health service found that while consumer representatives are optimistic that their contributions have an impact, they must operate in a "complex environment of people and systems that are

hard to work in and often frustrating."[44] And contrary to what might be expected, policies and procedures to support consumer representation can have the unanticipated effect of limiting the role of reps and compounding a sense of their difference from other committee members.[45]

It is sometimes argued that consumer representation constitutes a form of tokenism. The crux of this criticism is that a single consumer representative cannot be expected to reflect or advocate for the diversity of consumer experiences in a community. For example, Daya (2020) suggests that:

> *"Consumers are diverse, therefore single representatives cannot speak on behalf of everyone they are said to stand for… There can never be a single 'representative' consumer... who can speak authentically to all our needs.*
> *"Experiences vary in terms of demographics, identity, and culture [and]… consumers… also have differing experiences of… health treatment and care. Engaging with just one consumer… can never result in an authentic, respectful, or effective engagement process."*[46]

From this perspective, representative models should rightly "[be]… skittled,"[47] because they are unable to reflect the diversity of consumer views and experiences. The Victorian Royal Commission into Mental Health argued specifically that tokenism may include "relying on a single… representative to advocate for an entire community."[48]

While such arguments raise a valid concern, they are made in the well-documented absence of sound approaches to evaluating the impact of consumer representation programs. This means that positive impacts as well as challenges, are likely to go under-reported. We do not know enough about the impacts of consumer representation programs, or how participating consumers and health professionals resolve challenges related to representation and diversity. Without robust approaches to monitoring and evidence, the risk of tokenism is likely to continue to beset all approaches to consumer participation.

However, there is good evidence to suggest that successful consumer participation (regardless of model) is achieved when the shift toward this practice is system-wide, occurs at all levels of decision-making, employs multiple methods, and is supported by cultural change in organisations. Other ingredients for success include clarity about:

- What is meant by key terms (such as consumer voice, lived experience, engagement, participation and involvement).
- The aims of participation, and the expected level or depth of consumer impact on decisions.
- The extent of differences in perspective between consumers and professionals.

In practical terms, for consumer representative models, engaging more than one consumer in committees where possible is identified as a useful approach to strengthening participation.[49]

Health consumer and advocacy organisations play an important role in this evolving context, by providing support and advice to consumers and to health services seeking to navigate requirements and expectations related to consumer participation. These organisations also face new pressure to meet growing demand for a "secure supply" of diverse consumers willing to contribute to health service engagement activities.[50] This is a recognised challenge for programs such as the CRP.

It's in this context, characterised by increasing expectations that consumer participation will be meaningful and deliver impact, growing diversity of methods and approaches, and new challenges, that the HCCA Consumer Representatives Program operates.

Many of the themes in this review of literature and practice – including the challenges associated with participating in committee work as a single community member, and the complexities as well as rewards of advocating for a broad consumer interest – also emerged as issues for Chairs, Secretariat providers and consumer representatives who participated in interviews and surveys as part of the 2023 internal HCCA review of the CRP.

CRP Review Recommendations about **Quality Improvement and Risk Management** (Recommendations **H** to **J**) relate to the issues covered in this Attachment 2.

Attachment 3: Implementation of findings from previous reviews

CONSUMER PARTICIPATION PROGRAM 2012 REVIEW		
Recommendation	**Met/Not Met**	**Where are we up to**
Develop definitions and language around representation to enhance a common understanding amongst members and stakeholders	Met	This is ongoing as language continues to evolve. HCCA's Guide for Consumers helps embed common language.
Reinforce the message to consumer representatives about: - representing a broader view with current consumer representatives, along with guidance on how to obtain a broader view, and - their responsibilities to attend committee meetings and communicate clearly about their availability.	Met	Included in information provided during consumer participation training. This information is also included in the Guide for Consumers.
Provide regular avenues for Health Directorate Committee Chairs and Secretariat to seek support or report underperforming consumer representatives and have stronger processes around responding to feedback about underperforming consumer representatives	Unclear if met	- Committee Chairs and Secretariats can raise their concerns if they have any by emailing the consumer participation coordinator. - HCCA doesn't systematically don't ask chairs and secretariats about how reps are performing. -- Could implement formal check ins with them at least once every 1-2 years. - Have strengthened our policy on underperforming reps and continue to review the policy
Continue work to strategically rationalise and prioritise the committees to which the CRP supplies consumer representatives, while also working with the ACT Health Directorate to	Not Met	- HCCA hasn't been strategic about which committees we advertise. Opportunities advertised are at the discretion of HCCA Director and Deputy Director.

identify and introduce different models of consumer participation		- We need to improve our process of allocating representatives to committees where they can have the greatest impact. Currently, we advertise most committees that come to us. - Limited by health service willingness, capacity, and knowledge of different models of consumer participation - HCCA has conducted a comprehensive review of the committees reps sit on within CHS. Recognising the growing demand for consumer participation in research, HCCA has actively shifted our focus towards integrating consumers in research initiatives. Our aim is to empower and educate consumers on how they can actively engage and contribute to research efforts.
Determine the optimal and the maximum numbers of consumer representatives HCCA can effectively manage at one time, and if more recruits are needed, consider conducting a specific recruitment campaign to encourage new consumer representatives	Unclear if met	- Availability of committee roles is a factor here. - Number of committees and reps is currently manageable. - Level of engagement from members depends on their willingness and capacity to sit on committees. There has been a noticeable decrease in nominations and new consumer representatives since COVID-19 pandemic began
Develop and provide more ongoing training for existing consumer representatives to build their skills and expertise	Met	- HCCA provides sponsorship opportunities for individuals interested in attending conferences we identify may be aligned with their interests. - HCCA could do more identification of potential training for reps. - While HCCA has organised some training for representatives to attend, we acknowledge the need to increase the number of opportunities available and improve on identifying and sponsoring relevant

