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*“Of course it’s better if we’re there”:*

Consumer involvement in health infrastructure in the ACT, 2009-2016

**December 2016**

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# Acronyms

ACRS Aged Care and Rehabilitation Services

ACT Australian Capital Territory

CADP Capital Asset Development Program

CALD Culturally and Linguistically Diverse

CHC Community Health Centre

CRP Consumer Representatives Program

FSP Final Sketch Plan

HCCA Health Care Consumers Association

HIP Health Infrastructure Program

HPUB Health Planning Unit Briefs

ICT Information and Communication Technology

ILC Independent Living Centre

MHCN Mental Health Consumer Network

MLO Multicultural Liaison Officer

PCG Project Control Group

PDP Project Definition Plan

POE Post Occupancy Evaluation

PSP Preliminary Sketch Plan

PWD ACT People With Disabilities ACT

SFA Service Funding Agreement

# Foreword

Improvements to our health system infrastructure are essential and require forethought and well informed planning that involves consumers of health care. This report draws together information about the involvement and contribution of the Health Care Consumers Association staff and consumer representatives to health infrastructure projects undertaken by the ACT Health Directorate between 2008 and 2016. It is a unique account of the very significant partnership between the Health Directorate, the local ACT community and consumers of health care, and provides an in depth account of consumer participation in the design, planning, implementation and governance processes of the Capital Asset Development Program and later the Health Infrastructure Program. These projects ranged from hospital car parks to nurse led Walk- In Centres, Emergency Department upgrades to a new Regional Cancer Centre and the University of Canberra Public Hospital and refurbishment of three community health centres.

The analysis of the data is compiled from HCCA contract reports to government and the diverse experience of consumers involved in a range of committees, workshops, and broader community consultations facilitated by HCCA. The report focuses very much on how HCCA and consumer representatives were able to participate effectively in the process, be well resourced to do so, and more broadly, to have leadership support from government for meaningful engagement with consumers. It also identifies some of the mechanisms that did not work so well and which often seemed intractable, such as efficient information sharing and working with people from culturally and linguistically diverse backgrounds and from disadvantaged communities in the ACT.

While the report is not a formal evaluation, many themes and critical issues have emerged that highlight the challenges and achievements for both HCCA and the Health Directorate. A strong theme underlying the involvement of HCCA over this seven year period is the importance of building and maintaining respectful and productive working relationships between all stakeholders. This is the foundation of ensuring a shared vision to achieve the best outcomes for consumers in often changing political and fiscal environments.

It is clear from this report that the level of consumer involvement in the physical and spatial design of these health services and their patient centred models of care can and does contribute to improved outcomes for the whole community. It provides much to think about including how to improve models of consumer engagement in the future.

The author of this report Sarah Spiller, the Executive Director of HCCA, Darlene Cox and HCCA staff are to be commended on producing such a comprehensive and valuable document for all those committed to consumer centred healthcare.

Dr Sue Andrews  
HCCA President

# iii Acknowledgements

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Five consumer representatives share their experiences of participating in ACT Health infrastructure committees in this report. We thank Adele Stevens, Alan Thomas, Bill Heins, Russell McGowan and Trish Lord for their time and generosity.

Finally HCCA thanks the members of our Health Policy Steering Committee. Fiona Tito Whitehead, Joy Pettingell, Linda Trompf, Sue Andrews and Wendy Armstrong provided feedback on guidance on the report during its drafting.

*\* Organisational representative*

# Executive Summary

## 1.1. About this report

This report shares HCCA’s experience and lessons learnt from seven years of supporting consumer involvement in health infrastructure projects in the ACT (2009-2016). It describes the establishment and expansion of HCCA’s work in this area, and identifies key elements and outcomes of this work. It also details challenges to effective consumer involvement in health infrastructure and the strategies that we used to respond to these, and identifies factors for success in partnerships between consumers and government.

While consumer and community involvement in health infrastructure projects occurs in other Australian jurisdictions, this involvement is generally focused on the physical design of buildings and in particular the design of areas used by patients. What set apart the ACT’s approach from 2009 to 2016 was the level of involvement that consumers had in strategic decision-making and governance.

