

# Improving health care in the ACT: HCCA's contribution

2021–2024





This report was developed by Collective Action – a social impact consultancy specialising in designing and evaluating initiatives that challenge inequality and build safer and more inclusive communities.

We would like to thank the stakeholders we interviewed for their time and thoughtful contributions to this project.

Suggested citation: Collective Action. Improving health care in the ACT: HCCA's contribution 2021 - 2024. 2024

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# Executive summary

This report was developed by Collective Action to help Health Care Consumers' Association (HCCA) demonstrate its contribution to building a consumer-centred health system in the ACT that provides safe, accessible, and high-quality health care.

HCCA is the peak health consumer organisation in the ACT and a health promotion agency. HCCA works to improve the quality and safety of health services by shifting the role of consumers in the health system. It does this by providing a voice for consumers on health issues and providing opportunities for consumers to participate in all levels of health service planning, policy development, and decision making.

It can be difficult to demonstrate the contribution of organisations like HCCA that work to improve whole systems rather than individual services. This is because systems-level change doesn't happen in a straightforward way; it is influenced by a range of interconnected factors, it can take time to emerge, and it's achieved through the collective efforts of many people and organisations. To overcome these challenges, we drew from the field of systems thinking – an approach and set of tools for examining the wide range of factors, and the relationships between them, that drive problems and influence the effectiveness of interventions. We integrated systems-thinking approaches with theory-based approaches to evaluation, which aim to establish a cause-and-effect pathway from a program to the desired outcomes. Combining these approaches enabled us to create an evidence-based model and narrative demonstrating how HCCA contributes to systemic changes in the health system, and how these systemic changes contribute to improvements in health care.

In this report, we demonstrate HCCA's contribution to improved health care in the ACT during the period of its 2021–2024 strategic plan. We present 14 case studies that document examples where HCCA contributed to systemic changes in the health system. We map these case studies against the systems change model to demonstrate how these systemic changes contributed to improvements in health care. Using this approach, we demonstrate that HCCA contributed to significant improvements in health care in the ACT over the 2021–2024 strategic plan.

These improvements include:

-  The establishment of new consumer reference groups with governance mechanisms, processes, and practices that facilitate effective consumer participation.
-  The establishment of new health services that address unmet needs in the community, including a Paediatric Liaison and Navigation Service and a dedicated inpatient palliative care ward.
-  The co-design of new programs, such as a program supporting physical activity among women from multicultural backgrounds.
-  Improvements to the accessibility, safety, and quality of health infrastructure.
-  Improvements to health literacy information for consumers and health professionals.

# Overview of report structure

The report is presented in three parts. These are summarised below.

## PART 1:

### Our approach to demonstrating HCCA's contribution to improved health care

In this part of the report, we provide an overview of our methodology and present HCCA's Systems Change Model: an evidence-based model that illustrates how HCCA contributes to systemic changes in the health system, which in turn contribute to improved health care. The model is provided on [page 17](#).

We started by reviewing HCCA's documentation to identify examples of HCCA contributing to changes in the health system. We then substantiated these changes and HCCA's contribution to them through interviews with external stakeholders and publicly available documentation. We used this information to develop case studies that document HCCA's contribution to improvements in health care.

We performed cross-case analysis to identify patterns in HCCA's contributions across different cases. Our analysis was informed by the field of systems thinking. Systems-thinking approaches show that observable events and changes in systems, such as improvements in health care, are driven by systemic changes, such as changes in policies, practices, relationships, and resource flows. We integrated systems-thinking approaches with theory-based evaluation approaches to create an evidence-based model that illustrates how HCCA contributes to improvements in health care.

## PART 2:

### HCCA's contribution to improved health care in the ACT

In this part of the report, we provide an overview of the case studies and in-depth analysis of HCCA's contribution to systemic changes in the health system. We also highlight some key characteristics of HCCA that have enabled its contributions.

#### Case studies: Showcasing HCCA's contribution

We provide an overview of the 14 case studies, which provide examples of HCCA's contributions to improved health care in the period of the last strategic plan. We map these case studies against HCCA's Systems Change Model to demonstrate HCCA's contributions to each level of the model.

## In-depth analysis: How HCCA contributes to systemic changes that underpin improved health care

After demonstrating HCCA's contributions to each level of the model, we take a closer look at Level 1: Systemic changes in the health system that facilitate effective consumer participation. This level contains key factors that influence the way systems operate: policies, practices, resource flows, relationships, power dynamics, and mental models.<sup>1</sup> These factors can either enable or hinder systems change. We draw from the case studies to illustrate how HCCA helps to strengthen the enablers and reduce the barriers to effective consumer participation. HCCA's contribution to changing each factor is summarised below.



### Policies and practices

HCCA provides advice and practical support to health services, decision makers, and community organisations to ensure their consumer engagement activities are meaningful, transparent, supported, and inclusive. This includes drafting or providing input into governance frameworks, policies and procedures, and guiding practices.



### Resource flows

HCCA facilitates and strengthens the flow of information and resources between stakeholders across the health system, including consumers, health care providers, policy makers, and decision makers.



### Relationships

HCCA facilitates connection, communication, and collaboration between stakeholders across the health system, including consumers, health care providers, policy makers, and decision makers. This supports greater consumer participation in health service planning, policy development, and decision-making processes.



### Power dynamics

HCCA contributes to shifts in power dynamics that give consumers more influence in the design and governance of health services and in their own health care. One of the ways HCCA does this is by strengthening the influence of consumer representatives. By providing consumer representatives with training and support, HCCA equips them with the knowledge, skills, and confidence to contribute to decision making on advisory committees. HCCA also helps consumers build the knowledge and skills to participate in decisions that affect their health and wellbeing.



## Mental models

HCCA has been contributing to changes in how people think about consumer participation for decades. When HCCA was founded, the focus was on shifting mental models so that consumers would be viewed as active participants in their health care instead of passive recipients. While consumer participation is embedded in many aspects of the health system, HCCA continues to play an important role in maintaining and promoting mental models that strengthen the role of consumers in the health system.

## Enablers of HCCA's contribution: Trust, credibility, and partnerships

The case studies revealed that HCCA's significant contributions to improving health care in the ACT are enabled by its strong reputation as a trusted representative of consumers, a credible source of information and advice, and a valued partner. We draw from the case studies to describe these characteristics and how they enable HCCA's contribution.

### PART 3:

## Case studies

We present detailed case studies that illustrate HCCA's contribution to improved health care in the ACT. The case studies explain the change that occurred, why the change was significant, and how HCCA contributed to the change. All case studies have been substantiated, either through interviews with stakeholders or with publicly available information.





# Introduction



# Introduction

This report was developed by Collective Action to help Health Care Consumers' Association (HCCA) demonstrate its contribution to building a consumer-centred health system in the ACT that provides safe, accessible, and high-quality health care.

HCCA is the peak health consumer organisation in the ACT and a health promotion agency. HCCA works to improve the quality and safety of health services by shifting the role of consumers in the health system. It does this by providing a voice for consumers on health issues and opportunities for consumers to participate in all levels of health service planning, policy development, and decision making.

In this report, we present 14 case studies that highlight HCCA's significant contribution to improving health care in the ACT. Using these case studies, we demonstrate that HCCA contributes to changes in the health system that facilitate effective consumer participation. These changes contribute to building a more consumer-centred health system, which in turn leads to improvements in health care.

This report focuses on the work delivered and outcomes achieved over the life of HCCA's 2021–2024 strategic plan. For substantial periods between 2021 and 2024, health services, primary health care, and non-government organisations were operating at capacity and were focused on supporting community members through the pandemic. In this context, HCCA's work became more challenging but also more important than ever. We found that HCCA continued progressing toward its goals while also helping to ensure that consumers were informed, and the COVID response responded to consumer experiences and needs.

Collective Action and HCCA recognise that improvements in health care are achieved through the collective efforts of community organisations, government departments, services, and committed individuals across the health system. As such, the point of this report isn't to claim credit for such improvements, or attribute them to HCCA, but rather to capture how HCCA contributes to these collective efforts.

## About HCCA

HCCA is the peak health consumer organisation in the ACT and a health promotion agency. HCCA advocates for a consumer-centred health system that provides high-quality, accessible health care for everyone in the Canberra region.

Founded in 1978 by a group who wanted to improve how the ACT health system worked with consumers, HCCA is one of Australia's longest continually operating health consumer organisations. HCCA is built on the idea that health care consumers have a right and a responsibility to participate in decisions that affect them.<sup>2,3</sup>

HCCA's vision, mission, and values articulated in the 2021–2024 Strategic Plan are included below.



### Vision:

Consumers in control of our own health.



### Mission:

Improve the safety and quality of health care to meet the needs of consumers and communities.



### Values:

We value our members' knowledge, experience and involvement in our organisation and the consumer movement. The values of Integrity, Collaboration, Equity and Inclusiveness underpin our work.

HCCA provides a voice for consumers on health issues and opportunities for consumers to participate in all levels of health service planning, policy development, and decision making. It does this by:

1

**Developing policies** and position statements and contributing to health policy discussions.

2

**Conducting research** into the consumer experience of health care and supporting consumer participation in research.

3

**Building the health literacy skills** of consumers.

4

**Providing training, information sessions, and resources** to help consumers better manage their health and improve access to high-quality health care.

5

**Providing training and information to build the skills** of people working in the health system in the areas of health literacy, communication, and consumer participation.

6

**Supporting services** to engage with consumers effectively and collaboratively.

7

**Supporting consumers** to participate and provide effective input in a range of different ways and settings.

## PART 1:

# Our approach to demonstrating HCCA's contribution to improved health care

# PART 1:

## Our approach

### Methodology

HCCA aims to change the way the health system operates so it is more consumer-centred and delivers safer and better-quality services. It does this by contributing to changes in the underlying factors that affect how the system operates, such as relationships, resources flows, and policies and practices.

Demonstrating an organisation's contribution to changes at the systems level can be challenging because systems are complex, and change doesn't happen in a linear way. The health system is like a web of interconnected parts. Changes in a one area of the system (such as public health policy) can affect other areas of the system (such as the practices of health professionals). These changes can take time to appear and are influenced by many factors, making it hard to see the direct impact of one organisation's efforts. Additionally, reshaping the way the health system operates requires sustained and mutually reinforcing efforts by people, organisations, and institutions working across it.

Common approaches to evaluation and outcomes measurement centre around a theory of change. A theory of change is a diagram and/or narrative that articulates the desired outcomes of a program and how the program intends to achieve those outcomes. Evaluators then look for evidence to test the validity of the theory. Theory-based approaches work well for programs where there's a clear and linear cause-and-effect pathway from activities to outcomes. However, they don't work as well for activities that seek to influence changes in systems like the health system, because the relationship between activities and outcomes is much more complex.

There are a range of approaches and tools that can help design and evaluate activities that seek to change systems (known as systems change initiatives). These approaches and tools come from the field of 'systems thinking', which focuses on understanding the interconnected factors and patterns that drive problems and influence the effectiveness of interventions. While systems-thinking approaches and tools are valuable for understanding and mapping the complexity of systems, it can be difficult to highlight the contribution of one organisation with these approaches alone.

We drew from both theory-based and systems-thinking approaches to create an evidence-based model for demonstrating HCCA's contribution to improvements in health care. This combination of approaches enabled us to develop a detailed, evidence-based narrative of how HCCA contributes to improvements in health care, without losing sight of the complexity and interconnectedness of the health system. You can read more about these methods and why we chose them in Appendix A [on page 75](#).

