Reflections on Consumer Involvement in the Canberra Hospital Expansion Project

October 2023

Health Care Consumers' Association

100 Maitland Street

Hackett ACT 2602

Phone: 02 6230 7800

Email: adminofficer@hcca.org.au

Suggested citation: HCCA, *Reflections on Consumer Involvement in the Canberra Hospital Expansion Project.* Canberra, Australia. Health Care Consumers' Association. October 2023.

A catalogue record for this book is available from the National Library of Australia

ISBN: 978-0-6483157-9-7

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,
- 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-centred care meets the physical, emotional, and psychological needs of consumers, and is responsive to someone's unique circumstances and goals.

Contents

Acknowledgements

HCCA would like to thank all of the consumer and community organisation representatives who participated in CHEP committees, focus groups and user groups since the inception of the project.

The following people provided valuable insights which have greatly contributed to this report.

Alan Thomas
Anne Meuronen
Bianca Rossetti
C Moore
Darcy Whitmore
Geraldine Manser
Gev Khambata
Jo Bothroyd
Karin Calford
Kate Gorman
Louise Bannister
Nadia Owuor
Shobha Varkey

HCCA would like to thank staff of Major Projects Canberra, Canberra Health Services and the ACT Health Directorate who worked with us to ensure that consumer voices were heard in this project and made a difference to the outcome.

HCCA thanks the members of our Consumer Participation Committee, who provided feedback and guidance on this report during its drafting.

This report forms part of an overarching 2023 review of the HCCA Consumer Representatives Program. The larger review was completed by Dr Sarah Spiller.

The interview process for this report was conducted by HCCA staff Nadia Owuor and Darcy Whitmore.

Acronyms

ACTHD	ACT Health Directorate
AusHFG	Australasian Health Facility Guidelines
CHEP	Canberra Hospital Expansion Project
CHS	Canberra Health Services
CRG	Consumer Reference Group
CSB	Critical Services Building
CUG	Clinical User Group
ED	Emergency Department
EOI	Expressions of Interest
HCCA	Health Care Consumers' Association
MHCN	Mental Health Consumer Network
MoC	Model of Care
MPC	Major Projects Canberra
NSQHS Standards	National Safety and Quality Health Service Standards
PCG	Project Control Group
SDP	Service Delivery Plan
SPIRE	Surgical Procedures, Interventional Radiology and Emergency Centre (early name of the CHEP project)
UCH	University of Canberra Hospital

Executive Summary

This report documents the experience and reflections of consumer representatives, community organisation representatives, and HCCA staff on their involvement in the Canberra Hospital Expansion Project (CHEP). It captures the process, experience, and learnings of participation from a consumer/ community organisation perspective, with the intention of informing future consumer participation in health infrastructure projects.

From September 2019 until mid-2024 HCCA has been funded by Major Projects Canberra (MPC) to provide advice and the facilitation of consumer input to the Canberra Hospital Expansion Project (CHEP). The project is a $600 million investment to construct a new Critical Services Building on the Canberra Hospital campus.

There were several concurrent mechanisms for consumer participation in this project. The CHEP Consumer Reference Group (CRG) was established to provide guidance and advice through the design and construction phases of CHEP. Members of the group included HCCA, Carers ACT, Mental Health Consumer Network, the ACT Disability Reference Group, Ministerial Multicultural Advisory Council ACT and community representatives. The group met regularly and was chaired by HCCA.

At the beginning of the work, HCCA held three large, broad-ranging focus groups with a diverse invitation list of consumers and consumer organisation representatives. A fourth topic was also canvassed with consumer interviews and written input only. This helped us to make sure consumer representatives were informed by broad perspectives as they began their roles. In addition to this, there were three additional focus groups held throughout the project to provide input into specific consumer-facing aspects of the design. These were planned and co-hosted by HCCA and Major Projects Canberra.

Consumers were also members of selected clinical user groups. These are a series of design meetings where stakeholders progressively refine the design of a specific clinical or non-clinical area of a larger building.

This project began in an environment of change. A new government department, Major Projects Canberra, was only months old and oversaw the building of the Canberra Hospital Expansion Project. HCCA and MPC did not have a shared history of working together. Both needed to build relationships to support participation throughout the life of this project and develop a shared understanding of the value of consumer participation and its mechanisms. It took time to build relationships and shared processes that worked well for the project and the people involved on all sides. Consumers needed to learn about the roles of the different government and non-government partners, the parameters of the project the design process and

guidelines that would shape it. Meanwhile, our project partners learned about consumer participation and how to support consumer input into the design work.

Despite a slow start, over the course of the project, consumer representatives involved in CHEP successfully advocated for many design elements that go beyond what is required by the Australasian Health Facility Guidelines. Major areas of influence include greater accessibility for people with disabilities, safer and more comfortable family and carer spaces, better signage and wayfinding and dementia friendly design.

HCCA has distilled the following guidance for future projects from both our staff's experience and the feedback provided by consumer participants during interviews for this report:

1. Provide flexibility in how consumers participate: Encourage project partners to consider a range of different mechanisms for participation and support consumers to choose.
2. Include site visits to help consumer understanding of projects, and in-person meetings to consider project aspects such as finishes fittings, furniture, room layouts etc.
3. Provide training/ induction of project staff to consumer participation, the value it brings and how HCCA can coordinate consumer participation to improve design
4. Pursue diverse representation of community to participate in infrastructure projects
5. Provide infrastructure-specific training for consumer participants:
    a. Provide information about who the different government players are and what their specific roles in the project are.
    b. This includes Major Projects Canberra (MPC), Canberra Health Services (CHS), the ACT Health Directorate (ACTHD), as well as the various contractors and what they do.
    c. Include information about the AusHFG and other relevant guidance on design
6. Ensure that consumers are provided with an understanding of the project timeline, which includes when opportunities for input will be available on different aspects of the project.
7. Guide consumers' expectations of the work that they will be doing, as well as the timeframes and decision-making process involved. Create a draft work plan for the group which is regularly reviewed and updated. Have a schedule of planning meetings about the work of the group with project partners and HCCA which run in parallel to CRG meetings.