The report is structured chronologically, with Sections 3. to 5. describing the evolution of HCCA’s work on health infrastructure. These Sections include three case studies of consumer involvement in infrastructure projects: Community Health Centres, the Village Creek Centre and the University of Canberra Public Hospital. Section 6. identifies key elements of HCCA’s work in support of consumer involvement in infrastructure planning and governance, while Section 7. describes the key outcomes that this work achieved with and for health consumers in the ACT and region.

The appendices provide further detail on the governance of health infrastructure in the ACT, and HCCA’s work in support of consumer involvement (2009-2016).

HCCA anticipates that the report will be of interest to consumer organisations, government agencies and health services working in, or intending to work in, health infrastructure planning, service delivery and evaluation.

## 1.2. About HCCA

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

HCCA involves consumers through:

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

## 1.3. HCCA’s health infrastructure work

HCCA has a longstanding commitment to consumer involvement in health service planning, implementation and evaluation. Our work in this area expanded significantly between 2009 and 2016, when the ACT Government made specific funding available to support HCCA to engage consumers and the community in health infrastructure planning and governance, as part of a jurisdiction-wide program of health services expansion and redesign. This was initially called the Capital Asset Development Program (CADP), and in 2012 was re-named the Health Infrastructure Program (HIP). In most instances HCCA’s involvement in CADP and HIP projects took place through HCCA endorsed consumer representatives. In some cases this involved facilitating appropriate representation from organisations such as the Mental Health Consumer Network (MHCN) and People With Disabilities ACT (PWD ACT). HCCA also undertook extensive consumer and community consultation about CADP and HIP projects; and participated in ACT Health staff training, policy development and review in relation to consumer participation.

Between 2009 and 2016, HCCA supported consumer involvement in the following CADP and HIP projects:

* Mental Health Assessment Unit, Canberra Hospital (opened 2010);
* Surgical Assessment and Planning Unit, Canberra Hospital (opened 2010);
* Neurosurgical intra-operative Magnetic Resonance Imaging suite, Canberra Hospital (opened 2010);
* PET/CT Scanner Suite, Canberra Hospital;
* Southern Multi-Storey Car Park, Canberra Hospital (opened 2010);
* Village Creek Centre (relocation of rehabilitation, aged and community care services to the south Canberra suburb of Kambah) (opened 2011);
* Duffy House, accommodation for six patients undergoing cancer treatment and their unpaid caregivers, at The Canberra Hospital (opened 2012);
* Gungahlin Community Health Centre (opened 2012);
* Adult Mental Health Unit, The Canberra Hospital (opened 2012);
* Emergency Department Upgrade, Calvary Public Hospital (opened 2012);
* Belconnen Community Health Centre (opened 2013);
* Centenary Hospital for Women and Children (opened 2013);
* Emergency Department and Intensive Care Unit Extension, The Canberra Hospital (opened 2013);
* Canberra Regional Cancer Centre (opened 2014);
* Rehabilitation, Aged and Community Care Outpatient Services (New Building 15), The Canberra Hospital (opened 2014);
* Expansion and refurbishment of Tuggeranong Community Health Centre (opened 2014);
* Nurse-led Walk-In Centres, Tuggeranong and Belconnen, co-located with Community Health Centres (both opened 2014); and
* Calvary Hospital Car Park (opened 2015).[[1]](#footnote-1)

Major HIP projects in which HCCA supported consumer involvement and which were in design or construction at the time of writing include:

* Dhulwa Secure Mental Health Unit (expected completion 2016);
* Emergency Department Expansion, Canberra Hospital (expected completion 2017);
* University of Canberra Public Hospital (expected completion 2018);
* Ngunnawal Bush Healing Farm (expected completion October 2016); and
* A signage package for The Canberra Hospital campus.[[2]](#footnote-2)

In addition, HCCA supported consumer input into detailed Health Planning Unit Briefs (HPUBs) for projects that have not moved beyond the initial consideration and planning phase:

* Philip, Dickson and Civic Community Health Centres; and
* Canberra Hospital Clinical Services Building.

## 1.4. Key achievements

HCCA’s work and ACT Health’s approach to consumer involvement in health infrastructure (2009-2016) provided an unprecedented opportunity for health consumers in the ACT and region to contribute to strategic decision-making in relation to a major program of health infrastructure redesign and expansion.