### To produce this report, we:

- 1 Reviewed HCCA's documentation, including evaluations, funding reports, and annual reports, to identify key examples of positive changes in the health system that HCCA likely contributed to in some way.
- 2 Collected evidence to substantiate these changes and HCCA's contribution, including conducting 12 interviews with external stakeholders.
- 3 Developed case studies to document the examples.
- 4 Reviewed evidence-based frameworks and approaches for understanding and evaluating systems change.
- 5 Integrated the information we collected with both theory-based and systems-based approaches to create HCCA's Systems Change Model – an evidence-based model demonstrating HCCA's contribution to improved health care.
- 6 Mapped the case studies against the model to demonstrate how HCCA contributes to a more consumer-centred and responsive health system, and how this in turn contributes to improvements in health care.

# HCCA's Systems Change Model

HCCA's Systems Change Model (shown in Diagram 1) builds on systems-thinking literature, which explains that the visible changes in systems (in this case, improvements in health care) are driven by systemic changes in the factors that shape the way a system operates. The model shows that HCCA contributes to systemic changes, which facilitate more effective consumer participation. In turn, these changes contribute to improvements in health care, such as improvements in health service design and infrastructure. The model is depicted as an iceberg to highlight that visible improvements in health care are driven by systemic changes that are less visible. Each level of the diagram is explained below.

## Level 1: HCCA contributes to systemic changes in the health system that facilitate effective consumer participation

Systemic changes are changes in the factors that influence the way systems operate. These factors include policies, practices, resource flows, relationships, power dynamics, and mental models.<sup>4</sup> HCCA helps to change these factors to strengthen the enablers and reduce the barriers to effective consumer participation.

## Level 2: The health system is more consumer-centred

The systemic changes in Level 1 help to reshape the health system to be more consumer-centred. These changes appear just below the surface because changes are not immediately apparent, but shifts in the system are visible over time.

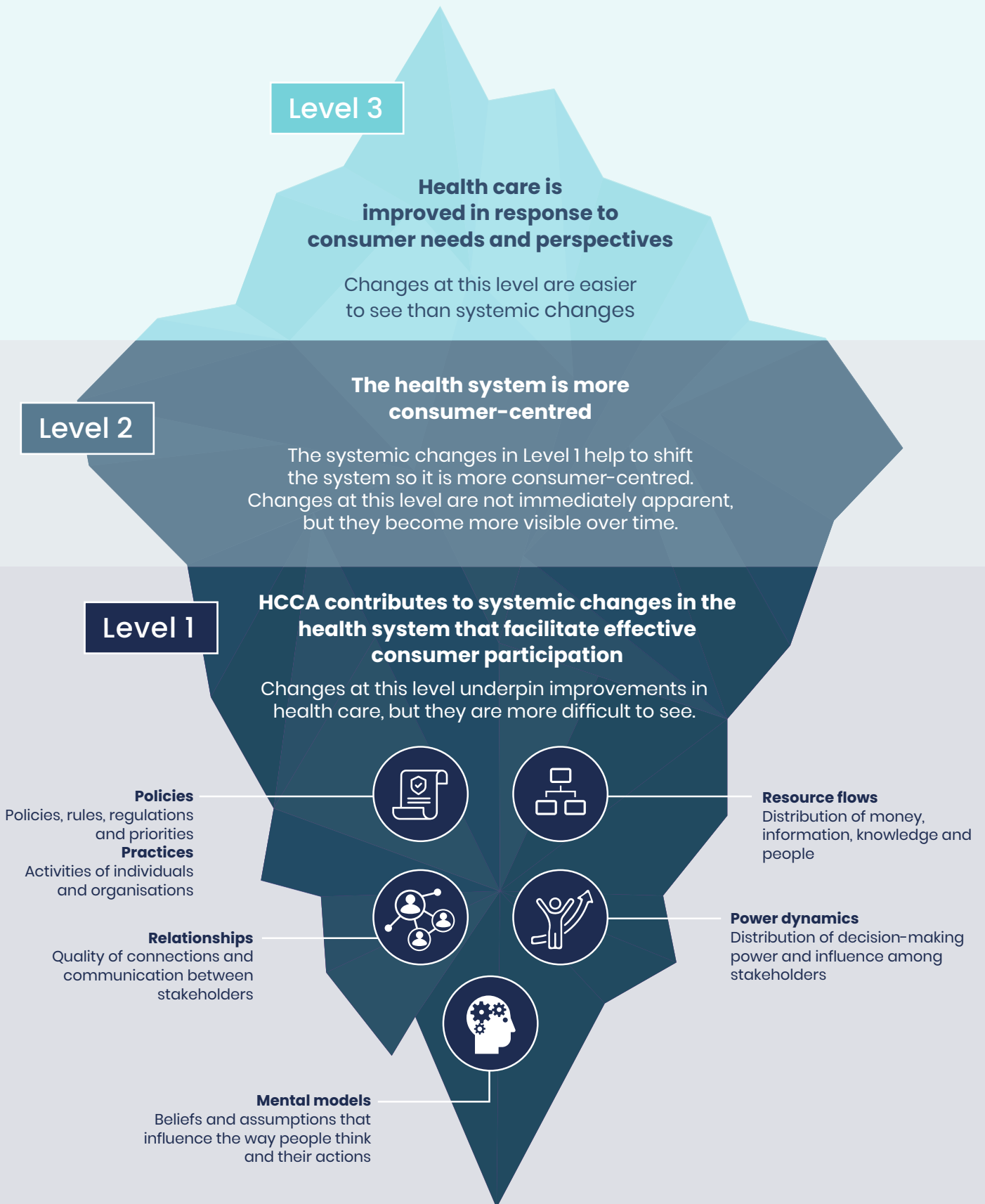
## Level 3: Health care is improved in response to consumer needs and perspectives

The health system responds to the needs and perspectives of consumers, which improves health care. These changes are shown at the top of the iceberg because they are the most visible.

The model is presented in three levels; however, these levels are interconnected, and they influence each other in a range of ways. For example, improvements in health care at level 3 contribute to positive changes in the beliefs and assumptions of stakeholders about the value of consumer participation.



Diagram 1: HCCA’s Systems Change Model





PART 2:

HCCA's contribution  
to improved health  
care in the ACT



## PART 2:

# HCCA's contribution to improved health care in the ACT

## Case studies: Showcasing HCCA's contribution

We developed 14 case studies that provide key examples of how HCCA contributed to each level of the model in the period of the last strategic plan. We provide a summary of the case studies below. The full case studies are provided in [Part 3](#) of this report, on page 37.

HCCA's contribution to systemic changes in the health system underpins all levels of the model. As such, all case studies highlight HCCA's contribution to systemic changes that facilitate effective consumer participation.

### Level 1:

## HCCA contributes to systemic changes in the health system that facilitate effective consumer participation

We developed five case studies that demonstrate how HCCA's contribution to systemic changes in the health system contributed to more effective consumer participation. These case studies demonstrate HCCA's contribution to strengthening consumer participation in the decisions that affect their health and wellbeing and strategic decisions about health policy, health service planning and design, and health infrastructure. These case studies are summarised on the following page.

### **Case study 1A: New ACT Ambulance Service consumer advisory group**

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ACT Ambulance Service established the group as part of their efforts to achieve accreditation under the Australian National Safety and Quality Health Service Standards and approached HCCA for assistance. HCCA provided advice and practical support with establishing the group, including providing input into governance documents, policies, and procedures, such as the group's terms of reference and its reimbursement policy. They also assisted with recruitment and provided training to advisory group members. The full case study is on [page 38](#).

### **Case study 1B: New ACT Government Health Infrastructure Consumer Reference Group**

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The Health Infrastructure Consumer Reference Group was established to sit across the design of all health infrastructure projects. The group is a new mechanism for embedding consumer voices in the design and construction of the health system, which is a notable shift from the project-based, time-limited committees that were common in the past. The establishment of the group builds on the success of consumer participation in the Canberra Hospital Expansion Project, which was led by HCCA. HCCA co-chairs the group, and the ACT Health Directorate recognise HCCA as being instrumental in guiding them through setting it up. The full case study is on [page 41](#).

### **Case study 1C: Co-design of Active Beginnings**

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HCCA led the co-design of Active Beginnings – a program aiming to increase physical activity levels and social connectedness of women of childbearing age from multicultural backgrounds. The program was led by the University of Canberra in partnership with HCCA and the Multicultural Hub of Canberra. HCCA played an instrumental role in facilitating the co-design of the program, which was crucial to the success of the project. The full case study is on [page 44](#).

### **Case study 1D: Accessible information about COVID-19**

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HCCA ensured consumers had access to relevant, tailored, and accessible information about COVID-19 so they could make informed decisions about their health and health care. HCCA did this by producing information that clarified and simplified government messaging, making it accessible to people with varying levels of health literacy. HCCA consulted with consumers and carers and provided updates to address questions and concerns. The full case study is on [page 47](#).

### **Case study 1E: Canberra Health Literacy Hub**

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HCCA created the Canberra Health Literacy Hub to provide consumers and carers with access to information to help them build their health literacy. This includes guidance on how to navigate the health system, make health-related decisions, and find relevant, high-quality information. Health literacy is fundamental for collaborative decision making and effective partnerships between consumers and health care providers. The full case study is on [page 49](#).

## Level 2:

### The health system is more consumer-centred

We developed four case studies that demonstrate how HCCA's contribution to more effective consumer participation has contributed to the health system becoming more consumer-centred. These case studies are summarised below.

#### Case study 2A: HealthPathways

HealthPathways is an online information platform for primary health care professionals that provides condition-based assessment, management, and referral information. Canberra Health Network collaborated with HCCA and the Chronic Conditions Network to update and improve the information on the platform. HCCA played an instrumental role in facilitating this collaboration, which enabled community-based chronic conditions support organisations to improve the quality of information available to patients with chronic conditions. The full case study is on [page 51](#).

#### Case study 2B: Advance care planning

Advance care planning is a process for people to record their wishes about future medical treatment and care, giving them more decision-making power and influence over their own care. Through providing community information sessions, training for health professionals, and health literacy materials, HCCA contributed to building a network of support and information to assist people in recording their advance care plan. The full case study is on [page 54](#).

#### Case study 2C: Canberra Health Services website

HCCA worked closely with Canberra Health Services (CHS) to develop a new website. The website aims to strengthen the health literacy environment by making it easier for consumers to find and understand the information they need to access ACT Government health services. HCCA provided advice, input, and feedback to CHS on what information to include, how to write the information, and how to make the information more accessible, and it connected CHS to consumers. CHS recognised HCCA as being 'extremely influential' in the design of the website, noting that 'every decision was consumer-driven to ensure the website truly reflects what is important to our community.' The full case study is on [page 58](#).

#### Case study 2D: COVID-19 visitation policies

At the peak of COVID-19, the ACT Government implemented restrictions on visitor numbers to health facilities. As the NGO and Community Liaison on the Clinical Health Emergency Coordination Centre, HCCA raised awareness of the important role that visitors play in the care of patients. The information shared by HCCA informed decisions around who was eligible for exemptions to the visitation restrictions. The full case study is on [page 61](#).

## Level 3:

# Health care is improved in response to consumer needs and perspectives

We developed five case studies that demonstrate how HCCA's contribution to a more consumer-centred health system has contributed to improvements in the accessibility, safety, and quality of health services. These case studies are summarised below.

### Case study 3A: **New Paediatric Liaison and Navigation Service**

The new Paediatric Liaison and Navigation Service provides a single point of contact for care, information, and support for families of children with serious conditions who need to access care across multiple healthcare providers. HCCA called for the establishment of the service in its research into consumer and family experiences and expectations of accessing interstate specialist care. HCCA also provided input and feedback into the model of care and facilitated a consumer reference group to co-design the service. The full case study is on [page 64](#).