8. Keep consumers connected with each other and the project as a whole: ensure that consumers can share their experiences and learnings with each other throughout their involvement with the project.
9. Continuous involvement of HCCA staff.
10. Establish a shared mechanism for tracking consumer issues or needs, including when what has been raised, when the decisions will be made and resulting outcome.
11. Ensure that there is a feedback loop to consumer participants, informing them of advocacy outcomes, and providing them with the opportunity for continued access to this information, even if they are no longer involved in the project.
12. In partnership with consumers, design and deliver an evaluation plan, which evaluates their contribution to the project and captures learnings for all partners. Include post occupancy evaluation of consumer led design improvements.
13. Embed a mechanism for documenting consumer led improvements and ensuring that these are transferred to future projects, thereby building on work already done.

This report documents HCCA's learnings though our involvement in the Canberra Hospital Expansion Project. Its intention is primarily to document lessons learned about how to lead consumer participation in health infrastructure projects. A list of consumer-led design elements in the CHE Project has been published by MPC on their website. HCCA would like to see consumer led design elements from CHEP well documented by partners CHS and MPC, and a mechanism for their transfer into new projects.

1. About this report

This report shares the experiences and reflections of some consumer representatives, community organisation representatives, and HCCA staff on their involvement in the Canberra Hospital Expansion Project (CHEP). The intention of this work is to document the process, experience, and learnings of being involved, to guide improvements in supporting consumer participation in future infrastructure projects and promote a consumer-centric approach to health infrastructure development.

This work forms part of the 2023 internal review of the HCCA Consumer Representatives Program.

This report:

- describes HCCA's overarching role in the project, including significant events and stages that influenced our contributions,
- identifies key elements that underpin HCCA's involvement and influence in the project, highlighting successful aspects of consumer advocacy, like design wins, while also addressing challenges,
- contains reflections from consumers who were involved in the project,
- reflects on our relationship with Major Projects Canberra (MPC),
- provides insights into how HCCA supported consumers in understanding and influencing the complex design process, and
- discusses strategies to overcome challenges encountered during the project and captures consumers' perspectives on transferring successful aspects to future projects.

1.1. Methodology

Semi-structured interviews were used to elicit experience and reflections on consumer involvement in the CHEP.

We interviewed consumers and HCCA staff members who participated in various stages of the project. Some were no longer involved as the project reached its conclusion.

Interview participants were:

- six consumers who were members of the CRG, and/or participated in user groups,
- one HCCA member (President) who chaired the CRG in earlier years
- one HCCA staff member who chaired the CRG in later years, and
- four HCCA staff members who participated in the CRG and user group discussions.

Interview participants were asked about:

- their overall experience with the project,
- where they felt the group had an influence on design decisions,
- the challenges involved,
- suggestions for improvements to the process,
- what advice they would give to other consumers participating in similar projects, and
- whether they would consider joining another infrastructure project in the future.

1.2. Limitations

This review is not comprehensive and is a point-in-time reflection on our process and experience. Major Projects Canberra conducted an evaluation workshop of consumer involvement in this project in October 2023. Future infrastructure projects would benefit from an evaluation designed and carried out as a joint project of HCCA, MPC and CHS.

2. Background

2.1. About the Canberra Hospital Expansion Project

In September 2019 HCCA was funded by Major Projects Canberra (MPC) to provide advice and facilitation of consumer input to the Canberra Hospital Expansion Project (CHEP). This contract has been extended twice to allow for HCCA to continue to provide advice and support for consumers to participate in the CHEP Consumer Reference Group (CRG), as well as clinical and other user groups, as the project progresses.

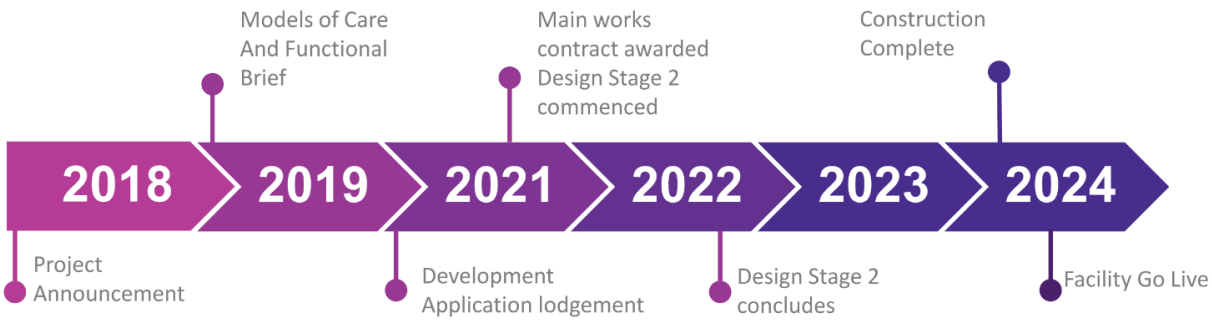
In 2020, Multiplex was selected to design and construct the new emergency, surgical, and critical health care building on the Canberra Hospital campus. HCCA has worked with staff from Major Projects Canberra, Multiplex, and Canberra Health Services (CHS) during this project.