### 1.4.1. Dedicated resources for consumer involvement

One of the key achievements for HCCA during CADP and HIP was to effectively lobby for and negotiate with ACT Health to secure additional funding to support and enhance consumer representation. The fact that HCCA was able to convince the ACT Health Directorate of the value of early and effective consumer engagement in a major infrastructure program was intrinsic to the overall process. The provision of additional funding for this work can be seen as recognition by ACT Health of the need for consumer input into health services and infrastructure planning.

This recognition and the subsequent funding arrangements established a consumer engagement model that can provide a guide for future work in the ACT and elsewhere, not only in health infrastructure but also in health services planning more broadly.

### 1.4.2. Consumer representation

The CADP and HIP articulated a strong commitment to consumer involvement, and established a clear role for consumer representatives in program and project governance. The design of the CADP and HIP reflected a key principle of good practice in consumer representation, namely that consumers should be represented at the highest possible level of governance.[[3]](#footnote-3)

Consumer representatives made substantial and valuable contributions of time, knowledge and skill to CAPD and HIP committees. They:

* Ensured that consumer perspectives, priorities and concerns were consistently articulated and considered by decision-making committees;
* Raised consumer issues that would likely otherwise have been overlooked;
* Kept consumer priorities ‘on the table’ as iterative infrastructure design processes evolved; and
* Brought a unique consumer perspective to deliberations that helped other committee members to make decisions that put patients and consumers closer to the centre of their considerations.

The high level of involvement required by consumer representatives in the CAPD and HIP highlighted several barriers to effective consumer representation. These included:

* The time demands and sometimes very high workloads placed on consumer representatives, who work as volunteers;
* The technical nature and complexity of infrastructure development processes;
* Disjointed information flow between committees operating in a multi-tiered governance structure;
* Variable awareness on the part of secretariats and other committee members of the role of consumer representatives and the value of consumer representation;
* Variable secretariat support;
* Rushed or unclear decision-making processes; and
* The power differential experienced by consumer representatives participating in committees otherwise comprised of people taking part in a professional capacity.

The time-urgent nature of much decision-making in the CADP and HIP contributed to what HCCA often experienced as ad-hoc or last-minute committee processes. For example, HCCA frequently received late notice of new User Groups requiring consumer representatives, and little communication about the roles and expectations of committee members or the scope of a committee’s decision-making. This allowed minimal time to orient new consumer representatives to their roles, and limited the extent to which HCCA could assist consumers to prepare for their committee work.

HCCA responded to these barriers by providing training, information, networking opportunities, and personalised practical support to consumer representatives. This included through the CADP Reps Network and HIP Reps Network, which met regularly (in the case of the HIP Reps Network, monthly). Under the HIP, HCCA altered our model of consumer representation with HCCA employees taking on roles on the overarching program governance committees. Though a departure from our longstanding organisational position that the role of staff is to support consumers at all levels of decision-making, this move responded to the intractable challenges that consumers faced on the program governance committees as well as the expressed preference of ACT Health. In this context the HIP Reps Network took on additional value as a forum for HCCA staff accountability to consumer representatives. HIP Reps Network meetings also enabled essential information-sharing between the consumer representatives and the HCCA staff undertaking committee work.

HCCA established effective mechanisms for supporting consumer representation on infrastructure committees. This included working with ACT Health to develop a confidentiality agreement for consumer representatives, which made it possible for consumer representatives to discuss their work with one another and HCCA while abiding by the strict probity requirements placed on all members of infrastructure committees.

As a consequence of the time-urgent and technical nature of health infrastructure projects, it was often difficult for HCCA and consumer representatives to identify the points in the process at which consumer input was critical to outcomes. We responded to this challenge by producing an Indicative Process Diagram that mapped the essential points for consumer involvement in infrastructure projects, including by the public, consumer representatives and HCCA. While never formally adopted by ACT Health this remains a useful document to inform future work in this area. It is provided at Appendix E.