### Case study 3B: **New dedicated inpatient palliative care ward**

The palliative care ward is a purpose-designed environment that will provide acute interventions to people receiving palliative care and/or approaching the end of their lives at Canberra Hospital. It will be the first inpatient palliative care facility at the Canberra Hospital. HCCA advocated for inpatient palliative care for decades and supported this advocacy with research into the consumer experience of dying and clinician preferences for hospital-based palliative care. Canberra Health Services recognised that HCCA's strong advocacy contributed to the success of getting the project to where it is today. HCCA played an instrumental role in ensuring the ward was informed by consumer experiences, needs, and perspectives, and their input and feedback resulted in significant improvements to the design. The full case study is on [page 67](#).

### Case study 3C: **Canberra Hospital Expansion Project**

In 2021 construction began on a new, seven-storey critical services building on the Canberra Hospital campus. The building will house an emergency department, intensive care units, and specialist surgical and inpatient areas. HCCA chaired the consumer reference group, and HCCA's Manager of Consumer Participation was a member of the Canberra Hospital Expansion Project Control Group. Many aspects of the building's design were the result of consumer leadership. The full case study is on [page 70](#).

### Case study 3D: Improved wayfinding at Canberra Health Services locations

Wayfinding refers to the use of design elements, including signage, to help people navigate a space. HCCA staff and consumers regularly provide input and feedback to Canberra Health Services (CHS) on how to improve wayfinding. This has contributed to improved wayfinding at several CHS locations, including better colour coding and more signs at key intersections. The full case study is on [page 72](#).

### Case study 3E: Improved public transport accessibility at Canberra Health Services locations

In 2024 public transport access was upgraded at several Canberra Health Services (CHS) locations, including the Canberra Hospital. HCCA advocated for, organised, and facilitated a workshop on bus stops that brought together key stakeholders across the health system. CHS credited HCCA with bringing together key people from different areas to improve bus stops. The full case study is on [page 74](#).

## In-depth analysis: How HCCA contributes to systemic changes

In this section of the report, we focus on Level 1 of HCCA's Systems Change Model: HCCA's contribution to systemic changes in the health system that facilitate effective consumer participation. We focus on this level because systemic changes underpin the visible improvements in health care.

Level 1 of the model shows the key factors that influence the way the system operates. These factors were drawn from a prominent, evidence-based framework for understanding systems change – The Water of Systems Change.<sup>5</sup> The Water of Systems Change framework identifies factors that typically play the most significant role in holding systems in place: policies, practices, resource flows, relationships, power dynamics, and mental models. The framework suggests that efforts to change a system will be most effective if they shift these factors. The authors of the framework note that while these factors can be independently defined, measured, and targeted for change, they are also intertwined and interact with each other.

While this report focuses on the period of the last strategic plan (2021–2024), the changes we documented build on HCCA's work over the last 40 years to strengthen consumer participation in the health system. As such, we start by providing an overview of HCCA's contribution to the significant shifts in the role of consumers in the last few decades, which created a strong foundation for the changes achieved in the period of the last strategic plan.



## Building the foundation: Strengthening consumer involvement

For over four decades, HCCA has worked alongside other consumer and carer organisations to shift the position of consumers in the health system from 'a passive body to be treated' to active participants in decision making. A book covering HCCA's history, *Making a noise: 40 years of consumer health advocacy in the ACT*,<sup>6</sup> documents HCCA's contribution to significant changes in the health system that have strengthened consumer involvement in health service design, health policy, and decision making. The book notes the critical shift that HCCA made 'from its role as an external advocate influencing (often powerfully) an issue here or there, to having a seat at the decision-making table, to a partnership between government, consumers and health services.'

A notable shift in the system was the introduction of the National Safety and Quality Health Service (NSQHS) Standards<sup>7</sup> in 2013. The standards emphasise the importance of consumer involvement. 'Standard 2: Partnering with consumers' requires that the safety and quality systems that relate to the Clinical Governance Standard involve engaging with consumers in the design, monitoring, and evaluation of services within a program, department, or the organisation.<sup>8</sup> HCCA was contracted by the Commission on Safety and Quality in Health Care to coordinate an ACT-based consumer workshop for feedback on accreditation reforms and draft standards. The involvement of consumers was further strengthened in the second edition of the NSQHS Standards, released in 2017.

The introduction of these standards was part of broader cultural shift toward greater consumer involvement in health care – from individual care decisions to health service planning, policy development, and decision making.

As consumer participation in the health system increases, HCCA works to ensure that participation is:

- meaningful, with opportunities being genuine and thoughtful, not tokenistic
- transparent, with consumers being informed about the limits to their influence and the outcomes from their input
- supported, with consumers receiving training and guidance to be effective participants
- inclusive, with participation that reflects the diversity of the community.<sup>9</sup>

## HCCA's contribution to systemic changes: 2021–2024

Drawing from the case studies, we illustrate how HCCA contributes to changes in the factors identified in The Water of Systems Change framework. This provides an evidence-based narrative of how HCCA contributes to systemic changes in the health system. We provide a description of each factor from The Water of Systems Change framework, and we list the factors in order from the most visible to the least visible changes.

### Policies and practices



**Policies:** government, institutional, and organisational rules, regulations, and priorities

**Practices:** activities of institutions, coalitions, networks, and other entities and the procedures, guidelines, or informal shared habits that comprise their work

HCCA regularly provides advice and practical support to health services, decision makers, and community organisations to ensure their consumer engagement activities are meaningful, transparent, supported, and inclusive. This includes drafting or providing input into governance frameworks, policies, and procedures and guiding practices. Between 2021 and 2024, HCCA informed the development of policies and procedures for consumer reference and advisory groups for a range of stakeholders, including Canberra Health Services, ACT Health Directorate, Healthcare Access at School, ACT Ambulance Service, and Women with Disabilities ACT.

Multiple interviewees commented on the valuable role HCCA played in helping them to establish governance frameworks and processes to ensure their engagement with consumers was effective. The interviewee from the ACT Ambulance Service provided examples of changes to policies and practices that were informed by HCCA. One example is when HCCA advised the ACT Ambulance Service on the need to establish safeguards and support mechanisms for consumers on the advisory group. In response to this advice, the ACT Ambulance Service arranged for advisory group members to have access to their employee assistance program. This measure aimed to reduce the risk of distress and re-traumatisation. The interviewee also noted that:

“ They've been very helpful with any questions I've had along the way, particularly leading up to the first meeting. There's a lot of information that I'd asked from them and asked them to review, such as our terms of reference and our reimbursement procedure, and they were very helpful.

Acting Ambulance Manager – Clinical Governance, ACT Ambulance Service

Another key example is the advice and practical support HCCA provided to the ACT Health Directorate to support the establishment of the Health Infrastructure Consumer Reference Group. HCCA shaped a range of policies, procedures, and practices to enable effective consumer participation. This includes informing a shift in practices for viewing the location of infrastructure projects, improving accessibility for people who face barriers to visiting sites in person, such as people with mobility impairments.

## Resource flows



The way money, people, knowledge, information, and other assets are allocated and distributed

HCCA facilitates and strengthens the flow of information and resources between stakeholders across the health system, including consumers, healthcare providers, policy makers, and decision makers. One way HCCA does this is by strengthening the flow of information and knowledge from consumers to decision makers. In the case studies of the palliative care ward and the Paediatric Liaison and Navigation Service, HCCA undertook research with consumers to understand their experiences, needs, and perspectives, which underpinned its advocacy for the establishment of these services. HCCA's research reports provided decision makers with an evidence base to support the case for and guide the establishment of the services.

Another key example of HCCA effecting resource flow changes was when it facilitated the two-way flow of information and knowledge between consumers and stakeholders in the COVID-19 response. HCCA consulted consumers to understand their experiences and perspectives. HCCA then used this information to inform its advocacy and input into decision making, including in the COVID-19 Health Emergency Control Centre (CHECC). HCCA also helped disseminate critical updates to consumers in a clear and accessible way. This two-way flow of information and knowledge supported consumer participation and consumer-centred health care.

## Relationships



The quality of connections and communication occurring between individuals, organisations, and institutions in the system, especially among those with differing histories and viewpoints

HCCA facilitates connection, communication, and collaboration between stakeholders across the health system, including consumers, healthcare providers, policy makers, and decision makers. This supports greater consumer participation in health service planning, policy development, and decision-making processes.

In many of the case studies, including the development of the Canberra Health Services website and the design of the inpatient palliative care ward, HCCA connected health care providers with consumers to enable consumers to provide direct input and feedback into service design, information resources, and infrastructure. Commenting on HCCA's role in facilitating consumer engagement in the development of the Canberra Health Services website, one interviewee said:

“ They opened doors for us. They create opportunities [for consumer engagement] that I think would be difficult for us to find easily.

Senior Director, Channels and Insights, Strategic Communication and Engagement, Canberra Health Services

HCCA also brings together stakeholders with shared interests and challenges to strengthen collaboration. For example, HCCA brought together stakeholders from different areas of government to improve public transport accessibility at Canberra Health Services locations. The interviewee commenting on that case study highlighted the important role HCCA played in facilitating collaboration:

“ Bringing together different groups of stakeholders, making sure they understand the issues, working together to work out how we can actually improve the situation was solely because of HCCA.

Senior Director, Project Delivery Infrastructure and Health Support Services, Canberra Health Services

The interviewee also noted that HCCA played an instrumental role in facilitating partnerships with organisations working with diverse communities, which has enabled them to ensure that the delivery of public health care is informed by the needs of the whole community.

In another example, HCCA established the Chronic Conditions Network to bring together community-based organisations providing support to consumers with chronic conditions, identifying issues affecting these consumers and strengthening collaboration on systemic advocacy. One of the outcomes of this network to date is that these organisations were able to improve the information available to health professionals when diagnosing or treating patients with chronic conditions.

## Power dynamics



The distribution of decision-making power, authority, and both formal and informal influence among individuals, organisations, and institutions

HCCA contributes to shifts in power dynamics that give consumers more influence in the design and governance of health services and in their own health care. One of the ways HCCA does this is by strengthening the influence of consumer representatives. HCCA works with healthcare providers to create meaningful opportunities for consumers to participate in and contribute to the design and governance of health services. It also provides consumers with training and support to strengthen their effectiveness as consumer representatives.

HCCA recruits, trains, and supports consumer representatives to equip them with the knowledge, skills, and confidence to contribute to decision making on advisory committees. Multiple interviewees highlighted that one of the key benefits of working with HCCA is that it provides training to consumers so they can contribute effectively.

“ The training was very helpful because there were quite a few members who had never been involved in a consumer advisory committee or group in the past.

Acting Ambulance Manager – Clinical Governance, ACT Ambulance Service

“ The benefit of working with HCCA is that the consumers are trained in their role ... It does take some skill, and knowledge, and boundaries to work effectively.

Professor of Midwifery, University of Canberra

Data from HCCA's internal evaluation of its Consumer Representatives Program validates that consumer representatives often influence the decisions of committees. Of the 24 survey respondents (both consumer representatives and Chairs and Secretariats), less than 12% said committees would make the same decisions whether a consumer was present or not.

The interviewee consulted about HCCA's role in the co-design of Active Beginnings noted that having HCCA as the Chair balanced the power dynamics so consumers felt comfortable to contribute freely.

“ There's always kind of a power dynamic with researchers working with a community group. I think the dynamic works best with a consumer representative leading that process rather than a researcher. It helps to set the right power balance.