		trainings for our representatives. This includes exploring opportunities for health-related topics and other social subjects of interest to our reps.
Collect performance information about the turnaround time on filling vacancies and consider developing arrangements so that consumer representatives then can be rapidly made available for short-term and one-off urgent projects.	Partially met	- We don't collect this information. - HCCA Director and Deputy Director identify and appoint reps in the short-term urgent projects. To address the tendency of relying on the same representatives repeatedly, we could consider establishing a register of individuals who are willing to be approached on short notice.
Identify and assess risks to HCCA relating to the Consumer representatives Program, including risks relating to underperforming consumer representatives and stakeholder perceptions	Met	The CPC formally assesses risks to the program twice a year and addresses emerging risks on an ad hoc basis.
Improve the selection procedures and dissemination of information about selection processes by: - reviewing documentation around selection processes and the confidential nature of deliberations - formalising the empanelment of the CRP Steering Group - streamlining and strengthening complaints and grievance procedures.	Met	- The selection process is well-documented and presented to the CPC. - HCCA regularly reviews the endorsement process and policy with the CPC to keep it up to date. - HCCA has a complaints process outlined in the Consumer Participation Program Policy, however streamlining complaints by and about reps could be better
Develop a template and guidance notes for consumer representatives to assist with reporting back and consider expanding the follow-up of report backs and reinforce expectations with consumer representatives on the overall importance of reporting back.	Not met	- HCCA has abandoned the requirement for representatives to submit written reports, as it posed a barrier to them taking up opportunities and proved arduous for reps and staff to maintain as a system and we were unclear of its value. This has resulted in some loss of visibility into the work our reps are doing. However, the people who wrote written reports

		were usually the same ones who attended meetings and kept in communication with HCCA in other ways. - QSCRG has verbal reporting for members committee work, which has proven effective in transferring and sharing information. These are some of our most active and influential reps, but not all of them. - There is still a communication/ visibility gap here.
Develop a Kit for Chairs of Committees that includes good practice guidelines for working with consumers.	Met	- We currently have a fact sheet available, but we do not have a complete kit. We share the fact sheet on an 'as needed' basis but not systematically. - CHS has their own resource for this purpose. HCCA periodically contributes to the review of this resource. - HCCA has considered the possibility of adapting the HCQLD resource, as HCCA has done for consumers. However, HCCA is still undecided whether this is necessary or the most efficient use of our resources.
Consider providing a "vacancy description" that provides potential nominees with more information about committee vacancies as they arise. More information would also need to be sought from requesting agencies.	Met	We share information about committee vacancies through our Consumer Bites and Ops newsletters, as well as consistently update the HCCA website with the latest listings. Our advertisements also encourage reps to reach out for additional information if they wish to.
The current grievance and dispute resolution policies and procedures need to be reviewed, streamlined and improved	Not met	This has not been updated for several years.
HCCA develop a policy and procedure for dealing with vexatious complainants.	Not met	An amendment has been made on the Consumer representatives code of conduct. However, no specific policy has been written on this in the consumer participation program policy. Could add something to the existing policy about this but feel that a separate policy not needed.
Review and expand the Code of Conduct	Met	The code of conduct reviewed early 2023

Consider introducing fixed terms for members of CP Steering Committee, and the election of at least two members by the membership every two years. The chair of the CP Steering Committee should be a member of the Executive Committee	Met	This requirement has been included in the current CPC TOR.
HCCA explore the features of the AutoResponder package currently being used to publish the Consumer Bites newsletter to see if other features are available	NA	This is no longer relevant as we use Mailchimp to publish Consumer Bites
Make some minor adjustments to the website and blog to improve functionality, for example: - ensure that links open in new windows, - refine the homepage to make it less 'busy' with information, and - update some content to target it towards first time visitors	Met	The HCCA website underwent a significant update and continues to be reviewed and improved

CONSUMER PARTICIPATION TRAINING REVIEW 2017		
Recommendation	**Met/Not Met**	**Where are we up to**
KNOWLEDGE & SKILLS		
Provide a structured modular training model which ensures clear distinctions between information and education for community and specific skills training for HCCA Consumer Reps. The expectation will be that the courses will be completed sequentially and in particular, that Navigating the Health System and Consumer Reps Basics will be requisites for the Advanced	Met	- Following the review, we conducted several trainings with a modified structure. However, this approach resulted in lower engagement compared to our previous methodology. We reverted to the previous structure 2-day structure that includes one day focused on understanding the ACT health system and individual

Consumer Reps skills course. The proposed courses would consist of the following hierarchy: A. Navigating the health system Structure of the system, clinical services framework, keeping yourself safe, shared decision making B. Consumer reps basics The value of consumer participation, what is consumer engagement, what is a consumer rep/meet a rep, responsibilities of a consumer rep, meeting skills, confidence, working in partnership, working in focus groups or consultations C. Advanced consumer reps skills Power and dynamics, problem solving, key HCCA policies, objectivity and empathy, thinking systemically. D. Consumer Research & Policy skills training What is research? Common ways of involving consumers, key skills		experiences and another day that focuses on community advocacy and consumer representation. This model has received the most positive feedback so far. - Additionally, since the review, HCCA has developed condensed versions of consumer representation topics for both in-person and online delivery. - Regarding item D HCCA has collaborated with organisations/institutions that conduct research (e.g. ANU) to provide specialised workshops about consumer participation in research.
Establish a program of 'mini-bite' training to be delivered at the quarterly HCCA Consumer Representatives Forums consisting of updates/refresh/specific skills and could include – social media, telling your story, negotiation skills, navigating the system updates, collaboration and co-production	Not met	The members forums have evolved to cover a broader range of interests beyond consumer representation.
DELIVERY MODEL		
Limit each module to a maximum length of 5 hours/one day in duration.	Met	Training is two-days. Day one is dedicated to understanding of the ACT health system and individual