### 1.4.3. Consumer consultation and community engagement

HCCA expanded and consolidated our health infrastructure work between 2013 and 2016. This was possible under a Service Funding Agreement (SFA) with ACT Health that made additional resources available to better meet the need for consumer involvement in the CADP and HIP. From 2013 we undertook a major program of community and consumer engagement and consultation about the HIP, meeting with peak health and social service organisations, community groups, and each of the ACT’s Community Councils as well as the Queanbeyan Community Council (NSW). This work raised community awareness of health infrastructure projects, and opportunities to have input into these projects.

Between 2013 and 2016 HCCA:

* Supported consumer representatives on 131 ACT Health HIP committees, who contributed 904 meeting hours, and 1,223 preparation hours;
* Undertook 23 community consultations;
* Shared 78 articles on HIP in the HCCA e-newsletter Consumer Bites (for example about HIP projects, openings, and changes to access due to construction); and
* Provided 107 community information sessions or presentations on new services and facilities.[[4]](#footnote-4)

This level of activity was possible as a consequence of the more holistic approach to consumer involvement made possible under the 2013-2016 SFA.

In 2012 HCCA successfully negotiated with ACT Health to obtain funding to employ a Multicultural Liaison Officer, enabling us to develop an appropriate approach to CALD community engagement. This approach focused on building trust with community members and community leaders, understanding community priorities and experiences of health services, supporting health literacy and meeting the demand from CALD community members for information about health services in the ACT. These were necessary precursors to more specific engagement of CALD communities about health infrastructure projects. This is a successful model that could be replicated to support CALD engagement in other areas of health service planning, and in future infrastructure projects.

### 1.4.4. Health services that meet consumer needs and expectations

Consumer involvement in health infrastructure projects (2009-2016) contributed to tangible positive outcomes in the design of health services. To take the example of the University of Canberra Public Hospital, these have included:

1. Inpatient areas and shared spaces that feature as much natural light as possible;
2. Inpatient areas and shared spaces that provide as home-like an environment as possible, appropriate to a rehabilitation facility;
3. Inpatient areas that offer consumer control, for example openable windows and a higher ratio of single bed rooms; and
4. Improved access to the facility, for example flat entrance surroundings, accessible car parking and underground car parking, improved signage and wayfinding, and connections to public transport.

Consumer involvement has also identified key gaps in services, and consumer representatives have successfully advocated in support of ACT Health proposals such as the provision of a Community Development Officer to be based at the Gungahlin Community Health Centre.

HCCA played an important role in supporting consumers to be involved in ameliorating challenges encountered in infrastructure projects. For example HCCA worked collaboratively with consumers and key consumer organisations to respond to the access issues created by the ACT Government’s unilateral selection of the Village Creek Centre site. HCCA also supported consumer involvement in designing post-occupancy evaluation (POE) criteria for the Village Creek Centre.

## 1.5. Key issues for ACT Health

### 1.5.1. Recurring issues for consumers

Through our work in support of consumer involvement in infrastructure, HCCA identified a number of factors that assist to deliver high quality, safe, health services that meet consumer needs and expectations. We detail these for consideration in future infrastructure projects.

1. Early consumer involvement in site selection will help government agencies to avoid the selection of sites that are inappropriate and inaccessible to consumers;
2. Early, ongoing, clear and appropriate communication with consumers and the community about infrastructure projects will build public awareness and consumer engagement, which in turn contributes to the delivery of health services that better meet community needs and expectations;
3. Transport to and from services is an important aspect of consumer access to services. New and redesigned health services must be accessible by frequent public and community transport that is suitable for people with disabilities or limited mobility; travel times must be reasonable; and sufficient accessible car parking must be provided;
4. When consumers are involved in planning for POE, including by defining evaluation criteria, the things that matter to consumers will be measured. A successful model of consumer involvement in POE was developed by HCCA in partnership with ACT Health in the development of the Village Creek Centre, and a model of this kind should be considered in future infrastructure projects. More generally, the lack of POE for many HIP projects and limited sharing of information about the findings of the POE processes that did take place limited the extent to which later HIP projects could learn from earlier projects;
5. Early and ongoing consumer involvement in developing models of care can assist to ensure that design and construction considerations do not overshadow consideration of the model of care to operate from new or redesigned health services; and
6. Consistent attention to signage and wayfinding is an essential enabler of positive consumer experiences of health services, during construction as well as in new or redesigned buildings.