Professor of Midwifery, University of Canberra

HCCA also contributes to shifts in power dynamics between health services and consumers. It does this by helping consumers build the knowledge and skills to participate in decisions that affect their health and wellbeing. For example, HCCA developed the Canberra Health Literacy website to provide consumers with information and resources to support them to navigate the health system and to participate in shared decision making. HCCA delivers community information sessions about advance care planning, which enables consumers to make advanced decisions about their health care. It also played an important role in keeping consumers informed during COVID-19 so they could make informed decisions about their health and their health care.



## Mental models



Deeply held beliefs and assumptions that shape behaviour and decision-making

As noted above, HCCA has been contributing to changes in how people think about consumer participation for decades. When HCCA was founded, the focus was on shifting mental models so that consumers would be viewed as active participants in their health care instead of passive recipients. While consumer participation is embedded in many aspects of the health system, HCCA continues to play an important role in maintaining and promoting mental models that strengthen the role of consumers in the health system.

Comments from multiple interviewees indicated that HCCA had helped them to consider consumer participation as a two-way relationship. That is, rather than only focusing on what consumers could offer them, they also considered how to ensure participation was meaningful and beneficial to consumers as well.

Another respondent noted that HCCA plays a valuable role in keeping consumers front of mind:

“ Just having HCCA, it kind of makes people think about consumers in the end as well ... And I've seen that lots of times and I think that's quite wonderful that they're able to do that.

Director of Clinical Liaison and Health Facility Planning – Capital Project Delivery, Canberra Health Services

Data from HCCA's internal evaluation of its Consumer Representatives Program shows that the program contributes to shifts in the way health services and decision makers understand consumer participation and their attitudes toward consumer participation. Survey results show that 80% of Chairs and Secretariat respondents (n=24) reported that they understand more about how to partner with consumers since working with consumer representatives.

A quote from one consumer representative interviewed as part of HCCA's internal evaluation demonstrates that HCCA still plays a role in shifting beliefs and assumptions about consumer participation:

“ 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.

## Enablers of HCCA's contribution: Trust, credibility, and partnerships

The case studies we developed show that HCCA's contribution to improving health care in the ACT is enabled by its long-standing reputation and history in the Canberra region as a trusted representative of consumers, a credible source of information and advice, and a valued partner.

### A trusted representative of consumers

In interviews we heard that stakeholders trust HCCA to provide input and feedback that reflect consumer experiences, needs, and perspectives. HCCA's existing reviews and evaluations also demonstrated the trust that consumers place in HCCA to represent them.

This trust in HCCA as a representative of consumers is validated by requests for HCCA to represent consumers on many high-profile and influential committees. Some key examples include the appointment of HCCA as the lead of the new Health Infrastructure Consumer Reference Group, HCCA's role as the NGO and Community Liaison on the Clinical Health Emergency Coordination Centre (CHECC) during COVID-19, and the Ministerial Appointment of HCCA's Executive Director on the ACT Health Services Council, which monitors the performance of the ACT Health System. Commenting on HCCA's role on the CHECC, the Clinical Director of the COVID Response said:

“ HCCA was certainly very helpful in strengthening the voice of [consumers] ... They provided us with a different viewpoint, and I think much of the time it was listened to and responded to.

This trust is founded on HCCA's strong and enduring connection with consumers and its deep understanding of consumer experiences, needs, and perspectives.

“ I know with HCCA it's not just those two people that have made those decisions and have thought of all of these things ... I know it's been widely discussed with consumers and then that idea has been brought back to us so as to incorporate into the build. I know that they're advocating for the community, and they advocate very well, and they advocate very strongly.

The Director Clinical Liaison and Health Facility Planning – Capital Project Delivery



“ We rely on HCCA to bring in knowledge and bring their experience and bring their membership to help us improve simple things like [wayfinding].

The Clinical Director of the COVID Response

“ It's a two-way relationship. There's a lot of opportunity that wouldn't necessarily be there for us in having access to consumer insight. And then we, as much as we can, make sure that we bring HCCA along for the ride because we get that incredible consumer insight.

Senior Director, Channels and Insights, Strategic Communication and Engagement, Canberra Health Services

Two interviewees commented that working with HCCA has ensured that their activities were informed by people from diverse communities and with diverse perspectives, including multicultural communities and people with disability.

The stakeholder interviewed about the co-design of Active Beginnings (page #) – a program for women from multicultural communities, spoke about how valuable it was that the Chair (HCCA's Multicultural Liaison Officer) was from a multicultural background. She explained that the Chair was very welcoming and inclusive when engaging with the group, and that this approach set the tone and dynamic for the group's interactions. The interviewee also noted how helpful it is that HCCA have staff from different backgrounds and with different perspectives.

The stakeholder interviewed about improved wayfinding at Canberra Health Services locations ([page 72](#)) explained that HCCA can provide a broad and diverse perspective:

“ They've been essential for us to make sure that our facilities cater for all. HCCA bring the advocacy and information that without which we would not have created the best facilities or had the best ability to deliver services to the whole community.

Senior Director, Project Delivery Infrastructure and Health Support Services, Canberra Health Services

This trust underpins HCCA's reputation as a strong and credible voice for consumers on health care, which bolsters the efficacy of its advocacy.

“ In the ACT, HCCA is known as the place that you go for a consumer voice and feedback. I think they're quite well known in that role.

HealthPathways Program Team Member

“ I don't think we would ever consider a project like that without involving HCCA. They're just critically important to make sure that we get that consumer viewpoint. We don't necessarily always have the same point of view, and I think that's why they're so valuable.

Senior Director, Channels and Insights, Strategic Communication and Engagement, Canberra Health Services

## A credible source of information and advice

In interviews we heard that stakeholders value HCCA's expertise in a range of areas, including consumer engagement, co-design, health literacy, advocacy, and service and infrastructure design.

“ We early on decided that we needed some good partners, so we partnered with both Multicultural Hub and HCCA. What we wanted from HCCA was really the consumer perspective and their expertise in co-design. We've seen some documents around the principles of co-design that they produced, and we knew they had some expertise there, so that's why we reached out to them.

Professor of Midwifery University of Canberra

The stakeholder interviewed about advance care planning ([page 54](#)) noted the benefits of having HCCA – a credible source of information and advice – deliver a session on advance care planning:

“ I feel like having a professional come in and talk about this topic really adds weight to the importance of it ... They're confident and knowledgeable about the topic and can answer all of the questions, because there's a lot to know.

Dementia Support Specialist, Dementia Australia

Two stakeholders noted that HCCA produces quality work, including research, that demonstrates its expertise and bolsters its credibility as a source of information and advice.

“ We were aware of these reports that HCCA used to put together called First Impressions reports ... They would go out to different health centres around Canberra ... and provide feedback, like it would have been useful to have information on the website about where to park. I knew from seeing those that HCCA had pretty good insight into what consumers were looking for.

Senior Director, Channels and Insights, Strategic Communication and Engagement, Canberra Health Services

“ I was honestly thrilled and impressed by the quality of the feedback and just how good it was for us as a group to get all this great information about what people are expecting.

The Director Clinical Liaison and Health Facility Planning – Capital Project Delivery

## A valued partner

In interviews we heard that HCCA has strong, collaborative relationships with stakeholders. We heard from many stakeholders that HCCA is very responsive to requests for support and input, and that they highly value having access to that resource.

“ It's enormously valuable to have HCCA there. They've been enormously generous, every time we've reached out to them, they've been able to put someone forward who has made an important contribution.

Professor of Midwifery University of Canberra

We heard that HCCA provides honest and constructive feedback, which is highly valued. Multiple stakeholders spoke about how much they value having a different perspective at the table, and that this leads to better outcomes.

“ I think HCCA for me was an important voice on CHECC ... It provided us with a different viewpoint, and much the time I think it was listened to and responded to.

Clinical Director of the COVID Response

Multiple stakeholders expressed their desire to continue working with HCCA in future projects due to the valuable feedback and consumer viewpoint it provides.

“ They're always in front of mind now. I don't think we would ever consider a project like that [website design] without involving HCCA.

Senior Director, Channels and Insights, Strategic Communication and Engagement, Canberra Health Services

“ I would like HCCA in any clinical builds that I'm doing, large or small. I think that the feedback we get is fantastic.

Director, Clinical Liaison and Health Facility Planning – Capital Project Delivery, Canberra Health Services

Stakeholders also noted that HCCA plays an important role as a critical friend – providing honest and constructive feedback in a way that supports learning and growth.

“ They're always really honest; they're never afraid to give us the hard truth. But they do it respectfully and collaboratively. So, if there is not so great feedback, it's usually presented with a path forward: "here's something that you could do to make it better."

HealthPathways Program Team Member

“ They've really been able to shine a light back on us to make sure that we're targeting materials at the right knowledge base and for the right audience.

Senior Director, Program Management Office, Infrastructure Delivery Branch, ACT Health Directorate

PART 3:

Case studies



## PART 3:

# Case studies

In this part of the report, we present detailed case studies that illustrate HCCA's contribution to improved health care in the ACT. We map the case studies against HCCA's Systems Change Model to provide examples of HCCA's contribution to each level of the model.

Each case study explains the change that occurred, why the change was significant, and how HCCA contributed to the change. When explaining HCCA's contributions, we highlight examples of changes to the systemic factors included in Level 1 of HCCA's Systems Change Model: policies, practices, resource flows, relationships, power dynamics, and mental models.

All case studies have been substantiated, either through interviews with stakeholders or with publicly available information. The sources are listed at the end of each case study. Where the case study has been substantiated through an interview, we use the generic term 'interviewee', and we include the stakeholder in the sources at the end of the case study (all interviewees are listed by their role).

## Level 1:

# HCCA contributes to systemic changes in the health system that facilitate effective consumer participation

## Case study 1A:

### New ACT Ambulance Service consumer advisory group

#### What has changed?

The ACT Ambulance Service (ACTAS) established a consumer advisory group to strengthen consumer participation and advocacy in ACTAS service development, planning, review, and decision making on matters involving consumers. The role of the group is to provide feedback and recommendations relevant to the lived experience of consumers.

## Why is this change significant?

The consumer advisory group was established as part of ACTAS' efforts to achieve accreditation under the Australian National Safety and Quality Health Service Standards. While ACTAS has a long-standing commitment to person-centred care and community engagement, this is the first formal mechanism for consumers to contribute to the governance of the organisation. The establishment of the group will contribute to more consumer-centred health care.

Patrick Meere, General Manager at ACTAS, shared the following statement on LinkedIn about the first consumer advisory group meeting held in early June 2024:

“ Today ACT Ambulance Service held its first ever consumer advisory group meeting. This is our commitment to make our consumers the very centre of all that we do. Lived experience, opinion and input. Moving forward this group will drive our business, operational and strategic decisions to be truly influenced and based on the perspectives of those who we provide care to every day, our consumers. Thank you to all that were involved, not least of which are our consumers, who we welcome to the ACT Ambulance Service family, and we will work closely with you to initiate genuine improvement and drive positive change!

## How did HCCA contribute to this change?

ACTAS approached HCCA for assistance with establishing the group. HCCA became an advisor on the project and provided guidance on establishing and running the group, including:

- providing input into governance documents, including the group's terms of reference and its reimbursement policy
- assisting with recruitment, including providing advice on recruiting members who were the right fit for the group, directly recruiting some members, and providing ACTAS with the details of organisations they could contact to ensure the group was representative of people with diverse backgrounds and experiences
- providing advice on reimbursement rates
- providing training to members on health care advocacy and their role as consumer representatives, including how to assess their readiness as consumer representatives if they had experienced medical trauma
- providing guidance on how to meaningfully engage consumers
- attending the first meeting, providing members with information about their involvement in the group and explaining how they can access support through HCCA
- providing advice on establishing safeguards and support mechanisms for group members to mitigate the risk of re-traumatisation from sharing or reliving stressful experiences.