		experiences, while day two focuses on community advocacy and consumer representation.
Trial a shorter evening module	Met	HCCA has delivered mid-year online training sessions consisting of four one-hour sessions in the evening. Depending on demand, we plan to offer the same format again in 2023.
Consider 'front loading' training modules with recommended pre-reading, video clips and relevant Consumer Bite articles and HCCA blog posts.	Partially met	HCCA sometimes does this, but not systematically
Take into consideration religious observances and festivals (e.g., Ramadan, Easter) as well as school holidays when planning program of modules	Partially met	HCCA needs to be more mindful of these considerations. HCCA is fairly good, but sometimes we don't remember them in our planning.
Plan a 12-month calendar of events	Met	Yes, HCCA does this annually
Training for Consumer Rep skills development to adopt a more 'activity-based learning' approach, using case studies and opportunities for participants to practice.	Met	- Yes, HCCA has a good variety of activities to engage attendees. - On Day 2 of training, HCCA conducts a consultation activity where representatives can actively participate and practice providing input. The feedback gathered during these sessions directly contributes to work HCCA engages with at that time.
Request that ACT Health participates as a trainer to talk about issues such as the value of	Met	This has been done in the past. However, the current structure for training doesn't

consumer participation, Responsibilities of a rep, 'Meet a Chair		allow time for this. Could be reintegrated into the training if deemed necessary.
Ensure training courses can be adapted to be delivered in a broader range of settings, for example shorter/bite sized versions for places of work, study and social clubs. This option could be used particularly for the 'Navigating the health system' course.	Met	- Yes, HCCA has a whole range of different lengths for online and in-person. Training has been delivered with interpreters, based on the needs of the consumer. - HCCA is also in the process of developing online self-paced training
Provide a clear program of HCCA follow up actions following training e.g. HCCA to contact participants within 2 weeks, 6 months and 12 months.	Not met	HCCA doesn't currently do this systematically and could improve. We contact people on an ad hoc basis.
MARKETING & COMMUNICATIONS		
Develop a succinct message for each training module and promote via online, hard copy and other media, particularly social media.	Met	HCCA has created social media tiles and promotional packages using Canva
Enable online booking and administration of training sessions and participants	Met	Yes, HCCA uses Humanitix for this
Broaden the sites where we advertise and promote the training, this could include: Youth Coalition, corporate sector, patient experience week, palliative care week, University Campuses, Community notice boards, online forums e.g. Canberra Mums.	Met	HCCA has a sufficient range of places to promote training (i.e. CDNet, City News, Facebook, etc.)
Develop specific training for ACT Health staff e.g. how to work with consumers	Met	Have done this in the past but demand is limited. CHS not aware of this HCCA offering.

EVALUATION		
Provide opportunity after each training session for trainers and HCCA staff members to reflect on the day using the What Went Well and What Went Less Well approach or real time Evaluation feedback	Met	- Yes, staff members debrief and capture their thoughts in a document on SharePoint. - The feedback is then reported to the CPC
ADDITIONAL RECOMMENDATIONS		
Consider other models for advocacy and consumer input, developing a road map for the future	Met	- HCCA is actively working on engaging consumers in research opportunities, involving consumers in health infrastructure project user groups, conducting more focus groups, and increasing our presence as speakers at various events, both as members and staff. - HCCA is also focused on building influential relationships to better understand where consumer representation is required and where it is heading. Furthermore, we aim to provide more media commentary to amplify consumer voices and perspectives.
Investigate options for becoming a recognised training provider to allow for 'Recognition of prior learning'	N/A	Investigated, decided not to pursue this

Attachment 4: Findings from surveys and interviews

1. Introduction

This document presents detailed findings from the 2023 Internal Review of the HCCA Consumer Representatives Program. It covers:

- Skills, knowledge and confidence of consumer representatives.
- Support provided by Chairs, Secretariats and committee members.
- Support from HCCA and the CRP.
- Relationships for consumer partnership.
- The role of the consumer representative.
- Diversity and transition among consumer representatives.
- Consumer representation and other approaches to consumer participation.
- Influence and impact of consumer representatives.
- Learning and capacity development for consumer representatives and health professionals.

2. Participants

2.1 Survey Respondents

Respondents to the consumer survey were currently, or had previously, participated in committees at CHS, Major Projects Canberra, ANU, CHN, UC, Calvary Public Hospital Bruce and Calvary Private Hospital. This included participation in governance and operational committees related to primary and ambulatory care, cancer care, palliative care, health records development and management, infrastructure, medication safety, research governance, maternity services, pathology, human research ethics, COVID-19, professional accreditation, and quality and safety committees. While this does not cover every area or every service where HCCA currently supports consumer representatives, it reflects a diversity of experiences including different requesting organisations, and different areas of committee focus.

Most consumer respondents were experienced consumer representatives. Only one respondent had been a HCCA nominated consumer rep for less than one year. Over 80% had been in Consumer Representative roles for more than three years, with 60% participating in consumer representative roles for between 5 and 10 years (26%) or more than 10 years (35%). A quarter had participated in 2 or 3 committees, with 62% participating in four or more committees. At the time of the survey, 40% of respondents were participating in two committees, 22% were participating in a single committee, 26% were participating in 3 or 4 committees, and 13% were not currently taking part in any committees. In short, the respondent group is comprised of experienced and active consumer representatives.

Health professional respondents work at the University of Canberra, CHS, CNH and the ACT Health Directorate. There were no respondents from North Canberra Public

Hospital (formerly Calvary Public Hospital Bruce), likely reflecting other demands on the time and attention of these professionals given the surveys took place at the same time as the ACT Government acquired Calvary Public Hospital Bruce. The issues and areas covered by the committees these respondents are involved in include clinical leadership, research governance and strategy, quality and safety, COVID-19, allied health and rehabilitation, nursing professional committees, maternity care, health service governance, mental health and infrastructure. There were equal numbers of Committee Chairs and Secretariat service providers. In terms of professional role, respondents included health researchers, clinicians, project managers and health service executives.

Similar to the consumer survey respondents, most professional respondents were experienced Chairs or Secretariat service providers. Just one respondent had worked with consumer representatives for less than a year, with the remainder working with consumer representatives for more than three years. Only one respondent had worked with just a single consumer representative, while 46% had worked with two or three consumer representatives, 38% had worked with 4-10 consumer representatives, and one respondent had worked with more than 10 consumer representatives. More than 60% of respondents had worked with Consumer Representatives for more than 3 years. In short, respondents to the survey are people with sound experience working with consumer representatives.