The Canberra Hospital Expansion Project began construction in 2021 and is expected to be completed in 2024. The project is a $600 million investment to construct a new Critical Services Building (CSB) on the Canberra Hospital campus.

HCCA has a longstanding commitment to consumer involvement in health service planning, implementation, and evaluation. Our work in this area expanded significantly from 2009 as part of a jurisdiction-wide program of health services expansion and redesign. This was initially called the Capital Asset Development Program (CADP) and later re-branded as the Health Infrastructure Program. Major Projects Canberra was established in 2019 to lead the procurement and delivery of the Territory's infrastructure program.

2.2. Project timeline

The following is a timeline outlining significant milestones in the CHEP.



Consumers were involved throughout the project to ensure that consumer perspectives were integrated in all the project's various stages, contributing to a more patient-centred and effective health care facility. For example:

- Consumers were represented within the Project Control Group through the CRG chair's role, to help ensure that their perspectives and needs influenced important decisions.
- The CHEP Consumer Reference Group provided a dedicated platform for consumer input from various health advocacy groups.
- Consumer engagement extended to focus groups and project user groups, where consumers actively participated in shaping several key aspects of the project, including the development of Functional Briefs, the design of Repeatable Rooms, and the progression through Design Stage One (DS1) and Design Stage Two (DS2)
- Consumers contributed to the drafting of Models of Care which will be used in the new facility.

3. Mechanisms for consumer participation in CHEP

3.1. Consumer Reference Group

The Canberra Hospital Expansion Project (CHEP) Consumer Reference Group (CRG) was established to provide guidance and advice through the design and construction phases of CHEP.

The role of the Group is to provide guidance, advice, and consumer insights on a range of matters, including:

- building design
- service accessibility – from a range of consumer perspectives
- consumer safety, including cultural safety
- consumer communications and engagement during the design and construction phases
- wayfinding and user journeys

The Group held its first meeting in September 2019 and met monthly between 2019 and 2022. For 2023, the Group met every two months, finishing in early 2024.

Members of the group have included HCCA, Carers ACT, Mental Health Consumer Network, the ACT Disability Reference Group, Ministerial Multicultural Advisory Council ACT, People with Disabilities ACT, COTA ACT, Aboriginal and Torres Strait Islander Elected Body, and the CHS Aboriginal and Torres Strait Islander Consumer Reference Group. The Group was chaired by Dr Alan Thomas from 2019 to 2021, who served as HCCA President at the time, and has since been chaired by Kate Gorman, HCCA Deputy Director.

HCCA and MHCN consumer representatives had completed consumer participation training prior to their appointment. A shorter, modified version of this training was presented to group members including partners in an early meeting. Staff representatives from Canberra Health Services (CHS), Major Projects Canberra (MPC), and Multiplex also attended CRG meetings.

3.2. Consumer Focus Groups

HCCA held three large, broad-ranging focus groups on separate topics with consumers and consumer organisation representatives as we began this project. A fourth topic was also canvassed with consumer interviews and written input only. This helped us to identify matters of importance to consumers and their impact on design, and make sure consumer representatives were informed by broad perspectives as they began their roles in the CRG and the detailed design stage and user groups.

The topics of discussion in the focus groups and interviews were:

- Getting to, from, and around campus
- Features of clinical areas used by consumers

- Public facilities and spaces in the Critical Services Building
- Designing an accessible and inclusive hospital for all consumers

A broad range of consumers and consumer organisation participants were invited to contribute on each topic. Focus group meetings were held online with several staff members from MPC, CHS, and ACT Health Directorate (ACTHD) also attending.

In addition to the early broad-topic focus groups initiated and convened by HCCA, there were three planned focus groups/workshops throughout the project (late 2021 to mid-2022) to provide input into specific areas of work. These were planned and co-hosted by HCCA and MPC. Focus groups were held in inviting venues with catering and presentation facilities. The presentations about the topics were pitched to ensure they were tailored to the knowledge of consumers. Architects and designers presented on specific aspects of the project and sought advice from the group for incorporation into design.

These groups considered the following topics (several topics considered in some groups):

- Landscaping, spaces and furniture in outdoor areas
- Hospital Road changes
- Wayfinding and signage
- Family respite lounge
- ICU Paediatric retreat
- Waiting areas
- Welcome hall and front of house amenities.

Focus groups proved to be both engaging and rewarding for consumers and had a noticeable impact on the design work. This is a feature to repeat in future projects, with thorough planning and early identification of topics, to embed focus groups throughout the design phases.

3.3. User Groups

Clinical user groups are a series of design meetings where stakeholders progressively refine the design of a specific clinical or non-clinical area of a larger building. These groups are very technical and consider architectural plans in increasing levels of detail over time. They are usually held in a series of three in short succession, with an expectation that participants will have considered the plans before attending. The participant group is made up of stakeholders of the area including senior clinicians, operational staff, work health and safety staff, infection control, consumer representatives, and relevant others. At each meeting design issues are raised and solved, until a final design is agreed and eventually signed off by the group.

HCCA was invited to provide consumer input into user groups. We went through a selection process to identify the user groups that aligned closely with consumer priorities. Some areas of the building were not consumer-facing (for example, loading docks and helipad) or were clinical spaces which did not require consumer input, for example, operating theatres. It was valuable to consider priority spaces for consumers and select where we would participate ahead of time.