These activities assisted ACTAS to establish mechanisms and processes that support effective, meaningful, transparent, supported, and inclusive participation. The interviewee for this case study provided multiple examples of HCCA's advice directly informing **policies and practices**. For example, in response to HCCA's advice about establishing safeguards and support mechanisms, ACTAS arranged for members to have access to their employee assistance program. The interviewee noted:

“ I found them to be very, very helpful. Particularly because this is so new for us.

## Sources

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## Case study 1B:

# New ACT Government Health Infrastructure Consumer Reference Group

## What has changed?

The ACT Government established a permanent consumer reference group to advise on the design of all health infrastructure projects, including the new northside hospital. The aim of the group is to ensure that health infrastructure projects consider accessibility, safety, and amenities for health care consumers and carers.

## Why is this change significant?

The ongoing, formalised nature of the Health Infrastructure Consumer Reference Group represents a change in the ACT health system that strengthens the enablers of consumer-centred health care. In announcing the group, Minister Stephen-Smith said:

“ The ACT Government is committed to working collaboratively with the community and clinicians, and the new Health Infrastructure Consumer Reference Group will embed those voices in the design and construction of our future health system.

“ Having a permanent consumer reference group that we can engage in these infrastructure projects really brings that expertise of lived experience of consumers and carers to the table alongside the experience of clinicians to help our infrastructure teams get the designs right from the start.

The group also ensures greater consistency between projects. As noted by the interviewee for this case study, the consumer reference group was created to make sure consumer engagement is done uniformly, and that decisions made in one project become the standard for future projects.

“ The key thing with consumer reference groups, if they come up with a great idea that's adopted on one project, that should be a base sort of requirement for the next project as well.

## How did HCCA contribute to this change?

HCCA advocated for the group directly through established relationships, and the success of the consumer input into the Canberra Hospital Expansion Project created a strong case for the benefits of an ongoing arrangement. This was highlighted by Minister Stephen-Smith in her announcement of the group:

“ This builds off the important work undertaken in the co-design of the Critical Services Building at Canberra Hospital. The thorough and comprehensive work by the Canberra Hospital Expansion Consumer Reference Group is a fantastic example of how we can incorporate important consumer and carer feedback into design.

HCCA has been working closely with ACTHD to set up the group and has shaped a range of **policies and practices** and influenced **resource flows**. For example, HCCA provided guidance on the structure and composition of the group and assisted with the recruitment of members, including developing the terms of reference and conducting interviews. The interviewee explained the central role that HCCA has played in shaping their thinking about the role of the group (**mental models**):

“ HCCA were instrumental in guiding us through how the consumer reference group might be set up and how it could have that broad focus, while still enabling members to feel that they're going to be heard and that the advice they provide will be taken on board.

HCCA has also been providing training and support to staff in the Infrastructure Delivery Branch (the area responsible for the consumer reference group) on supporting meaningful, transparent, supported, and inclusive consumer participation. The interviewee highlighted that HCCA's guidance and support increased the team's understanding about how to consider issues from a consumer perspective and how to engage consumers to achieve the best results, such as how to present and provide information.

HCCA's guidance also established new ways of working (**policies and practices**) to increase the accessibility of consumer participation. For example, the group planned to visit the site of the North Canberra Hospital; however, the plan created barriers to a member who uses a wheelchair. In consultation with HCCA, the Infrastructure Delivery Branch organised a drone to film the site, and the consumer reference group viewed the footage together. The interviewee explained that the approach was not only more accessible, but it was also more effective at getting a shared understanding of the site:

“ HCCA provided a different lens on how to communicate and build consumer reference group members’ understanding of hospital infrastructure and health infrastructure generally ... It was actually really valuable because just in thinking through accessibility and the ‘how to’, I think we came up with a far better option.

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## Case study 1C:

# Co-design of Active Beginnings

### What has changed?

The Active Beginnings program aims to increase physical activity levels and social connectedness of women of childbearing age from multicultural backgrounds to improve maternal physical and mental health. To achieve these aims, the program established a co-design group of women from multicultural backgrounds. The group helped to develop culturally relevant information resources about the benefits of exercise, including an animation, and a program of culturally appropriate activities that women could try out over a six-week period.

Some key aspects of the program that were informed by the co-design group are detailed below:

- Information resources were simplified and written in plain English to reduce communication barriers for people who do not speak English as their first language.
- Timing for promoting physical activity was adjusted to be appropriate for those who observe Ramadan because fasting can impact their ability to exercise.
- Yoga was not included as it has religious connotations for people from some cultures; stretching was incorporated as it is more universally acceptable.
- The animation was edited to be more culturally relevant (for example, it included how people from each culture would dress and what they would say).
- The measure of physical activity (International Physical Activity Questionnaire) used to evaluate the program was amended to include exercise examples that are more appropriate for multicultural communities.
- Evaluation surveys were simplified and written in plain English.

### Why is this change significant?

Physical activity is important for women who are planning to have children because the best pregnancy outcomes are achieved when mothers begin pregnancy in good physical and mental health. Regular physical activity can also reduce the risk of cardiovascular disease, diabetes, and obesity, and it promotes good mental health and social connectedness.

Women from multicultural backgrounds experience a range of barriers to exercise and opportunities for social connection, including a lack of culturally appropriate physical activities and health information. Creating culturally appropriate and relevant information and opportunities for physical activity is important for overcoming these barriers and supporting women from multicultural backgrounds to exercise.

## How did HCCA contribute to this change?

Active Beginnings stems from a research group at the University of Canberra called *Brighter Beginnings: maternal wellness and the first 2000 days*. The University of Canberra identified HCCA as a key partner in ensuring the program was informed by a consumer perspective. The partnership also included Multicultural Hub Canberra.

HCCA was responsible for leading the co-design and chairing the co-design group. HCCA's contribution to the co-design process was significant. It facilitated co-design workshops, contributed to creating communication materials, and led the community dance evening. This work was headed by HCCA's Multicultural Liaison Officer.

The interviewee for this case study confirmed that the co-design process was crucial to the success of the project, and HCCA played an instrumental role in ensuring the co-design process was effective.

“ If we had developed the program without co-design, it wouldn't have been nearly as relevant to the community that we were targeting. We probably wouldn't have reached as many interested women.

The interviewee highlighted that HCCA plays a valuable role in ensuring that consumer participants have the necessary training and support to participate constructively. She also highlighted that having a consumer representative chair the group, rather than a researcher, was crucial to the success of the project; it enabled them to create an inclusive and equitable space where participants felt comfortable to share their experiences and perspectives (**power dynamics**).

“ They are skilled at chairing, and it facilitated the right dynamic in the group.

HCCA also supported the project by writing communication materials that were easy to read and accessible to people who speak English as a second language. The interviewee noted that:

“ The communication was vastly improved because of their help ... and it likely contributed to the reach and high levels of engagement in the project.

Commenting on HCCA's contribution, the interviewee said, 'Ultimately, [because of HCCA's involvement] the program was much more appropriate and relevant to the communities we were targeting.'

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## Case study ID:

# Accessible information about COVID-19

## What has changed?

The community received regular updates on COVID-19 that responded to questions and concerns raised by consumers and carers. The updates contained information tailored to population groups who had specific information needs, including women, older people, migrants and refugees, and people with disability, and they provided information about and links to resources in languages other than English.

## Why is this change significant?

The updates provided by HCCA improved consumer access to quality information that could be easily understood by people with varying levels of health literacy. Providing consumers and communities with access to consumer-friendly information is essential for supporting consumers to understand and use health information, participate in decisions about their care, access the services they need, and navigate the health and social support systems.

The COVID-19 updates were developed to address consumer concerns about the lack of quality, consumer-friendly clinical advice and the lack of tailored communications to multicultural and community groups. The need for the updates was validated by research conducted by the Sydney Health Literacy Lab in 2020, which found that people with lower health literacy and who spoke a language other than English at home had poorer understanding of COVID-19 symptoms. They were less able to identify behaviours to prevent infection and experienced more difficulty finding information and understanding government messaging about COVID-19. They were also more likely to endorse misinformation/conspiracy beliefs about COVID-19 and vaccination.

Studies since then into the quality and accessibility of public health information about COVID-19 in Australia have found that most information was too complex to be easily understood by general audiences. Additionally, relevant information was largely inaccessible to people with lower health literacy and people from non-English speaking backgrounds.

## How did HCCA contribute to this change?

Between January 2020 and December 2023 HCCA provided regular updates about COVID-19 that aimed to address questions and concerns of consumers and carers and clarify and simplify government messaging.

The COVID-19 updates were created in response to the information needs of consumers. HCCA received a large number of calls from consumers at the beginning of COVID-19 and created a register of their questions and concerns, which it addressed through its

updates. HCCA also conducted a regular consumer survey to find out what information consumers and carers were looking for about COVID-19 and to identify questions that were not being answered. HCCA utilised its strong **relationships** with the ACT Government, healthcare providers, peak bodies, and community organisations to find answers to consumer questions and concerns. These relationships enabled HCCA to support the dissemination of public health information to consumers (**information flows**). By ensuring consumers and carers had access to relevant, tailored, and accessible information about COVID-19, HCCA strengthened the health literacy environment and enabled consumers to participate in decisions about their care, access the services they need, and navigate health and social support systems (**power dynamics**).

For the period 17 August 2021 to 28 January 2022, during one of the lockdown periods, HCCA sent 27 COVID updates to consumers and organisations on their mailing list. The updates contained information and resources relevant to both community members and organisations. The updates were sent to 590 people and were opened by approximately 40% of people who received them. The information was also available on HCCA's website.

HCCA received feedback from some members at their general meeting that they greatly valued the updates.

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## Case study 1E:

# Canberra Health Literacy Hub

### What has changed?

The Canberra Health Literacy Hub began as part of the Community Health Literacy Project and acts as a central point for health literacy information, training, and resources for the ACT. Through the website, consumers and carers now have access to information that is accessible and responds to their needs, including guidance on how to navigate the health system, make health-related decisions, and find relevant, high-quality information. The website also provides health practitioners and community organisations with information and resources to equip them to strengthen the health literacy environment, such as how to assess and support the health literacy of clients and how to communicate health information to clients.

### Why is this change significant?

The term 'health literacy' refers to people's capacity to find, understand, and use health information in their daily lives. Strong health literacy enables high-quality health care, improved health outcomes, better recovery from illness and injury, and better management of long-term health conditions.

Health literacy is fundamental for collaborative decision making and effective partnerships between consumers and health care providers. Enhancing consumer knowledge and capability to make health care decisions reduces demand on the health system, supports a more patient-centred approach, and contributes to a safer, higher-quality health system.

Health services and health care professionals benefit when they understand and respond to the health literacy challenges of consumers. By doing so, these organisations can provide more cost-effective and higher-quality care that aligns with consumer needs and preferences.

### How did HCCA contribute to this change?

The Canberra Health Literacy website was developed and is maintained by HCCA as part of the Canberra Health Literacy Project. HCCA was funded by the ACT Government in 2019 for the project, which aims to 'help patients better navigate our health system'. As part of the project, HCCA conducted an environmental scan of community health literacy strengths and opportunities in the ACT, created the Health Literacy Framework, established the Canberra Health Literacy Network, and produced resources for consumers and health professionals.