2.2 Interview Participants

There were seven health service participants and eight consumer participants in interviews. In addition, the HCCA Executive Director participated in an interview. Four consumers participated in a small group interview; the remainder were one-on-one semi-structured conversations. In addition, one consumer representative provided extensive notes by email. Most consumer participants in interviews had extensive experience as committee members – just one consumer had participated in a single committee, while the remainder had contributed to several committees.

Most of the health service participants were experienced clinicians, working in leadership roles. Two participants provided Secretariat services; the remainder were committee Chairs. Participants contribute to committees across CHS and Major Projects Canberra. Consumer participants also contribute to ANU and UC committees. Areas in which these committees are active include hospital food services, professional appointments committees, governance committees, quality and safety committees, clinical standards committees, faculty-level research advisory committees, community advisory committees, clinical councils, policy committees, and consumer reference groups. These cover clinical areas including medical services, pathology, primary care, infant child and adolescent health, rehabilitation services, medical imaging, pharmacy, infrastructure development, palliative care and the Canberra Hospital Expansion Project.

3. Findings

3.1 Overall satisfaction with the CRP

Consumer representatives, and committee Chair and Secretariat providers, reported overall very high levels of satisfaction with their experiences of the Consumer Representatives Program. Chairs and Secretariat providers had a high degree of confidence that **HCCA-nominated consumer representatives have the skills, knowledge and abilities they need** to contribute effectively to committee and related processes. Consumer Representatives were similarly confident in their skills and knowledge to participate.

3.1.1 Consumer Representatives

Consumer Representatives who participated in the Review expressed a strong sense of confidence in their skills and knowledge to contribute to committee work. For example, 100% of consumer rep survey respondents felt they have the skills they need to participate; 91% said they have the knowledge they need to participate; 91% were confident to ask questions and raise issues; and 91% felt they were able to bring an informed perspective on issues affecting health consumers.

3.1.2 Chairs and Secretariat providers

Chairs and Secretariat providers, with very few caveats, value the skills, knowledge and contribution of consumer representatives highly. For example, 83% of Chair and Secretariat survey respondents said that consumer representatives “always” or “often” have the skills they need to participate in discussions and decisions (with a further 14% saying this was only “sometimes” or “rarely” so). 80% said that Consumer Representatives always or often understand committee processes (with 25% saying this was “sometimes” so); and around 80% said that Consumer Representatives have the knowledge they need to participate, are confident to ask questions and raise issues, and bring an informed perspective on issues affecting consumers. Around 80% said that Consumer Representatives have a positive influence on discussions and decisions and give a lot of their time to participate.

These results indicate high satisfaction with the skills, knowledge, and confidence of Consumer Representatives. However, they also suggest that a minority of people who work closely with consumer representatives (survey results indicate around 2 in every 10 people who work closely with Consumer Representatives) have lower confidence in the CRP’s capacity to provide consumer representatives with the knowledge and skills they need to participate in committees. A quarter of survey respondents felt Consumer Representatives only “sometimes” or “rarely” understand committee processes. This suggests a particular opportunity for requesting agencies to enhance the information that is provided to Consumer Representatives in induction and ongoing training, and potentially a role for the CRP in providing additional information or support in this area to personnel in requesting agencies and/or to consumer representatives.

Chairs and Secretariat providers who took part in interviews expressed great appreciation for the contribution Consumer Representatives make to committees. However, a minority of participants in interviews noted that the confidence and ability

of reps to contribute to committee discussions varies. For example, one interview participant observed that while reps are generally confident to “speak up” in meetings, this is not always the case particularly for less experienced Consumer Representatives or people new to a committee. Another interviewee shared their view that on occasions reps may not understand the limits on the role and scope of committees, meaning “questions can be asked that are not relevant.” These issues suggest that Chairs, Secretariat providers and consumer representatives require ongoing support to ensure that everyone’s expectations of reps’ contributions are reasonable, and that reps receive the support they need to contribute to committee discussions.

In this context, and noting the overall very high level of satisfaction with the Program from both groups of the participants, priorities for the CRP and requesting agencies relate to:

- Ensuring Consumer Representatives have opportunities to develop specific technical knowledge they may need on particular committees.
- Matching the “right rep” to the “right committee” to ensure a good alignment of interests and skills.
- Ensuring Chairs have easy-to-access and easy-to-use information about how to most effectively involve Consumer Representatives in meetings (and between meetings where appropriate), particularly for less experienced reps and reps new to a committee.

3.2 Support from Chairs, Secretariats, and committee members

3.2.1 Consumer representatives

Most Consumer Representatives who participated in the Review were positive about the extent to which committee members, in particular Chairs and Secretariats, understand and support their contribution. For example, 100% of survey respondents felt their contribution is respected and valued (36% always, 50% often, and 13% “sometimes”). Two-thirds of consumer rep survey respondents felt that committee members appreciate their time (70% always or often), and a majority felt the time commitment is reasonable (80% always or often). Just under three quarters of survey respondents (73%) said that Committee Chairs understand and support their role “always” or “often”, while a further 17% felt that Chairs support and understand their role “sometimes.” A similar proportion (72%) said that committee members welcome their participation and ideas always or often, with 23% saying this happens sometimes.

While a majority of consumer rep survey respondents were satisfied with the quality of support they receive from committee Secretariats, survey and interview responses suggest there are opportunities to strengthen assistance in this area. Just under 70% of consumer rep survey respondents indicated that Committee Secretariats provide the support they need, however 23% of respondents said this happens “rarely” or “never.” A majority of survey respondents (71%) felt that meetings are always (40%) or often (31%) well organised. 63% of respondents said the policy for reimbursement was always (50%) or usually (13%) clear; however, in practice only 40% of

respondents said they were always or usually reimbursed on time. Indeed, 11% were rarely or never reimbursed on time and 32% were only sometimes reimbursed on time. Around half of all survey respondents reported that their committees provided a good induction process, while 15% said there was never or rarely a good induction process and 30% said this was "sometimes the case."