The ACT Health committee secretariats and committee members with which HCCA worked had varied levels of understanding of the role of consumer representatives, and varied capacity to support consumer representatives. This underscores the value of practical training for health professionals about consumer representation. HCCA is well-equipped to provide this service.

HCCA’s 2013-16 SFA expressed our aspiration to undertake annual planning processes in partnership with ACT Health, and to jointly develop consumer engagement plans for each major infrastructure project. Though unfortunately these processes did not take place, they have the potential to provide a more responsive and holistic approach to consumer involvement. This approach could be implemented in the future.

These considerations are likely to also apply in other contexts where health infrastructure projects take place. Thus they suggest issues of ongoing importance both to health infrastructure planners and to consumer organisations.

### 1.5.2. Partnership with HCCA

Through our partnership with ACT Health (2009-2016), HCCA supported consumers to make a unique contribution to health infrastructure decision-making. This was recognised by key ACT Health personnel with whom we worked:

*“From my perspective the immense value of consumer involvement was that it allowed consumers an equal voice at the design table. All too often health services are designed to suit the needs of providers. The other value-add was that in the absence of evidence for designing a facility in a particular way, we could utilise the expertise of the end user” – former ACT Health Executive Director Government Relations and Planning ACT Health Megan Cahill[[5]](#footnote-5)*

Among the contributions that HCCA made to health infrastructure projects in the ACT between 2009 and 2016 were:

1. Translating technical and bureaucratic terminology into consumer-relevant language to build consumer awareness and involvement in health infrastructure projects;
2. Presenting consumer experiences and priorities in ways that gained traction in health infrastructure decision-making;
3. Partnering with health services to improve signage and way finding both in new and redesigned services and during construction;
4. Sharing knowledge, consumer experience and evidence in relation to site selection, models of care, access barriers and patient-centred design including of inpatient areas, shared spaces, and furniture, fixtures and equipment;
5. Coordinating consumer input into complex and time-urgent infrastructure processes;
6. Supporting high quality POE that involved consumers as partners; and
7. Raising consumer and community awareness of infrastructure projects and opportunities to have input.

HCCA invested in our understanding of evidence-based design and good practice in consumer involvement in infrastructure. This included by conducting interstate site tours of infrastructure facilities, and researching issues including the patient experience of different room types in inpatient facilities and the benefits of single bed rooms in hospitals. This enabled HCCA to advocate for change from an informed evidence base, and to share this knowledge with ACT Health.

Consumers’ views and ideas were not always accepted in the planning and governance of CADP and HIP. However, this does not distract from the fact that consumers were at the table and able to present our views, a number of which made a significant difference to planning outcomes. There is clearly room for a greater level of consumer involvement in this type of strategic health services and infrastructure planning but this model provides a foundation on which to build.

Importantly, the relationships developed between HCCA, some areas of ACT Health and other community organisations during the CADP and HIP have strengthened HCCA’s capacity to continue our work in supporting effective consumer involvement in health service planning into the future.

# An overview of HCCA involvement in health infrastructure

Consumer involvement in health service planning, delivery and evaluation has been a central area of interest for HCCA since our organisation’s incorporation in 1978. HCCA recognises that the location and design of the buildings in which health services are delivered, and the models of care that operate from these buildings, are key factors that influence healthcare quality, safety and accessibility. Over the years, HCCA’s activities in relation to health infrastructure have included:

* Consumer representation on decision-making committees;
* Consumer and community consultation;
* Provision of information to consumers and the community, including through information sessions and regular HCCA member communications; and
* Provision of policy advice to government and health services.