HCCA developed the website to provide consumers with information about their health and health care to strengthen their individual health literacy. This supports consumers to participate in shared decision making with their health care providers (**power dynamics**). Information and resources on the website are designed to meet the needs of diverse communities, including tailored information on mental health care and palliative care. Resources are available in multiple languages and accessible to people with disabilities, with options to enlarge text and convert text to audio. Additionally, content on the website was tested with consumers before launching, ensuring ease of use.

At the same time, HCCA raised awareness about health literacy and equipped health practitioners and community organisations with information about supporting consumer health literacy. The information on the Canberra Health Literacy website was informed by consumers. For example, consumer representatives shared perspectives about community health literacy strengths and opportunities in the ACT through the environment scan in 2019. These consumer-informed resources have been used by health professionals and organisations to support the health literacy of consumers. Between December 2022 and May 2023, visitor numbers for the website increased; most visitors to the site access pages with information targeted to health workers. Furthermore, HCCA's internal report demonstrates that the Canberra Health Literacy website helps to increase the capacity of health professionals and organisations to respond to health literacy issues in the ACT.

In a survey with Canberra Health Literacy Network members in 2021, more than 80% of participants indicated that they have visited the website. Of these, 90% agreed that it offers practical information that is relevant to them. In terms of reach, visitors to the Canberra Health Literacy website have increased steadily, growing from 489 in December 2022 to 1,415 in May 2023.

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## Level 2:

# The health system is more consumer-centred

## Case study 2A:

### HealthPathways

#### What has changed?

Information about services and referral pathways on HealthPathways ACT and Southern NSW – a free online platform for primary healthcare professionals that provides condition-based assessment, management, and referral information – is more patient centred and up to date.

#### Why is this change significant?

One of the primary functions of HealthPathways is to support primary healthcare providers to more easily provide referral pathways for their patients. Ensuring that information about available services and their details, such as contact information, is accurate and up to date is essential. It helps ensure that consumers and carers have access to the information and support they need.

“ We hope that by the information being available on a free website that all health professionals can access, that we are supporting health professionals in providing better care for their patients.

HealthPathways Program Team Member

The accuracy of information about services and referral criteria is also crucial to the use of HealthPathways among health professionals. An evaluation of HealthPathways in 2020 found that out-of-date and inaccurate information diminished trust in the data available in the system. The evaluation concluded that ensuring information on HealthPathways is current and relevant to its users would improve its value and trustworthiness among healthcare providers.

## How did HCCA contribute to this change?

In 2023 HCCA created the Chronic Conditions Network (CCN) with the goal of ‘identifying key issues affecting consumers with chronic conditions and strengthening collaboration on systemic advocacy.’ The CCN is made up of approximately 30 community-based chronic conditions support organisations that meet monthly to discuss challenges faced in the ACT and Southern NSW health systems.

In mid-2023 CCN members discussed the challenge of raising awareness about their services among GPs so that the information is available to consumers during diagnosis and treatment. HCCA reached out to the HealthPathways team at Capital Health Network (CHN) to work together to address this challenge.

HCCA collaborated with CHN to deliver a series of workshops about HealthPathways, and CHN provided key representatives from the organisations involved in the CCN with access to HealthPathways to provide feedback on the platform. HCCA and CHN then ran a direct feedback day for organisations to provide feedback on each of the pathways related to the condition they support.

The feedback process was enabled by the HealthPathways team expanding HCCA’s stakeholder engagement practices to give community organisations access to the ACT and SNSW HealthPathways site.

“ We made a special case for the Chronic Conditions Network to have access, so they could look at what was available. They were provided with temporary access so that they could make sure that what we had was up to date and to provide feedback.

HealthPathways Program Team Member

In response to the feedback, CHN updated information on more than 20 pathways, including service description improvements, adding new resources/links for health professionals and new links to patient information resources and support services, and updating outdated information.

Some organisations also raised awareness about the experiences of the people they support when navigating through the system with a chronic condition.

“ The process created an opportunity to get feedback on what a consumer’s experience might be.

HealthPathways Program Team Member

The improvements to HealthPathways were enabled by the **relationships** established and strengthened in the CCN.

“ In terms of the impact, it’s more up to date because of those relationships ... Having that existing network there changed the way we approached those organisations, because we had the starting point to ask them for information about their services so that we could update the referral information that’s on HealthPathways ... and where there’s a change, they will contact us. So instead of finding out by an error, they will send us an email to say this number has changed or this service name’s changed. HCCA is in the middle of all of those relationships. And so that information [on the HealthPathways platform] wouldn’t be as up to date without HCCA.

HealthPathways Program Team Member

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## Case study 2B:

# Advance care planning

### What has changed?

Advance care planning is a process for people to record their wishes about future medical treatment and care, with the aim of ensuring they receive medical care consistent with their preferences if they lose decision-making capacity. Advance care planning gives consumers more decision-making power and influence about their own care – a significant shift in **power dynamics** in health care.

People in the ACT can access a network of support and information to record their advance care plan, including support from Council on the Ageing, the Advance Care Planning team at Canberra Health Services, Dementia Australia, and HCCA.

### Why is this change significant?

Estimates suggest that less than one third of Australians aged over 65 have some form of advance care planning documentation. There are many barriers to advance care planning, with health professionals, consumers, and family members all finding it a challenging topic, requiring specialist knowledge.

“ It’s a really big topic and it’s a really confronting topic.

Dementia Support Specialist, Dementia Australia

Support for advance care planning is particularly important because many people become aware of the process at an already difficult time in their life. For example, in the case of dementia:

“ At every stage, from the moment you have a suspected diagnosis – and you go through this massively long process of getting a diagnosis – and then there’s so many different steps you have to take to get support, to understand the aged care system, and then there’s advance care planning too.

Dementia Support Specialist, Dementia Australia

There is no data on whether the support and information provided in the ACT is making a difference to the longer-term outcome of more people having advance care plans in place. Further, it would be difficult to separate the effects of the different supports available, particularly because there is often a gap between information being provided and advance care plans being completed. However, having consumer-focused information and a network of support helps to put the choice about completing the advance care plan in the hands of the consumer.

““ What we know is that people will work through this process in their own ways. There’s so much grief intertwined with a diagnosis of dementia. Some people respond to grief by getting busy and getting active, they just get everything done; it’s all sorted. But other people work through it on a much more emotional level and might come to it later. So really, we’re just planting the seed, and hoping that down the track, people will do it.

Dementia Support Specialist, Dementia Australia

## How did HCCA contribute to this change?

### Community information sessions

HCCA delivers community information sessions about advance care planning. Between July 2022 and June 2023, HCCA delivered 10 sessions, reaching 177 attendees. These included sessions held at community groups such as Dementia Australia, Carers ACT, Heart Support ACT, Capital Health Network, and Goodwin Village.

Such information sessions consistently receive positive feedback from consumers in post-session feedback, with comments such as:

““ Thank you for making this available. It helped immensely.

““ I feel comfortable and clear on how to proceed.

The interviewee for this case study noted the benefits of having HCCA – a credible source of information and advice – deliver a specific session on advance care planning:

“ I feel like having a professional come in and talk about this topic really adds weight to the importance of it.

“ They're confident and knowledgeable about the topic and can answer all of the questions, because there's a lot to know.

HCCA also refers community members to the Advance Care Planning team, or directly assists people to complete advance care planning documentation.

### **Training for health professionals**

HCCA provides training to health professionals on advance care planning, including how to raise the issue of advance care planning with consumers and how to support them to complete their advance care plan. The program officer at Canberra Health Network noted that the post-event survey showed positive feedback, and participants felt all their questions had been answered.

### **Health literacy materials**

HCCA's website provides a list of resources for advance care planning. These include resources developed by HCCA, such as a comprehensive fact sheet, tailored information for multicultural and LGBTIQ+ people and their carers, and a plain English version of the Advance Care Plan Booklet, as well as resources developed by others, such as the Capital Health Network's *Be My Voice* website. HCCA promoted these resources through diverse channels including HCCA's newsletter and Facebook page. HCCA also provides community groups with hard copy information to ensure consumers can access information in their preferred format.

HCCA partnered with Dementia Australia on a section of the website to provide information for people with younger onset dementia, including information on advance care planning.



## Contributing to the network of support

HCCA's strong **relationships** in the Canberra community enable it to play an effective role in the network of support. For example, the program officer at Canberra Health Network noted that she had contacted HCCA for assistance with staff training because a colleague knew of their work through HealthPathways.

The interviewee also confirmed the positive relationships between the different sources of support in the Canberra community:

“ I feel like we all work together really well in the ACT.

“ I'm sure that if [the Health Literacy Project Officer] was coming across people in the community that needed support around dementia, they wouldn't hesitate to send them our way.

HCCA also continues to advocate for further improvements to the supports available in the ACT, including more tailored support for multicultural communities.

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## Case study 2C:

# Canberra Health Services website

### What has changed?

Canberra Health Services (CHS) developed a new consumer-centred website to provide consumers with information about public health services. Launched in April 2022, the website provides information about services and clinics; what consumers can expect before, during, and after their stay; and details about the location of and directions to health services.

### Why is this change significant?

The CHS website strengthens the health literacy environment by making it easier for consumers to find and understand the information they need to access public health services. When this information meets consumer needs and preferences, it reduces the burden on consumers and the level of individual health literacy required to access, understand, and use information.

Health literacy is a key enabler of safe, quality, and person-centred health care. It enables consumers to make informed decisions about their health and health care, and it is fundamental to shared decision making and effective partnerships between consumers and healthcare providers.

The way that the website was developed is also significant. CHS and HCCA recognise this project as a true collaboration and partnership between a health service and consumers. In the *Exceptional Health Care Report*, CHS state that:

“ The website was designed to meet the needs of Canberrans ... Every decision was consumer-driven to ensure the website truly reflects what is important to our community.

The interviewee for this case study highlighted the significance of the website and the way it was designed:

“ It was a website that was designed by consumers for consumers ... and anything that's designed by consumers is going to be helpful for consumers.

## How did HCCA contribute to this change?

HCCA worked closely with CHS on the development of the website between 2020 and 2022 and during subsequent reviews and updates. HCCA provided advice, input, and feedback to CHS on the type of information to include, health literacy principles, and how to meet the needs of specific users.

HCCA also connected CHS with consumers, which provided CHS with an opportunity to learn firsthand about the needs and preferences of consumers when accessing information. By facilitating connections and communication (**relationships**) between CHS and consumers, HCCA further strengthened the voice of consumers in the development of the website.

The design of the new website was featured in the CHS report *Exceptional Health Care Report 2021/22*. In the report, CHS state that the 'successful collaboration between us and our consumers' is best summarised by Darlene Cox, Executive Director of HCCA:

“ The CHS communications team ... frequently spoke to us formally and informally to seek advice and feedback, joined our meetings to hear from our members, and kept us up to date with what they heard from other parts of their extensive consumer consultation outside of HCCA. They have considered previous work HCCA has produced on environmental health literacy. They were always keen to hear from us when we had feedback about improvements that could be made to the website – at any point in its development – and included our staff and members in user testing when it got to that point. We could see, in user testing, how improvements had been made in response to feedback we had given ... As well as upgrading the website functionally, in response to what they heard from consumers in consultation, they have courageously changed the whole look, tone, and focus of the website to become genuinely consumer-centred.

HCCA's contribution to creating a website that addresses the needs and preferences of consumers was validated by the interviewee, who commented that HCCA were 'extremely influential'. She provided a range of examples where HCCA's feedback directly contributed to improvements to the website, including:

- **The information provided about healthcare services:** HCCA raised awareness of the importance of providing consistent information about all services and clinics listed on the website. They reviewed a template to be used on the website. As a result, information provided about services is consistent across the website.
- **Canberra Hospital wayfinding:** HCCA raised awareness at CHS that people orient themselves when accessing a hospital or health service by finding a cafe or toilet, and this information is featured on the website. In addition, HCCA suggested an interactive map and a wayfinding video for a centre (the cancer centre) that did not appear on Google Maps. CHS also drew on the findings of HCCA's First Impressions reports to inform the wayfinding information provided on the website.