Consumer Representatives who took part in interviews discussed their experiences of variably quality secretariat support. As with many aspects of the relationship between Consumer Representatives and committees, consumer representatives who had participated in many committees had some very positive experiences of secretariat and administrative support, and some less positive experiences. These two examples indicate the contrast:

> *"My years on [that] committee were the pinnacle! My comments were always minuted. It was a privilege, a really positive experience."*

> *"My committee keeps cancelling meetings without telling beforehand. I've waited for up to 20 minutes online trying to find out what has happened, this happened on more than two occasions."*

Specific issues identified by Consumer Representatives include lack of clear policies on reimbursement, late reimbursement (or non-reimbursement), late provision of papers, frequent changes in meeting times, late cancellation of meetings, and frustration about incorrect minuting of comments. Some consumer representatives also reported difficulty accessing committees preferred online platforms for remote meetings and out of session document review.

3.2.2 Chairs and Secretariat providers

These participants were generally positive about the quality of support their agencies provide to consumer representatives. For example, 88% of survey respondents said they provide the support and information that consumer representatives need. Chairs and Secretariat providers who responded to the survey were markedly more confident about the quality of induction processes than consumer representatives were. Compared with 50% of Consumer Representatives who said they experienced a "good" induction process, 73% of Chairs and Secretariats reported that Consumer Representatives always or often receive a good induction (with a further 38% saying this was sometimes the case). In interviews, Chairs and Secretariat providers recognised the importance of clear, prompt processes particularly relating to remuneration.

3.2.3 Impact of COVID-19

Many committees moved online during COVID-19 and have continued to meet mostly online since this time. Consumer representatives observed that this can lead to "people losing the history" of the committee, and the relationship with the consumer representative. The shift to digital meetings has reduced the ability of committee members to develop the trust, rapport and personal relationships that can be essential to good committee discussions. This challenge has been compounded

by significant workforce pressures and staff turnover which has coincided with the ongoing COVID-19 pandemic. Chairs and Secretariat providers also acknowledged that it is important to ensure easy access to IT platforms for remote meetings.

3.3 Support from HCCA and the CRP

3.3.1 Consumer Representatives

Consumer Representatives provided strong positive feedback on the support provided by the CRP. For example, all (100%) consumer rep survey respondents said the HCCA staff team would help solve a problem with committee work if they had one.

> *"Very positive and responsive team at HCCA. I am very confident that they would help me out anytime I needed and have done in the past."*

All respondents knew who to contact if they had a problem and felt that the process for advertising and nominating representatives was fair. Just under 70% said they have enough opportunities to connect with other representatives, with around 30% feeling this was not the case. Consumer representatives who participated in interviews also raised this issue, suggesting that they would value less formal peer support opportunities focused on the practical challenges of consumer representation – for example sharing strategies for dealing with difficult situations in committee work, or examples of their impact on committees.

> *"Maybe Consumer Representatives could have some 'networking' time?"*

> *"I think a rep get-together would be great!"*

The CPR is well-placed to consider opportunities to support reps in this way.

3.4 Chairs and Secretariat providers

Chairs and Secretariat providers offered positive feedback on the services they receive from the CRP; however, their responses also indicate opportunities for HCCA to proactively promote information about CRP processes and resources. Three quarters of survey respondents agreed that the HCCA staff team would be able to help resolve a problem involving a consumer representative. A similar proportion felt that HCCA provides trained, effective reps. Around 80% knew who to contact at HCCA for assistance with a problem. However, less than half (40%) understood HCCA's process for advertising, nominating, and supporting consumer representatives. Under 40% of survey respondents (37%) have used HCCA's information for Chairs and Secretariats, and just 40% of respondents felt this information was useful. This suggests some areas in which committee Chairs and Secretariat providers have variable knowledge of HCCA and CRP processes. In this context it may be appropriate for HCCA to consider how best to actively promote the services and processes of the CRP including for people who new to roles working

with consumer representatives, and personnel who might benefit from updated information about specific areas.

In relation to the HCCA nomination process, interview participants and survey respondents raised a variety of issues. Among these, some survey respondents (a minority, 3 participants) expressed the view that committees should have the option to select who will join committees rather than accepting a HCCA nominee:

> *"We don't have the opportunity to select, i.e., given a selection of reps to choose from to determine who would be best suited to a committee."*

One interview participant observed that the HCCA nomination process can take some time, which can delay administrative processes associated with the establishment of committees. Another participant was unclear about when it is appropriate to approach HCCA, or another consumer organisation, to request a consumer representative. Finally, another interview participant observed that they are unclear on whether it is appropriate to directly invite or appoint a HCCA-nominated consumer representative to join another committee. This range of issues suggests some additional matters about which Chairs and Secretariats may not realise they can seek information from HCCA, and about which they might benefit from proactive provision of information by the CRP.

3.5 Relationships for consumer partnership

This section considers the working relationship between consumer representatives and other committee members. It finds that the CRP supports Chairs, Secretariat providers and consumer representatives to build strong relationships of trust that are an essential foundation for effective consumer representation. Consumer Representatives experience challenges related to unequal participation, and health professionals experience challenges related to lack of clarity about the role and potential contribution of consumer representatives. However, the CRP provides a framework that allows consumer representatives and personnel in requesting agencies to develop learning relationships, jointly define the role of the consumer representative, and work productively together. This builds individual and system capability for consumer partnership.

3.5.1 Equal membership and inclusion in decisions

Consumer representatives have varied experiences of full (or partial) inclusion in committee work. A majority of consumer rep survey respondents said they are regarded as equal members of the committee, always (33%) or usually (47%) (with around 15% feeling they are rarely or never regarded as equal). However, most of the survey and interview respondents felt that they had experienced token involvement to some extent: only 33% of survey respondents said committees never involved them in a tokenistic way, while 30% said this rarely or sometimes happens and 18% felt this happened always or often.

Just under 85% of Chairs and Secretariat survey respondents said that Consumer Representatives are always or often equal members of committees (15% said this is

sometimes or rarely so). Only 8% felt reps are always or often left out of decisions, 45% said this is sometimes so, and 45% felt this rarely or never is the case. A minority (12%) said that committees often involve reps to "tick a box" or in a tokenistic way, while 70% were of the view that this rarely or never (45%) happens. 60% said that committees have the time and resources to involve and support reps, with 45% saying this is only sometimes the case.