HCCA participated in the following user groups and meetings to shape the following areas and functions:

- Reception/triage
- Emergency Department
- Mental Health Short Stay Unit
- Behavioural Assessment Unit
- Acute treatment zone
- Paediatrics
- Admissions, discharge, and delivery
- Intensive care unit
- Cardiac inpatient unit
- Inpatient unit
- Wayfinding and signage
- Front of House and Welcome Hall
- Landscaping
- Interiors
- Acoustics
- Art

3.4. Aboriginal and Torres Strait Islander consumer participation in the Canberra Hospital Expansion Project

Major Projects Canberra also involved consumers in this project through the ACT United Council of Ngunnawal Elders, and the CHS Aboriginal and Torres Strait Islander Consumer Reference Group. This participation influenced spaces within the project which were specifically for Aboriginal and Torres Strait Islander community members and staff, and some of the public artwork. HCCA provided consumer participation training for the Aboriginal and Torres Strait Islander Consumer Reference Group and advised and attended several of their early meetings about the CHE Project. Beyond this, HCCA was not involved in this element of consumer participation for the CHE Project.

4. Challenges for consumer advocacy and participation in CHEP

4.1. Consumer understanding of different roles of partners and stakeholders

At the start of HCCA involvement, Major Projects Canberra (MPC) was a brand-new government department that had come into existence on 1 July 2019, only months before funding HCCA to support consumer participation in the Canberra Hospital Expansion Project (CHEP, then known as SPIRE) in September of that year. Up until that point, HCCA's main partnerships in consumer participation had been with public health services, supported by long-term relationships with the individuals working within them. HCCA and health service partners share a considerable history and body of knowledge about consumer participation, underpinned by Standard 2 (Partnering with Consumers) of the National Safety and Quality Health Service Standards (NSQHS Standards).

At the beginning of HCCA involvement in this project, we needed to build with MPC both a shared understanding of the value and mechanisms of consumer participation, and the relationships to support participation throughout the life of this project. HCCA and the broader community had little knowledge of the role of MPC and how it would play out in a health infrastructure project of this size. On reflection it is fair to say that there was goodwill from both organisations, but little knowledge of each other as the project started.

> "We didn't know what they didn't know about consumer participation and partnerships, and they didn't know what we didn't know about infrastructure builds" - HCCA staff member

Adding to consumer's confusion about roles was the separation of Canberra Health Services and the ACT Health Directorate, which had occurred in October 2018. This resulted in a service delivery arm of health care in the ACT (Canberra Health Services, or CHS) and a policy and planning arm (the ACT Health Directorate, or ACTHD). Functions and roles within these two organisations were still solidifying as this project began, and consumers did not yet have a clear understanding of which functions had been delegated to which organisation, and what this meant for how to direct advocacy around consumer issues in health care.

Overall, these major changes in Government partner functions and relationships translated into some challenges for consumers at the beginning of the project.

While in interviews it was clear that relationships and processes improved significantly over time, there were several instances during the initial stages of the project that left consumers feeling frustrated and discouraged. The challenges that interviewees spoke about during the early days of the project included limited consumer engagement opportunities, their difficulty understanding the complexities

involved in building a hospital, a lack of communication from project leads, and feeling excluded from decision making.

Some interviewees told us the challenges of CHEP had come as a surprise after hearing of the success of consumer involvement in the earlier University of Canberra Public Hospital (UCH) project. Throughout the UCH project, consumers had worked hard to build a level of trust and understanding of the value of consumer input. Consumers who joined CHEP after hearing of the successes at UCH were disappointed to realise that successful approaches to consumer engagement had not necessarily been carried over. Although consumers had spent time advocating for inclusive design elements during the UCH project, these would not necessarily be automatically included by those working on CHEP.

These challenges make sense given the changed government structures and the introduction of Major Projects Canberra as a new department since the UCH project. While a few of the CHEP staff had worked on both developments, most had not, and were not aware of that history. Many had not worked with HCCA or consumer representatives before. Several HCCA staff were new to infrastructure too.

For CRG members it took time to understand how the complexities of the project, and the many stakeholders involved, influenced the timeline of the project.

> "…building a state-of-the-art hospital from scratch in an existing complex, necessitating demolitions and relocations, etc. is a very complex, intricate and technologically challenging process involving not only builders and clinicians, hospital administrators, but also the politicians, several government departments and ministries as also the full force of the bureaucracy and red tape. Things move at glacier speed cutting through the mountains of paperwork, Tenders, compliances, approvals needed and the lot." – CRG Member

In participating in the early stages of the Consumer Reference Group (CRG) and user groups, consumers became aware that there were different priorities in the stakeholder mix, and the consumer priority of universal design elements was not equally prioritised by some other stakeholders. Consumer representatives worked to convince stakeholders and partners to support and prioritise consumer-centred design.

Consumer representatives involved in CHEP were challenged with awareness of the tensions between the priorities of politicians, funders, clinical staff, and consumers, learning about the role planning and design guidelines had in shaping what was possible, while still advocating for additional and changed design elements to benefit the community using these spaces.

4.2. Partner knowledge and experience of the value of consumer participation

Consumers who had been involved from an early stage questioned if project partners and contracted designers/architects understood or had experienced the value of consumer expertise and input in a project like this before.

> "People had their heart in the right place but there was no clear understanding of what a consumer can offer [to this process]. Sometimes it felt as if consumers were placed off to the side." – CRG member

> "… people not understanding the value of consumer input and just viewing it as 'window dressing'" – User Group participant

> "They [Multiplex contractors] could only respond hypothetically based on high level generalised plans and certain assumptions. This made us feel a bit demoralised at that stage thinking that they were going through the consumer engagement process just to tick off the boxes. Fortunately, things would change." – CRG member

When discussing the value of consumer knowledge many consumers highlighted that they were unclear what architects and planners understood about consumer-centred design and standards in health care. Some consumers remarked that consultants, architects, or planners involved were not aware of the 'Partnering with Consumers' Standard that is an overarching standard of the NSQHS Standards. It codifies consumers as partners in the planning, design, monitoring, and evaluation of health care services. While this standard applies to the design and delivery of health services, consumers had an assumption that its principles would be understood by partners and applied to their participation in a health infrastructure project. This was not necessarily the case.