- **Questions in the online tool for consumers to identify their healthcare options:** CHS developed a tool on their website to help consumers identify what services they have access to. The tool guides consumers through a series of questions about their health and healthcare needs. The interviewee commented that HCCA's feedback has been incorporated across the tool: 'This entire tool is filled with things they've improved on. We've kept the same questions, but we've just improved them because of specific feedback that they've given.' A key example of improvements made in response to HCCA's feedback is the question that asks consumers to select the cards they have, such as a Health Care Card or Veterans Affairs Card. HCCA user-tested the tool and provided feedback that it's helpful to show consumers photos of the card so they can look for them in their wallet. The interviewee commented, 'It's a much more health literate way to ask the question.'

In addition to directly contributing to the accessibility of information on the CHS website, HCCA also contributed to changes in **mental models** and **policies and practices** that will assist CHS in ensuring future communications materials are accessible and strengthen the health literacy environment. As the interviewee explained:

“ HCCA were really good at putting that health literacy lens over information, and that has certainly rubbed off on us. That's something that we do now, just as a matter of course: It's improved what we do. For the first time, we now have an accessibility checklist where we talk about health literacy and plain language, and we get people to consider those things as they're producing communications rather than as an afterthought. That certainly didn't happen as a matter of course when I joined the organisation six or seven years ago.

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## Case study 2D:

# COVID-19 visitation policies

### What has changed?

At the peak of COVID-19, the ACT Government implemented restrictions on visitor numbers to health facilities to help slow the spread of COVID-19 and ensure the safest environment possible for patients and healthcare workers. Decisions about who was eligible for exemptions to the visitation restrictions were informed by an understanding about the important role that visitors can play in a patient's care.

### Why is this change significant?

Engagement of families and loved ones in a person's care is vitally important to successful outcomes for patients, families, providers, hospitals, and communities. Visitors, such as family members and friends, can play an important role in supporting patients through their healthcare journey, including through providing psychological, emotional, and social support; assisting with the physical care of patients, such as feeding, hygiene, or supervision; and supporting medical decision making through advocacy and/or providing additional information. They also improve the quality and safety of health care as they can provide healthcare providers with information, context, care coordination, and help with the transition home.

### How did HCCA contribute to this change?

HCCA was appointed the NGO and Community Liaison on the Clinical Health Emergency Coordination Centre (CHECC). Established in April 2020, the CHECC brought together health services across Canberra to deliver a coordinated and unified response to COVID-19. The CHECC was comprised of senior leaders in the health system. It provided advice to the Chief Health Officer on the clinical response to COVID-19 in public and private hospitals, as well as services delivered at Walk-in Centres and community health centres.

HCCA's involvement in the CHECC was enabled by their strong **relationship** with the ACT Government, established over decades of communication and collaboration. As the NGO and Community Liaison, HCCA's role was to talk with consumers and community organisations about their experience of COVID-19 and ensure these perspectives were considered in CHECC decision making. HCCA maintained its strong connection to consumers during COVID-19. HCCA received many calls from carers and consumers asking questions and expressing concerns, and it created a register of consumer questions and concerns and used this to inform its input and feedback at the CHECC and through other channels.

HCCA's strong relationships with the ACT Government and consumers enabled it to facilitate the flow of information from consumers to decision makers involved in the COVID-19 response (**resource flows**). This strengthened the voice of consumers and equipped decision makers to centre consumers in the COVID-19 response.

“ HCCA was certainly very helpful in strengthening the voice of [consumers] ... They provided us with a different viewpoint, and I think much of the time it was listened to and responded to.

The Clinical Director of the COVID Response

One of the issues that HCCA raised with the CHECC on behalf of consumers was the impact of visitor restrictions on patients, carers, and people accessing care. While HCCA recognised that restrictions on visitor numbers at health facilities were essential to prevent and control COVID-19, it also advocated for visitor exemptions in situations where visitors played an important role in the care of the patient. The interviewee for this case study commented on HCCA's advocacy:

“ HCCA advocated for situations where it was really important for the carer to be considered as a visitor ... so we built up a case of who could come into the hospital. It was good to have HCCA's input into those situations.

The interviewee recognised that while the CHECC would likely have come to the same decision without HCCA at the table, HCCA's advocacy sped up the process:

“ I suspect we would have heard from our nursing staff that it is impossible to manage patients appropriately without their normal carers. I certainly think HCCA sped things up in terms of what we did do.

The interviewee also highlighted that HCCA raised awareness of the barriers that some people were experiencing to getting vaccinations, which contributed to the decision to establish access and sensory clinics.

“ [HCCA] helped us understand a little bit more of the vulnerable communities ... Darlene was a great advocate for those that found it really difficult to get vaccinated. And we did set up clinics to ensure that these people, particularly children, were going to get vaccinated in very special environments which supported them.

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## Level 3:

# Health care is improved in response to consumer needs and perspectives

## Case study 3A:

### New Paediatric Liaison and Navigation Service

#### What has changed?

The Paediatric Liaison and Navigation Service (PLaNS) launched in September 2022. PLaNS provides a single point of contact for care, information, and support for families of children with serious conditions who need to access care across multiple healthcare providers, including interstate providers. In August 2023, the service celebrated having provided support to 100 children and their families.

In March 2024, Canberra Health Services (CHS) conducted a survey to seek feedback from clients and their families about the service and identify areas for improvement. Survey questions were developed by the consumer reference group. Thirty-two clients responded to the survey. The report produced by CHS notes that ‘the results demonstrate that most of the desired outcomes of the service are being met, particularly regarding care planning, family involvement, and information sharing.’

This finding is supported by the comments from respondents about their positive experiences with the service. Numerous respondents expressed that the service has been critical in helping them navigate services and in getting their children’s needs met. For example:

“ Our experience with the PLaNS service has been exceptional. Despite being a highly educated and experienced health professional, navigating multiple health systems has been extremely challenging. The PLaNS team have advocated for my children, and followed through on absolutely everything. I couldn’t recommend the PLaNS team more highly.

Survey respondent



“ PLaNS has changed our family’s life for the better. When we joined, we were regularly admitted and presenting to emergency departments and our experiences were traumatic for everyone involved. My son had 14 specialists and the admin/communication sharing was a full-time job. PLaNS helped us to streamline communication and admissions to reduce trauma for my child.

Survey respondent

## Why is this change significant?

HCCA’s research report, *Kids Interstate Shared Care Report: Consumer and Family Experiences and Expectations of Accessing Interstate Specialist Care*, outlines the stress and trauma that Canberran families experience when their child needs interstate care, including the financial impacts of being away from home and the difficulties of navigating bureaucratic silos. PLaNS was designed to help families overcome such challenges.

## How did HCCA contribute to this change?

HCCA was commissioned by the ACT Health Directorate to explore the experiences of families whose children received interstate health care, following concerns that were raised with the Health Minister. The resulting research report, submitted in May 2020, called for the establishment of a paediatric navigation service.

This report contributed to CHS committing to establish a paediatric navigation service, and it was listed as a key document informing the ACT Government’s Child & Adolescent Clinical Services Plan 2023–2030.

The design of PLaNS embedded lived experience from the start: HCCA facilitated a consumer reference group to co-design the service with staff from the Canberra Health Services Integrated Care Program team. ACT Health Minister Rachel Stephen-Smith referred to the development of the program as a learning experience for health authorities, highlighting the importance of improving service coordination and incorporating feedback from families into service design.

HCCA provided secretariat support to the Paediatric Navigation Consumer Reference Group. The group brought together parents of children who travel interstate for specialist medical care and representatives of Arthritis ACT, the Stella Bella Little Stars Foundation, ACT Down Syndrome Association, and Diabetes NSW and ACT. The consumer reference group provided advice to inform the draft model of care and reviewed job descriptions and recruitment processes. Minutes show that consumer input emphasised the importance of coordination, connection, and relationship building.

HCCA was also responsible for sharing the draft model of care with other interested community and consumer organisations (**relationships**).

In a follow-up survey about the experience of group members, one member of the reference group mentioned that the collaborative approach of the consumer reference group was extremely rare in health work (**power dynamics**). They expressed hope that this approach might be implemented in other areas of health care. Members of the consumer reference group reported that participating in the design was a positive experience. They highlighted how the collaborative design efforts resulted in a service that meets families' needs and was not just a 'box-ticking exercise' for the hospital. They felt that HCCA had helped to build a strong sense of trust and shared a common goal.

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## Case study 3B:

# New dedicated inpatient palliative care ward

## What has changed?

The ACT Government committed \$15.5 million over four years in the 2023–24 Budget to design and construct a palliative care ward at Canberra Hospital. At the time of writing (June 2024), the final design of the ward was complete in preparation for commencement of construction in 2024.

The ACT Infrastructure Plan update describes the Acute Palliative Care ward as 'A purpose designed environment that will provide acute interventions to people who are receiving palliative care and/or are approaching the end of their lives at Canberra Hospital. The setting will provide a significant enhancement to the existing environment to ensure dignity and comfort will be provided to patients and their families.'

## Why is this change significant?

The new ward will be the first inpatient palliative care facility at the Canberra Hospital. The establishment of the palliative care ward addresses a significant gap in services in the Canberra region. Prior to the establishment of the new ward, the only other inpatient palliative care facility was Clare Holland House, which is unable to meet the increasing demand for palliative care. Additionally, the lack of a dedicated specialist inpatient service at the Canberra Hospital was identified as a key factor contributing to the number of patients dying in discomfort or pain; respiratory distress; and restlessness, agitation, or delirium at the Canberra Hospital.

The design of the ward is also significant because the physical environment can influence patient outcomes, safety, and the level of stress and fatigue experienced by patients, their family, and staff. An integrative review by Zadeh et al., which examined environmental design for end-of-life care settings, found that 'environmental factors can ... influence patients' ability to tolerate disease symptoms and assert control of their bodies and emotions and can enhance caregivers' abilities to meet the needs and wishes of people who are terminally ill.' The new ward will include a dedicated resting place for carers as well as an outdoor space – identified as two key features of an ideal hospital-based palliative care setting in HCCA's research into consumer and clinician preferences for the physical environment in hospital-based palliative care.

## How did HCCA contribute to this change?

HCCA has been advocating for the need to increase the range and quality of palliative care services available to residents of the ACT and its surrounds for over a decade. Over the years, HCCA has advocated for an inpatient palliative care unit at the Canberra Hospital in meetings and discussions with government ministers; in submissions,

including their submission to the Senate Inquiry into Palliative Care in Australia in 2012 and annual budget submissions; and consultations, including the Palliative Care Service Function Review. HCCA's advocacy was informed by extensive engagement with consumers. This included input from the Health of Older People Consumer Reference Group, research into the consumer experience of dying while a patient of the Canberra Hospital in 2017, and research into consumer and clinician preferences for the physical environment in hospital-based palliative care in 2018.

Together, HCCA's consumer engagement, research, and advocacy support the flow of information and knowledge from consumers to decision makers (**resource flows**). This enables decision makers to make decisions informed by consumer experiences, needs, and perspectives.

The interviewee for this case study was aware that HCCA had advocated for a palliative care ward for a long time, and he believed that this advocacy likely contributed to the success of getting the project to where it is today.