These findings indicate that while there is some room for improvement and consolidation in the relationship between consumer representatives and committees, a majority of both groups are overall positive about the quality of this relationship. Importantly, the CRP has created an opportunity for around 80% of consumer representatives to experience meaningful opportunities for equal participation on decision-making committees – if not always, at least some of the time.

In interviews, consumer and professional participants identified many positive characteristics of the relationships between consumers and committees. Generally, Consumer Representatives reported that interactions with Chairs and committees are "respectful" and committee members are "grateful" to have a consumer representative present. Consumer representatives and Chairs reported a willingness to listen and learn from one another's perspectives. Some of the most positive experiences were characterised by flexibility to experiment or innovate with committee processes to find the best ways for individual consumer representatives to contribute. For example, some Consumer Representatives prefer to contribute by finding relevant research that other committee members might not have time to search for, other consumer representatives had suggested changes to how consumer experience data is considered in meetings, and some Chairs and Consumer Representatives created a dedicated agenda item in meetings for the consumer member to raise particular issues. In the words of one consumer participant, in these positive experiences "the goodwill is there."

Nonetheless, a majority of Consumer Representatives who participated in interviews indicated that the potential for tokenistic involvement is ever-present in committee work. One consumer participant in interview said that, "The criteria for 'successful' consumer representation could be expressed as: 'If a rep is present, we've satisfied "consumer engagement"'. Similarly, both Consumer Representatives and professional participants in interviews identified that the requirement on health services to include consumers in some committees (in particular to meet the requirements of ACSQHS NHSQSS Standard 2) can foster a sense of "ticking the box" in relationship to consumer participants. As Consumer Representatives put it:

> *"They are ticking the box. They have to do it. They don't always follow through [on commitments], but they do include me."*

> *"Sometimes I feel the advice is too late in the project, and the fundamental decisions have already taken place. So, you become a token and/or there is too much focus on project milestones!"*

Consistent with this view, consumer representative survey respondents identified situations in which they were not fully included as equal committee members. For

example, only 22% of survey respondents said they are *never* left out of committee decisions; while 41% were often (9%) or sometimes (31%) left out.

Consumer Representatives can feel that, as external committee members, they are often excluded from information shared, and decisions made, between meetings. For example, Consumer Representatives recounted that:

> *"Much happens in between meeting that is resolved separately in the normal course of business. At times there's assumed knowledge of these matters as many members work together already."*

> *"I find not being involved in the day-to-day processes and discussions that occur in the workplace around the committees I am involved in frustrating, but unavoidable."*

> *"I am aware that I am kept in the dark regarding certain decisions."*

Some consumer representatives find workarounds that assist with these situations, for example contacting the committee Chair to discuss matters out of session. In the main, Consumer Representatives felt they are left out of decisions because of the inherent challenge of being the only external member of committees made of up colleagues. As one participant said:

> *"I think being a little on the outer is unavoidable but can be a challenge. Possibly it is also an asset in some ways, as a consumer rep one can take a more objective position."*

However, in some instances, broader cultural or attitudinal barriers compound the challenges of being an external committee member. Specifically, a minority of Consumer Representatives had experienced what they perceived to be deliberate exclusion from decisions, which they felt stemmed from a level of defensiveness on the part of health service personnel. This underscores the complexity of the settings in which consumer representatives contribute, and which the CRP seeks to influence.

Consumer Representatives who had been involved in many committees highlighted the variability in both a) the quality of their relationship with Chairs, Secretariat and committees, and b) the extent to which they are included as equal committee members:

> *"The committees and how they work, including with consumers is often dependent on the chair. Some are better than others at making me feel like a strong and valuable member of the group."*

> *"I've had vastly different experiences with two universities."*

> *"[Two of the committees I'm involved with] … are high quality experiences where I feel valued and have been able to make changes to benefit consumers. [The other] Chair and committee manager often act in a dismissive way, and I usually have to fight to have any changes made..."*

This underscores the importance of the role of Chair in setting a tone for the relationship between Consumer Representatives and the committees to which they contribute.

3.6 Role of the consumer representative

For Chairs and Secretariat providers who participated in the Review, uncertainty about the role and potential contribution of consumer representatives is a significant challenge. As discussed above, almost without exception professionals who took part in the Review regard consumer participation and representation as important and valuable. Yet in interviews, Chairs and Secretariats expressed uncertainty about precisely what to expect from consumer representatives, how to work most effectively with them, and how to achieve the best possible outcomes from working with a consumer representative. A survey respondent expressed the challenge as follows:

> *"I feel like the engagement can become a bit tokenistic if it's not 100% clear on the role of the consumer rep. More work needs to be done on the health services side to be clear about how they can leverage her involvement of Consumer Representatives."*

One specific area in which Chairs and Secretariat providers were uncertain, relates to what it is appropriate to expect from Consumer Representatives outside of meetings. For example, one survey respondent was unsure whether reps can be expected to read and comment on documents, or follow up on action items, outside of meetings.

Professional participants in interviews and surveys had diverse expectations about what the ideal contribution of consumer representatives should be. Some health service personnel expressed a strong interest in securing participation from people with recent personal lived experiences of specific health services or specific health conditions:

> *"The majority of consumers I have worked with don't have recent lived experience."*

By contrast, other participants valued the contribution of consumer representatives who can provide a "broad perspective" or "informed view" on issues affecting health consumers. For example, one survey participant valued that CRP-supported consumer representatives are:

> "*Well-connected to their community and community groups… and understand the needs, wants, challenges of the consumer they represent and can represent… rather than [bringing] their own personal agenda… they are representative of all consumers of that service."*

Both consumers and professional participants recognised that to bring this perspective effectively often requires advanced negotiation and advocacy skills as well as community connections. One consumer representative said it had "taken

years to become less daunted" in using these skills as a committee member. Recent lived experience perspectives, and consumer representation, are equally valuable but they are distinct roles for consumers. Which role is most appropriate depends on the specific context, aim and work of each committee.