Several consumers interviewed suggested it would be useful for infrastructure staff to have an induction on consumer participation to understand the value it brings and how HCCA can coordinate consumer involvement and insights to improve design.

One of the results of this lack of experience was that there was no clear work plan and limited opportunities for input in the consumer reference group's early meetings. Participants shared that early on they were often simply presented with information about the project, which although valuable, was only part of what they expected. They hoped for a genuine platform to have conversations and provide advice about consumer and carer needs.

> "Sometimes meetings were a presentation not a conversation. This is not necessarily a good use of consumer time if you are being shown a design that doesn't really meet consumer needs, yet you have no opportunities to change it." – User Group Participant

Several interviewees spoke about how, over time, consumers were given more opportunities for input, with interactions with partners in the Consumer Reference Group (CRG) shifting from presentations to conversations. Many of those interviewed attributed this to the relationship building between HCCA and MPC led by the chair of the CRG.

> "The inclusion of consumer ideas came from strong interpersonal relationships that the chair put a lot of effort into building" – User Group participant

4.3. Consumer understanding of the infrastructure design process and timeline

An added challenge for consumers was in not understanding the project timeline, or what happened in each stage and where the opportunities for influence lay. This was a source of frustration for consumers. Without a clearly documented timeline for consumer participation, it was difficult to establish when consumer input could be most useful. This made it difficult to prepare advocacy points for meetings or understand when to raise issues and suggestions. The absence of a clear timeline may reflect a lack of experience of the project partners in working with consumer participants, and the responsibility partners have to provide the background and education required for people who are not medical or infrastructure experts to be able to usefully contribute.

Several consumers felt disheartened at speaking up and then being told they would have a chance to contribute 'down the track' with no clear understanding of when or how this would happen.

Several interviewees explained how important it was to have clarity about the opportunities for influence and understand the decisions that have already been made (and therefore what the limits to influence are). However, this was limited to information presented in the early stages of the project, which led to confusion over how and when consumers could best contribute.

It would also have been very useful for consumer participants to have started the project with access to data to back up the rationale for the new building and what services would be provided inside it.

HCCA and consumer representatives did not have enough (or in some cases any) understanding of the Australasian Health Facility Guidelines (AusHFG) minimum standards for health buildings, and other relevant design standards. It would have been useful for consumers to understand these minimum requirements, to assess where and how consumer needs go beyond what is specified in the guidelines, to guide their advocacy. This would also have been useful groundwork for HCCA to have carried out in the very early stages with the ACT Health Directorate and Canberra Health Services, so that we could share an understanding about what

constituted the bare minimum in design, and what level of commitment and funding there was to go beyond that minimum.

We also didn't know that in addition to the AusHFG, CHS maintains its own internal health infrastructure guidance document which was also relevant at times.

Over the course of the project, consumer representatives involved in CHEP successfully advocated for multiple design elements that go beyond the AusHFG. Some examples include dementia-friendly design, greater wheelchair accessibility, safer and more comfortable carer spaces, and better signage and wayfinding.

Consumers involved in user groups and the CRG expressed frustration that substantial amounts of time were spent on elements that were too late for input, too soon, or were perhaps not important in the larger scheme of things. This illustrated a real need for clearer communication about where the decision points in the process lie, and honest conversations about where consumer input can be influential.

While not directly a responsibility of MPC, it would have been useful for the consumers at user groups to understand more about the models of care that were currently being used and would be transferred (or adapted to) to the new building. We didn’t have enough knowledge about the models of care for each space and it would have been helpful to have seen this documentation, or had a discussion with the clinicians about it, ahead of each design user group. While models of care would need to be revised for the new building, a basic understanding of the ways health services are provided would have helped consumers provide relevant advice.

Despite the challenges, user group meetings were an influential place for consumer representatives to be, and many of the design inclusions we achieved were made through participation in these groups.

The ramp to Building 6 was an example of where a lack of information led to confusion and frustration for consumer participants. An existing ramp to Building 6 (next to the Critical Services Building, or CSB) was demolished to make way for the CSB. A new ramp was required in a different location to replace it, as a condition of development approval.

The infamous Building 6 ramp

CRG members with expertise in advising on accessible design spent time and effort advocating for improvement details on the excessively long ramp such as rest points, incline, and the need for shelter. We later discovered that the ramp was always intended to be temporary, as it was part of the next stage of the campus redevelopment plan that both Building 6 and its ramp would soon be demolished. Had we known this, we would not have wasted time trying to improve the ramp, however this information was not shared with the group at the time. The consumer reference group was also not advised until quite far into the discussions that the ramp does not provide access to areas used by consumers, being attached to a building used mostly for administrative work. Any staff member with mobility issues would be able to access an elevator with a staff pass.

4.4. Tracking progress of consumer advocacy

An important element of consumer participation is for project partners to ‘close the loop’ and provide information back to their consumer partners about when their advocacy has been considered, what the decision or outcome was, and why.

An issue for consumers and HCCA was that once an advocacy point or design need had been raised, we lost sight of whether or when it was going to be considered, and if it had been, what the outcome was. We needed a shared mechanism with MPC to

track the needs and issues consumers raised, when they would be considered, what the outcomes were, and why. While this was recorded in internal processes by MPC, it was not visible to HCCA and consumer participants and therefore could not inform our understanding. HCCA maintained our own records of the issues that consumers had raised but could not always include what progress had been made, and therefore were unclear what needed to be pursued or when.