“ HCCA have certainly pushed this [the need for a palliative care ward] very, very well and they are very passionate about it.

The ACT Government consulted with HCCA and provided opportunities for input and feedback throughout the project. HCCA was expressly asked to provide feedback on the model of care, it was a member of the Delivering a New Palliative Care Ward at the Canberra Hospital Project Control Group, and it supported a consumer representative on the design user group. HCCA also connected Canberra Health Services to consumers to hear directly from consumers.

The interviewee acknowledged that consumer input and feedback, provided by HCCA and directly from consumers, significantly influenced the design of the service model and the building.

“ When the model of care went out for consultation to HCCA, the feedback that came back was fantastic. I was honestly thrilled and impressed by the quality of the feedback and just how good it was for us as group to get all this great information about what people are expecting. Some of it didn't fit in a model of care, but it then informed our design.

He highlighted the following aspects of the design that were heavily influenced by HCCA:

- increasing the size of the outdoor space and landscaping gardens
- an area for carers to rest, including a bed so that they can stay overnight
- a breakout room for staff.

Canberra Health Services valued the role HCCA played in ensuring the ward was informed by consumer experiences, needs, and perspectives (**resource flows**) and in facilitating connections and communication between Canberra Health Services and consumers directly (**relationships**).

When asked if the project would have had the same level of consumer engagement without HCCA's involvement, the interviewee commented:

“ I can't see how we would do it without HCCA, unequivocally. I could think of nowhere else that you could easily go to get the advice and support that we do [from HCCA].

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## Case study 3C:

# Canberra Hospital Expansion Project

## What has changed?

In 2021 construction began on a new, seven-storey critical services building on the Canberra Hospital campus, which will house an emergency department, intensive care units, and specialist surgical and inpatient areas.

Many aspects of the building's design were the result of consumer leadership. Key examples include:

- patient rooms (carer zones and fold-out beds, dimmable lighting, increased natural light, and power points to allow consumers to charge their devices)
- family spaces (a private family respite lounge with kitchenette, meeting room and showers, as well as a patient and carer lounge)
- Aboriginal and Torres Strait Islander lounge (enabling access to support in a centrally located position, with an outdoor space and yarning circle)
- improved accessibility (such as service counters at wheelchair level, and more intuitive wayfinding and signage)
- emergency department (a reception centre for better patient flow, a kid's play zone, and a sensory room)
- other amenities (outdoor gardens, improved public spaces, and personal storage areas)
- a 'Changing Places' bathroom (facilities larger than standard accessible toilets with additional features, including a ceiling track hoist system to meet the needs of people with disability and their carers).

Some of these design components may be incorporated into the Australasian Health Facilities Guidelines.

## Why is this change significant?

The design features listed above will make the new hospital facility a more comfortable, more accessible, and less stressful experience for patients and their families and carers. Some of the features will also remove barriers to accessing health care or visiting loved ones in hospital. For example, the 'Changing Places' facility was implemented after feedback from people with disability and their carers about being reluctant to attend the hospital because they weren't sure if there would be a bathroom that would meet their needs.

The addition of the design features to the national guidelines means they will be incorporated into future health infrastructure projects, including Canberra's new northside hospital.

Also significant is the extent of consumer input into the building design. The Canberra Hospital Expansion Project Consumer Reference Group was established in late 2019 to hear from patients, carers, and their families on the design, delivery, and operation of the new facility. The group met monthly until it finalised its work in late 2022.

In a media release to note the new guidelines, Health Minister Rachel Stephen-Smith said:

“Consumer involvement throughout the Canberra Hospital Expansion Project has fundamentally altered how we think about health infrastructure ... This work highlights the importance of a consumer-focused approach in hospital design.

## How did HCCA contribute to this change?

HCCA chaired the consumer reference group, and HCCA's Manager of Consumer Participation was a member of the Canberra Hospital Expansion Project Control Group.

HCCA co-hosted workshops and focus groups on specific topics. Examples included:

- a workshop in June 2022 to provide consumer input into landscaping, courtyards, wayfinding, and other signage
- a workshop in July 2022 to consider the design of the family respite lounge, and design features to support consumers with dementia
- a community showcase event in February 2023 to demonstrate the difference consumer input had made to the design.

HCCA's role in facilitating consumer engagement in the project helped to build **relationships** between consumers and decision makers and enhanced the influence of consumers (**power dynamics**). HCCA also supported the two-way flow of information between consumers and decision makers (**resource flows**).

Throughout the design stage, HCCA received positive comments from participants about the workshops, noting they were 'interesting and useful' and 'not too technical'. Members of the consumer reference group also saw the updated designs that incorporated their feedback.

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## Case study 3D:

# Improved wayfinding at Canberra Health Services locations

## What has changed?

Wayfinding refers to the use of design elements, including signage, to help people navigate a space. Since 2021, Canberra Health Services (CHS) has improved wayfinding at several of its locations, including better colour coding and more signs at key intersections.

## Why is this change significant?

Poor wayfinding can add to the existing stress of attending a medical appointment or visiting a loved one in hospital. Challenges with finding a carpark and the correct room in a facility can cause consumers to run late for their appointments, which in turn may cause the health service to run behind schedule. We may not be conscious of wayfinding as an important element of an accessible health service, but if getting to appointments is confusing, frustrating, and overwhelming, this can be a barrier to care.

## How did HCCA contribute to this change?

HCCA staff and consumers regularly provide input and feedback to CHS on consumer issues, including how to improve wayfinding. For example, the HCCA Health Literacy Project Officer sits on the Canberra Health Services Wayfinding Working Group, and HCCA provides regular advice and input to the work of the Infrastructure and Health Support Services team.

In addition to such formal committees, HCCA provides input through ad hoc discussions and feedback, as well as informal quarterly meetings that were established to ensure nothing is missed via formal avenues.

The interviewee for this case study confirmed the importance of HCCA's role in ensuring consumers are represented:

“ We rely on HCCA to bring in knowledge and experience through their membership to help us improve the consumer experience, which may be through simple things like wayfinding improvements.



He also noted how HCCA had helped shift the organisation's approach to wayfinding:

“ They do bring a tremendous benefit to our consumers and helping our staff to think a different way ... Rather than doing it piecemeal reactive to a complaint, you might say HCCA has helped us think about the whole consumer journey.

Through these activities, HCCA facilitates the flow of information from consumers to decision makers (**resource flows**). It also demonstrates how HCCA's strong **relationships** contribute to the health system being more consumer-centred.

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## Case study 3E:

# Improved public transport accessibility at Canberra Health Services locations

## What has changed?

In 2024 upgrades were completed to public transport access at several Canberra Health Services locations, including the Canberra Hospital. This includes more sheltered and seated bus stops, improved pathways to bus stops, and more signage to guide people from bus stops to accessible entryways.

## Why is this change significant?

These upgrades make it easier for consumers, especially consumers with disability, to access Canberra Health Services via public transport, thereby improving health care accessibility.

## How did HCCA contribute to this change?

HCCA advocated for, organised, and facilitated a workshop on bus stops with staff from Canberra Health Services and Transport Canberra, members of the ACT Ministerial Disability Reference Group, and HCCA members from the Accessibility and Design Consumer Reference Group.

The interviewee for this case study credited HCCA with bringing together the key people from across different areas to address the issue of bus stops, overcoming the challenge of working across silos and creating a shared drive for change. He noted that while Canberra Health Services had responsibility for wayfinding and other aspects of managing the hospital infrastructure, different government stakeholders were responsible for bus stops, roads, and pavements, making it difficult for any one team to identify and fully resolve issues.

“ It wouldn't have happened if HCCA were not advocating that things need to change.

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# APPENDIX A: Methodology



## APPENDIX A:

# Methodology

To demonstrate HCCA's contribution to improved health care, we drew on multiple approaches and methodologies to create a tailored approach. This enabled us to build a credible, evidence-based picture of how HCCA contributes to changes in the health system, and how these changes contribute to improved health care.

## Phase 1:

### Data collection

Our data collection approach was influenced by Outcomes Harvesting, an evaluation methodology that identifies ('harvests') evidence of what has changed ('outcomes') and then works backward to determine how a program or initiative contributed to these outcomes. This approach contrasts with conventional evaluation methods that start with activities and look for evidence that these activities achieved the desired outcomes. Outcomes Harvesting informed our approach to interviews: we started with the outcome and asked stakeholders to comment on how HCCA had contributed to this outcome. We also drew on the case study approach used in many outcome harvest reports.

The data collection phase included the following steps:

- **Review of HCCA documentation:** We conducted a thorough qualitative analysis of HCCA's documentation to identify significant outcomes that occurred during the strategic plan that HCCA is likely to have contributed to in some way. Using Dedoose, a qualitative data analysis software program, we reviewed documents including activity and project reports, annual reports, the book *Making a noise: 40 years of consumer health advocacy in the ACT*, Executive Committee reports, newsletters, the consumer and community participation framework, and evaluation reports.
- **Gathering information from HCCA staff:** We gathered additional information from HCCA staff through meetings and email correspondence.
- **Interviews with stakeholders:** We conducted semi-structured interviews with 12 stakeholders to gather in-depth insights into how HCCA contributed to identified outcomes. The interviews provided qualitative data to substantiate HCCA's contributions and helped us to understand the context and significance of the outcomes.

- **Internet search for publicly available information:** Where needed to further triangulate the data, we searched online using tools like Google, Perplexity, and journal databases for additional evidence to support the identified outcomes. Sources included government media releases, news articles, scientific journal articles, and stakeholder websites.

## Phase 2: Data analysis

Using the collected data, we created detailed case studies documenting how HCCA contributed to each change. We then performed cross-case analysis to identify patterns in HCCA's contributions across different cases.

Our analysis was informed by systems thinking – an approach and set of tools for examining the wide range of factors, and the relationships between them, that drive problems and influence the effectiveness of interventions. System thinking shifts the focus from responding to events in a system to identifying and understanding the patterns and underlying structures that drive these events.<sup>10</sup>

We identified two prominent systems-thinking tools that aligned with the themes we identified in the case studies. These were:

- **The Water of Systems Change:** This framework identifies six interrelated conditions that hold complex systems in place: policies, practices, resource flows, relationships, power dynamics, and mental models. The framework is based on extensive research, which shows that these six conditions can either enable or hinder systems change. While these conditions can be independently defined, measured, and targeted for change, they are also intertwined and interact with each other.<sup>11</sup>
- **The Iceberg Model:** The iceberg model is used as a metaphor and visual tool across various sectors and settings to explore the underlying drivers of problems, events, or changes. An iceberg is a useful metaphor because only a small portion of the iceberg is visible above the water, and the majority is submerged and unseen. In systems thinking, the visible part of the iceberg represents the observable events that occur in a system, such as improvements to health services. The larger, submerged part represents the deeper layers of patterns, structures, and mental models that drive these events.<sup>12</sup>

## Phase 3:

# Development of HCCA's Systems Change Model

We created a model that illustrates how HCCA contributes to systemic changes in the health system, and how these changes contribute to improved health care. The model draws from systems-thinking approaches and tools, particularly The Water of Systems Change and the Iceberg Model, as well as theory-based approaches to evaluation. Combining these approaches enabled us to develop an evidence-based model that articulates HCCA's contribution to systems change.

## Phase 4:

# Validation

We conducted a workshop with HCCA employees to validate our findings and test the systems change model. This approach ensured that our interpretation of the data was accurate and aligned with HCCA's experiences and perspectives. The workshop provided an opportunity for HCCA staff to give feedback on our findings and helped us refine our analysis. HCCA staff and the Executive Committee also reviewed the report and provided further input into the systems change model.

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