Of Chairs and Secretariat providers who competed the survey, around 80% felt that Consumer Representatives always or often bring and informed perspective on issues affecting health consumers. About 30% felt that Consumer Representatives mostly share their own experiences rather than a broader perspective, while 70% felt this was not so or only sometimes so. This result is somewhat difficult to interpret, given some health personnel would value this recent lived experience, while others actively seek a broader perspective. Nonetheless it indicates the CRP is overall achieving its goal of supporting consumers to provide an informed consumer view on issues.

Requesting agencies appear to be seeking a range of different consumer perspectives, ranging from recent lived experience to highly skilled consumer advocate or representative roles. While this suggests a positive interest in diverse approaches to participation, the CRP may have a role to play in assisting health service personnel to:

- understand the range of contributions that consumers can make as representatives (from recent lived experience to consumer advocate/representative).
- clarify their expectations of consumer participation, including by understanding different levels and types of consumer participation (for example via orientation to the various "ladders" of participation commonly used in good practice approaches).
- clarify their expectations of consumer representation/participation in specific projects and committees – to assist in best matching consumers' experiences and interests to the opportunities that exist.
- take a risk-aware and trauma-informed approach, particularly to recruitment and support of community members who are sharing recent lived experiences of health services (in which the potential for sensitive or difficult personal experiences is always inherent).

3.7 Diversity and transition

Chairs and Secretariat providers consistently expressed a concern that HCCA-nominated consumer representatives may not fully reflect the diversity of ACT communities. There is a perception that HCCA consumer representatives "have limited diversity of background." Professional participants in this Review would welcome visible participation of people with "diverse backgrounds who represent our community." Specific characteristics of diversity identified by participants include gender, age, professional background, cultural and linguistic diversity, neurodiversity, carer and kin perspectives, participation of people from LGBTIQ+ communities, and people with a wide variety of lived experiences of health services and health care.

This presents an opportunity for the CRP to consider its approach to attracting and retaining a diverse pool of people interested in consumer representative opportunities. It could also prompt the CRP to consider how it celebrates and demonstrates the diversity of consumer representatives who are currently active within the Program.

Some Chairs and Secretariats expressed a perception that some consumer representatives "have been reps for a long time and across many different committees." This may reflect a perception for Chairs and Secretariats that the CRP favours experienced consumer representatives, rather than focusing on opening opportunities for new consumer representatives. One health service survey respondent expressed concern that this:

> *"May create a dynamic where reps that always agree are always used rather than the one that provides more candid feedback."*

The CRP may wish to consider how it communicates with requesting agencies about its approach to proactively supporting the development of new and less experienced consumer representatives, while also communicating the benefits of working with experienced consumer representatives. This is information that could be shared in updated HCCA website information addressing key questions about the CRP, and/or in a brief annual review of CRP successes for consumer representatives and requesting agencies.

3.8 Committee work in a wider context of participation

Both consumers and health service representatives acknowledge that health committees have inherent limitations. These include limits on the scope and responsibility of committees, unpredictable delays in decision-making, and change in key personnel responsible for progressing committee recommendations. Because there are organisational expectations that a consumer should participate in some committees (particularly those related to NQSHSS Standard 2), there is sense from both consumer and professional participants in this Review that there is a "consumer there because we have to." In this context, both consumers and health professionals who participated in interviews expressed an interest in exploring the potential of other approaches to participation. Approaches mentioned by participants include Consumer and Community Advisory Groups, short-term opportunities for participation in quality improvement and service design processes, proactive collection of better consumer experience information to drive quality improvement, and contributions to teaching and learning processes. Capacity allowing, the CRP would be well-placed to initiate conversations with interested Chairs and Secretariats in this area.

3.9 Consumer representatives: Influence and impact

Consumer and professional participant in the Review identified a variety of practical impacts that Consumer Representatives have on committees. These are a mix of positive impacts on processes, and outcomes.

3.9.1 Consumer representatives

Consumer representatives who participated in surveys and interviews identified a range of ways in which they influenced committee processes and outcomes. For example, 80% of survey respondents said they had asked questions or raised issues a committee would not otherwise have considered. Over three-quarters (76%) said committees had made better decisions because of their participation (46% said this was often or always the case, 30% saying that this was “sometimes” true). Over 80% said their contribution had led to better outcomes for consumers or the services (45% said this was sometimes so, 31% often, and 9% always). 73% had made suggestions that improved committee processes. These findings indicate Consumer Representatives’ confidence in their impact, despite the challenges discussed earlier in the Review.

In interviews and survey responses, Consumer Representatives identified a wide variety of practical ways in which they positively influenced committees. These include:

- Making practical suggestions about delivery of care (which are often adopted), asking questions that lead to changes in policies and procedures, suggesting improvements to consumer feedback processes, and encouraging transparency by requesting that reports be circulated more widely than initially proposed.
- Ensuring implementation plans are developed, to guide and track implementation of committee recommendations.
- Giving advice that significantly improves the relevance and readability of consumer and public information resources.
- Providing practical recommendations to improve the physical accessibility of services.
- Identifying the need for targeted advice, and/or seeking this advice, from organisations connected to under-served communities.
- Making suggestions that lead to changes in models of care, or provision of additional staff training in specific areas.
- Checking budgets, costings, and spending for certain projects.

Consumer Representatives also influence committee processes for the better. For example, they request changes to minutes so that these are accurate, they ask questions about process that lead Chairs to clarify meeting requirements for all members, and they suggested changes to how consumer experience is heard by committees. Committee Chairs report that consumer representatives also bring a difficult-to-quantify but essential perspective that is “less inward focused” and “more real world.”

The examples below are a small number of the practical impacts that consumer representatives identified their participation has had:

"[I] got [a report] circulated to clinical staff including JMOs not just tabled at Executive meetings."

"I asked questions about policy regarding records kept on people requiring treatments, which led to changes in process for noting unnecessary or unasked for observations about a person."

"I proposed a regular follow-up satisfaction survey for the staff to give to the consumers of their services. I think the feedback they receive is worthwhile and helps them make changes as needed."

"[I} raised the issue of difficulty for a frail consumer negotiating [a] heath centre entrance. [The] issue was taken to building owners to address"

"I suggested a stamp or flag be used in the patient notes to identify when an intervention was used. This was adopted… with good effect."