Due to this, sometimes it has taken a long time for consumer participants to realise that a design feature advocated for in the early stages of the project has in fact been included in the design and is a win for consumer advocacy. Participants who have not stayed involved in the project may not have realised the fruits of their labour. An example of this is individually dimmable lighting in patient bedrooms. The CRG was surprised and pleased to find in 2023, when provided with an opportunity to test the lighting in the prototype shed, that this feature had been included. It had been raised in 2019, and the group had not been advised of its inclusion.

> "It was hard to track where exactly our influence happened – sometimes you would advocate over and over for a particular element and learn years later that it had in fact already been included" – HCCA staff member

This matters because it affects the motivation of the consumer participants. In general, people participating in consumer advocacy roles need to feel heard and able to influence the project in some way. When advocacy does not appear to have an effect, people become discouraged and may stop participating. Knowing that some design decisions are not made until later in the project, people will continue participating and wait for the outcome of a decision, as long as they know that it is pending.

Due to this lack of clarity about influence, those who did not continue in the later phases of the project were less positive about the overall experience. Those who left the project were also less clear about what had been successfully advocated for. They were also less likely to participate in infrastructure projects again.

This differs from the experiences of consumers and HCCA staff who remain involved in the process in 2023. Those still sitting on the CRG when interviewed were able to quickly identify multiple clear design 'wins' from the group's advocacy. These participants were also more likely to want to contribute to an infrastructure project again.

5. Reflections on process and practicalities

5.1. Timing of consumer participation

HCCA was not involved in the very early stages of the Canberra Hospital Expansion Project (CHEP). Therefore, many project parameters were already set when our facilitation of consumer participation in the project began. This was a missed

opportunity to more fully partner with consumers and centre their needs in the project. While the consumer reference group may not have been the right vehicle for participation at the early stages of the project, it would have been appropriate and very worthwhile to include consumer advice right from scoping studies and the creation of a budget bid to fund the feasibility of this project.

Providing input into the early documentation could have embedded consumer-centred design elements from the very beginning, removing the need to continuously advocate for certain elements of design or inclusion of consumer advice, and setting expectations for all parties about the role of consumer advice in this project.

This project could have had greater alignment with other ACT initiatives and 'big picture' work. There were several relevant strategies and action plans occurring alongside CHEP, in the context of disability (the Canberra Health Services Disability Access and Inclusion Plan; the ACT Disability Strategy) and sustainability (the ACT Circular Economy Strategy). These strategies involved community consultation and research. This work could have been drawn upon to ensure the CHEP meets community needs and complements other local approaches to health, infrastructure, and service delivery.

5.2. Meeting arrangements

While COVID posed an unexpected barrier to attending design sessions in person, consumers highlighted that there were already some participation barriers prior to lockdown. One user group member raised the issue that drawings and maps were too difficult to read on their own laptop. They resorted to printing these materials off in a larger format at the local library. Another user group member said it would be valuable to be invited to a boardroom in person, so that designs could be laid out and explained. However, some consumers shared with us that there were several occasions when they tried to show up to meetings in person and found the meeting had been cancelled, or they were unable to enter passkey-protected areas.

For some participants, the necessity to hold meetings solely online due to COVID *enabled* their participation, where previously they had not been able to participate if they could not attend meetings in person. Online meetings benefited consumer representatives who did not drive, had mobility issues, were immune compromised, or were caring for others.

5.3. Supporting and coordinating consumer advocacy

For consumer representatives, and consumer advocacy organisations, there are several challenges involved in attending user groups. User groups are highly technical and there are limited consumer representatives who have an interest in the fine detail of health infrastructure and want to do this kind of work. It can be challenging to find enough people for consumer representation on a large project with multiple concurrent groups. Meetings are long, sometimes two or three hours each, and there is often lengthy discussion about detailed topics which are not consumer-facing and consumers cannot easily contribute to. Meetings are often

cancelled and moved with very short notice, around the availability of senior clinicians. It is therefore difficult for consumer representatives to have availability for the meetings, and even when they had initially agreed to participate, when the timings changed at short notice HCCA staff would often need to proxy for the original representative.

Consumer representatives who participated in user groups felt it was important to have at least two consumers in each meeting. It was more difficult to emphasise consumer perspectives alone without support. User group participants shared that they felt dismissed at times by clinical staff, architects, or planners who didn't recognise the specific role of a consumer representative, saying 'we are all consumers'. This indicates a lack of awareness that other group members were (due to their attendance as employees) prioritising non-consumer perspectives while acting in their professional capacity, while consumer representatives attended to act as an advocate for the community.

A successful aspect of participation in user groups was HCCA's development of a template that consumer participants used to document concerns and issues they had raised in each user group, so that they could be shared with others and consumer influence tracked more easily. We also shared the completed templates with MPC so they could understand and have documentation of consumer perspectives, needs, and concerns.

Consumers raised the topic of broad community representation several times. They emphasised the need for a greater diversity of consumer representatives on projects such as CHEP. Several consumers felt that we need to see some younger consumer representatives to provide input about what younger people need in health care.

> "We need to make sure people who are using these spaces are heard from, and not just having their needs assumed" – CRG member

Consumers involved with CHEP shared it was also important to hear insights from past representatives about how to advocate effectively, and to maintain a sense of connection with other consumer representatives working in infrastructure. They emphasised that it is crucial to keep in contact with other representatives for opportunities to debrief, support each other, and understand where areas of progress and challenge are happening in the project. This can help consumers to remain confident while also guiding their advocacy.