"The most obvious example is when I'm asked to review a new or revised consumer information document. Committee members frequently seem to suddenly "get" how vast the gap is between their understanding of a hospital's processes, environment and policies when my feedback about the document is discussed."

"There is now a traffic island with pram cut out, and a pram ramp [outside the service]."

"I expressed concern that unintended impacts to patient care as a result of building works were a common occurrence, despite following existing hospital processes. Processes were put in place to improve the application of existing hospital process, no further impacts were reported, so I took that as a win."

3.9.2 Chairs and Secretariat providers

Chairs and Secretariat service providers also identified the difference that Consumer Representatives' make to committee processes and outcomes. Of respondents to the survey, just 12% of respondents felt committees would make the same decisions whether a rep was present or not. These participants also identified a wide variety of positive impacts that consumer representatives had achieved as committee members. These include asking questions about implementation of recommendations, emphasising the importance of clinical processes and documentation related to consumer informed consent, requesting data and evidence for decisions, and gathering or requesting feedback on proposed changes from community groups.

Professional participants observed that public documents and consumer information are greatly improved by advice from a consumer representative. They pointed to examples including research ethics applications, journal articles, and consumer information about clinical procedures. In all these examples, review by Consumer Representatives removes jargon, makes “wording more patient friendly,” helps committees be “more mindful of the community we are serving”, “ensured the document was well-rounded” and provided “great feedback about health literacy from a consumer perspective.”

Health service participants observed that Consumer Representatives consistently bring the committee’s conversation “back to the patient experience.” This can bring a different perspective that would otherwise not be considered, particularly when discussions get “too technical”:

“Having someone there from the community, looking out for the community is always grounding.”

While it is a difficult impact to quantify, Chairs and Secretariats consistently observed that having a consumer representative present in meetings changes the tone of conversations and the way issues are discussed. Consumer representatives bring a different “awareness and sensitivity” to the discussion, and a “different pair of eyes.” This can help committees refocus on the consumer or public interest, for example when balancing dual aims of developing evidence-based best practice clinical resources for patients that also acknowledge consumer priorities and questions.

“On multiple occasions I have witnessed reps ask questions or make comments which supported the committee to realise they were making a decision based on health service rather than consumer/patient/community member priorities.”

The examples below illustrate some of the ways that Chairs and Secretariat providers have observed Consumer Representatives influencing outcomes.

“[Reps ask] questions about data and evidence, for example “‘why results are improving?’”

“By keeping staff to account, for example by asking for follow-up of work that was implemented and how improvements have been sustained.”

“Recommending education platforms, inclusive practices and engagement ideas.”

“The consumer rep used her contacts with carer groups to provide information [on a particular topic].”

“Validating a direction the committee is reaching for… by providing research, policy framework or form of words.”

“Giving a more real world and less inward facing perspective on research and policy decisions.”

"The voice of the consumer has an immediacy and potency that the dry research/policy does not have."

"A reps presence keeps us focused on our patients and their families (we do anyway but it is a reminder."

3.9.3 Capacity development: health services and consumer representatives

In addition to the impacts on outcomes and processes, participating on committees also has an impact on consumer representatives themselves, in the form of enhanced knowledge and skills. This is also true for participating health service personnel.

Among consumer representatives who responded to the survey:

- 87% report they know more about the health system or services since becoming a report.
- 100% have learnt more about being an effective consumer advocate.
- 84% report they are part of a network of reps who support one another.
- 95% report positive relationships with health service staff
- 95% feel optimistic about consumer participation.
- 95% understand more about the challenges for health services.

Over 80% of Chairs and Secretariat providers report that they understand more about how to partner with consumers since working with consumer representatives.

3.10 Building a relationship

Consumer Representatives, and health service personnel, build these skills and knowledge in the context of a relationship. This can be considered a learning relationship, in which Consumer Representatives and Chairs/ Secretariat providers work together and invest the necessary time to build a sense of shared priorities, mutual trust and an understanding of how to enact the principles of consumer participation. One consumer representative in interview simply observed that "it takes time to get to know one another." A Chair similarly described that:

"Continuity is important. When the consumer rep becomes familiar to the committee they are included much more in the decision-making process."

A consumer rep recounted the process as follows:

"I think that sometimes other committee members see me as irrelevant, interfering, and ignorant. They somehow feel threatened and annoyed by my presence initially, until they see I am not the enemy they perceive me to be. I am there to help. We all share a common goal – I hope […] over time they become more accepting of me, and my role."

Both groups of participants identify that the quality of the relationship between each consumer representative, and each Chair and committee, is key to maximising the potential impact and contribution of consume representatives. Building a relationship of trust and mutual respect can take time, but it is essential to reaching a clear understanding of the role and contribution that the consumer representative can make and enabling their positive impact. This indicates that the CRP supports participating consumers and professionals to learn, gain and develop skills for consumer partnership. This is an important resource for health care quality improvement in the ACT.

Part of the process of building a relationship to support consumer representation relates to confidentiality. Chairs and Secretariat providers described the difficulty of balancing confidentiality around sensitive issues, with ensuring reps are provided with full information. Consumer representatives also identify this as a challenge, with one noting that “years down the track, they know I’m not a blabber.” Consumer representative and Chairs identified that it is harder to develop this necessary trust when committees meet entirely virtually. This is an area for continued attention by requesting agencies, Chairs, and the CRP.

4. Key outcomes

Overall, the range of positive impacts on committee outcomes, process and relationships indicates the CRP is successfully driving change in health care in the ACT and region by delivering:

- *Process outcomes* (such as better models of care and better design of specific health service initiatives).
- *Community outcomes* (for example, more relevant and readable consumer information resources which in turn enable better community health literacy).
- *Partnership outcomes* (in particular through mutual satisfaction with the quality of consumer partnerships).
- *Empowerment outcomes* (including for consumer representatives who develop their knowledge and skills in consumer advocacy).[51]

These four areas are recognised as key metrics of impact for consumer participation programs[52], and the CRP is making a positive difference in each of them.

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[14] See Note 12

[15] See for example Cancer Australia, Consumer Involvement Framework (page 9): national_consumer_framework_web_504af020f2184.pdf (canceraustralia.gov.au).

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