> "It is vital to keep consumers chatting to each other, even just for a quick coffee or zoom meet up. Things can become very siloed and you do become quite focused on your own area. It's important to keep sharing updates amongst each other." – User Group participant

A user group participant said it was useful to hear what had already been agreed to in other areas. Architects and designers were often assigned to different areas and not necessarily communicating across the project about decisions. When consumers were able to share with architects that consumer-centred design had already been confirmed in a different area, it was more likely to be incorporated quickly, speeding up the advocacy process.

Multiple interviewees appreciated HCCA staff attending user groups to be able to support the advocacy of consumer representatives. HCCA staff having good oversight of the conversations and decisions in user groups led to better coverage, support, and coordination of advocacy.

5.4. Supporting consumer understanding

Many consumers interviewed highlighted the value of the prototype shed in helping them to understand aspects of design and layout, and make better design decisions. The prototype shed was constructed by Multiplex and opened in February 2022. Its purpose was to provide scale mock-ups of key hospital rooms and spaces, as well as a selection of repeatable rooms. It is also intended to be further used for staff training and induction.

Consumers reported that they were well-supported by CHEP staff to view and attend events at the prototype shed. The prototype shed helped consumers to understand if design elements were suitable by allowing them to interact directly with the spaces, layout, furniture, and fittings. A consumer described the walking through the prototype shed as a very validating experience.

The shed became a useful tool for consumers to explain how to make environments more accessible, as well as an encouraging space for them to see tangible evidence of their advocacy.

Site walk-throughs were also raised as an important tool for consumer understanding of infrastructure. Consumers noted that it is important for people with disabilities to move through a campus or building to test its level of accessibility. Without this, it is difficult to understand if campus modifications are safe and accessible for people who are unwell and/or have a disability to navigate. While a drawing may contain these details, it is easier to see and feel an incline, footpath cutaways, and pathway condition or size.

> “The prototype shed was really useful. We need to keep using models like this so people can test ideas and spaces” – HCCA staff member

> “It was great to see people who had been a part of the process, visit the prototype shed and hear them say ‘wow we helped you design this’.” – CRG member

“The prototype shed was good, especially for accessibility design aspects. Having the shed felt like it was a good way to identify issues and pick up on things before it was too late” – HCCA staff member

6. Impact of consumer participation

Those who participated in the project were able to identify multiple design 'wins' to come from consumer advocacy. As the project had a 'repeatable rooms' methodology, any improvements are repeated across every room of the same type, across the building. For example, when a power outlet is added in a patient room for consumers and carers to charge their devices and equipment, it is added to every patient room of that type.

Consumers and HCCA staff members reflected that, over time, it became evident that project partners considered consumer needs more often and became more open to incorporating suggestions that went beyond the Australasian Health Facility Guidelines (AusHFG). This reflected growing trust for the advice of consumers and an understanding of the value they can bring to health infrastructure design.

Consumers shared that as trust was built, those making design decisions genuinely listened and made clear efforts to integrate features to improve accessibility. Many participants identified these accessibility features as a major win from their advocacy.

6.1. Dementia-friendly design

An important example of improved accessibility for consumers is the inclusion of elements of dementia-friendly design. HCCA directed planners to Dementia Australia contacts. Dementia Australia creates relevant resources such as a guideline for dementia-friendly environments. Consumers were strong advocates of making key design elements dementia friendly.

It appeared that project and contractor staff were not always aware of what dementia-friendly design was, yet began to include some elements because of consumer knowledge sharing and advocacy. The inclusion of dementia-friendly design was cited as a source of pride for many of the people we interviewed, with one consumer highlighting that this type of design will clearly benefit our ageing population for years to come.

6.2. Wayfinding and signage

A few interviewees highlighted wayfinding and signage as an example of good communication between planners and consumers in the Canberra Hospital Expansion Project (CHEP) process. HCCA had previously collected consumer feedback on wayfinding and signage from other work on the Canberra Hospital campus and the focus groups held at the beginning of the project. This included consumer experiences of trying to navigate websites and physical spaces, as well as communicating with staff and understanding where to go when on campus. Planners incorporated this research where they could, while also informing consumers when and why particular advocacy bids could not always be included. This ultimately resulted in more intuitive wayfinding design such as better colour coding and ensuring signs were placed at crucial decision points.

6.3. Physical Accessibility

Planners also listened to consumers when they made suggestions about how to make spaces more welcoming and accessible for wheelchair users. Clear wins in this area include automatic doors on public toilets, improvements to the layout and fittings within bathrooms, beverage bay design, and the placement of accessible reception desks. The changes in design to meet the needs of wheelchair users illustrate how making design more accessible can meet the needs of all consumers, carers, staff, and visitors who use these facilities.

For example, lowering the height of reception counters benefits not only wheelchair users, but also those with health issues which mean they would prefer to sit in a chair, and it also creates an environment where a receptionist employee can be a wheelchair user. A consumer highlighted that replacing heavy doors with automatic ones allows sick or older people to go to the bathroom without help opening the door, giving them more independence. Automatic doors are also more hygienic and prevent the spread of illness for everyone using the public bathrooms.

An important design win was the inclusion of a "Changing Places" bathroom. These bathrooms are designed for people with high support needs to be able to use the bathroom. Changing Places include a height-adjustable, adult-sized change table, a ceiling hoist, a privacy screen, a central toilet with space for carers, extra circulation space, and an automatic door. The concept behind these bathrooms is to place them in common public places to allow for everyone to be able to participate in the community. Before this inclusion, there was not a public bathroom on the whole Canberra Hospital campus that could serve an adult person with a disability who requires a ceiling hoist and change table. We heard from consumers in the course of this project who told us that they would not attend the hospital campus for any reason if they could not be sure a suitable public bathroom was available to them if they needed it.

Over time the consumer reference group reflected that the strong advocacy from organisations supporting people with disabilities led to improvements that benefited everyone, not just people with a recognised disability. In fact, because it's a hospital campus, many if not most of the consumers visiting will have some form of impairment whether temporary or permanent, and designing to support these needs often means adopting universal design, which improves accessibility for everyone.

6.4. Carers and family

Carers and family members are an under-recognised part of the health care team which supports a patient. Designing health care facilities with carer and visitor experiences in mind supports the care and wellbeing of patients. Interviewees shared how their successful advocacy for safe and comfortable carer spaces was one of the most rewarding parts of the project. Many interviewees mentioned the family and carer lounge as a key design win. As many CRG members were carers or

had been cared for, they understood the need for families and carers to have a safe comfortable space while visiting the hospital.

> “The biggest win for me would be the family and carer lounge. Having a locked, safe space for carers and seeing it come to light from our vision was rewarding. Because it’s key pass protected, if you fall asleep you can feel safe. There is opportunity for carers and visitors who are travelling long distances to have a shower space with towels provided. Having a social worker there to help people also feels really important with the aftercare element.” – CRG member

> “People have to spend a lot of time in the hospital and they need to have spaces where it doesn’t feel like a hospital. It is important to have a welcoming safe space where people don’t feel anxious and exhausted.” – CRG Member

7. Guidance for success in future projects

From the experiences and knowledge of the consumers and HCCA staff interviewed for this report, we can draw the following guidance to inform our work in future projects:

1. Provide flexibility in how consumers participate – encourage project partners to consider a range of different mechanisms for participation and support consumers to choose.
2. Include site visits to help consumer understanding of projects, and in-person meetings to consider project aspects such as finishes fittings, furniture, room layouts etc. Include consumers in off-site visits by the project team to other facilities to provide greater knowledge for consumer participants.
3. Provide training/induction of project staff in consumer participation, the value it brings, and how HCCA can coordinate consumer participation to improve design.
4. Pursue diverse representation of community to participate in infrastructure projects.
5. Provide infrastructure-specific training for consumer participants:
    a. Provide information about who the different government players are and what their specific roles in the project are.
    b. This includes Major Projects Canberra (MPC), Canberra Health Services (CHS), the ACT Health Directorate (ACTHD), as well as the various contractors and what they do.
    c. Include information about the Australasian Health Facility Guidelines (AusHFG) and other relevant guidance on design.
6. Ensure that consumers are provided with an understanding of the project timeline, which includes when opportunities for input will be available on different aspects of the project.
7. Manage consumers' expectations of the work that they will be doing, and the timeframes and process involved for decision making. Create a draft work plan for the group which is regularly reviewed and updated. Have a schedule of planning meetings about the work of the group with project partners and HCCA which run in parallel to Consumer Reference Group (CRG) meetings.
8. Keep consumers connected with each other and the project as a whole: ensure the ability for consumers to share their experiences and learnings with each other throughout their involvement with the project.
9. Ensure continuous involvement of HCCA staff.
10. Provide a shared mechanism to track the consumer issues or needs that have been raised, when decisions will be made, and what the outcomes are.

11. Ensure that there is a feedback loop to consumer participants to inform them of the outcome of the advocacy, and that they have an opportunity to be connected to this even if they leave the project.
12. In partnership with consumers, design and deliver an evaluation plan, which evaluates their contribution to the project and captures learnings for all partners. Include post occupancy evaluation of consumer led design improvements.
13. Embed a mechanism for documenting consumer led improvements and ensuring that these are transferred to future projects, thereby building on work already done.

8. The future

Many of those we interviewed stressed that they would like to see successful design wins from this project recorded and committed to in future projects. Consumers expect to be involved in future projects, and should not need to explain why the same design elements should be included in each different project.

> "Whatever we've learned from CHEP, we need to transfer to future infrastructure projects, specifically Northside, there are design features that really should be repeated. "– CRG Member

HCCA would like to see learnings from the Canberra Hospital Expansion Project (CHEP) well documented by partners Canberra Health Services (CHS) and Major Projects Canberra (MPC), and a mechanism for their transfer into new projects. Future project staff will then have a valuable resource to support consumer needs in health infrastructure design. It would be great to see government partners carry knowledge about best practice consumer partnerships and practical information about consumer needs in infrastructure into future projects.

When interviewees were asked if they would participate in a similar infrastructure project again, they said:

> "Yes, because we can actually point to wins and stay motivated." – HCCA staff member

> "Of course! I am really proud of the results that HCCA have had. The hospital is not perfect, but it's better off because of the hard work and input provided by HCCA consumer representatives." – CRG member

For some, design wins were evidence of the consumers' influence on the project:

> "I feel lucky to know that a lot of what we did helped make the design better" – User Group participant

> "As a group CRG has had some excellent wins" – CRG member

> "This experience really exceeded my expectations of what could be included in a new space" – CRG member

9. Appendices

9.1. Detailed design wins

This link provides a more detailed list of consumer-led design improvements on the Canberra Hospital Expansion Project.

Consumer groups - Canberra Hospital Expansion (act.gov.au)

9.2. Consumer advocacy brief

This link provides a background briefing document, created for consumer representatives participating in user groups on the CHE Project. It gives a good overview of the needs and concerns consumers had shared with us to inform advocacy in this project.

CHEP: Briefing Document for Consumers - HCCA