From the mid-2000s consumers, health providers and the ACT Government recognised that the Territory’s ageing health infrastructure would be ill-equipped to cope with expected future growth in need for services and changing patterns of demand for healthcare.[[6]](#footnote-6) In response the ACT Government established the CADP in 2008. Planned as a 10 year program of health system redevelopment and expansion, the CADP brought with it new opportunities for consumers to participate in the governance of health infrastructure projects through representation on ACT Health committees, and an increased need for HCCA advice and advocacy in relation to infrastructure matters. Following negotiations between HCCA and ACT Health, in 2009 the ACT Government funded HCCA specifically to support consumer engagement in CADP projects, under a one-year non-ongoing contract. This modest, time-limited, funding allowed HCCA to employ a Consumer Coordinator (0.4 EFT) for twelve months to support consumer representatives and to undertake community liaison and information-sharing activities related to health infrastructure.[[7]](#footnote-7) In 2010 the ACT Government provided a further year of funding to continue this work, with HCCA providing additional funding from organisational reserves to expand the Consumer Coordinator role to 0.5 EFT in order to meet the need for the work this position undertook.[[8]](#footnote-8)

In 2012, the CADP underwent a name change to become the Health Infrastructure Program. The ACT Government extended the HIP’s timeframe to 2022 and took on the program manager role that had previously been outsourced to the management consultancy, THINC Health.[[9]](#footnote-9) In response to HCCA’s proposal to increase the involvement of culturally and linguistically diverse communities in health infrastructure planning, in mid-2012 the ACT Government provided HCCA with additional time-limited funding to employ a part-time Multicultural Liaison Officer from August 2012.[[10]](#footnote-10) In 2013 HCCA’s work in health infrastructure was strengthened and consolidated under a three year Service Funding Agreement (2013-16). This allowed an increase in activities, a more holistic approach to consumer involvement, and a particular focus on involving CALD communities in health infrastructure planning. Appendices G to J provide an indication of the scope of the work HCCA undertook during this time. This increase in activity was supported by funding to employ a 2.5 FTE staff team comprising the Multicultural Liaison Officer, a Project Officer, and Consumer Coordinator, along with a component of the Executive Director’s time and administrative support.[[11]](#footnote-11) The Health Infrastructure Program was terminated in June 2016.

### *Timeline: HCCA involvement in the CADP and HIP*

Mid-2000s: HCCA experiences strong growth in demand for consumer representatives on ACT Health service planning and policy committees.

2008: ACT Government establishes the CADP.

2008: Increase in HCCA workload to place and support consumer representatives on ACT Health committees related to the CADP.

2008-09: Liaison and negotiation with ACT Health to secure additional resources to provide adequate support for consumer representation in CADP committees, and additional forms of consumer engagement in health infrastructure development.

2009: Service Funding Agreement altered to provide specific resources to support 0.4 FTE Consumer Coordinator for CADP, for twelve months.

2009 – 10: Liaison and negotiation with ACT Health to secure further funding for Consumer Coordinator role.

2010-11: Twelve month extension of contract to support consumer involvement in the CADP, with HCCA providing funding from reserves to increase Consumer Coordinator role to 0.5 EFT.

2012: CADP renamed the HIP.

Mid-2012: ACT Government provides 12 months of funding to HCCA to employ a Multicultural Liaison Officer to support multicultural community engagement in the HIP.

2013: HCCA and the ACT Government negotiate a three year contract to support consumer involvement in the HIP, with HCCA employing 2.5 FTE staff (Consumer Coordinator, Project Officer and Multicultural Liaison Officer with an additional component of the time of the Executive Director and Administration Officer).

2013: HCCA undertakes substantial grassroots engagement and consultation about health infrastructure projects including with Community Councils in the ACT and Queanbeyan (NSW), peak community organisations, health consumer and self-help organisations, community groups, and with CALD networks and organisations.

2013-2016: During this time HCCA:

* Supported consumer representatives on 131 ACT Health HIP committees, who contributed 904 meeting hours, and 1,223 preparation hours;
* Undertook 23 community consultations;
* Shared 78 articles on HIP in the HCCA e-newsletter Consumer Bites (for example about HIP projects, openings, and changes to access due to construction); and
* Provided 107 community information sessions or presentations on new services and facilities.[[12]](#footnote-12)

2016: HIP terminated in June 2016, cessation of funding for specific consumer input into health infrastructure decision-making.

# Consumer involvement in health infrastructure projects in the ACT, prior to 2009

HCCA’s first Service Funding Agreement with the ACT Government ran from 2004 to 2007. During this time we experienced steady growth in our work related to health service planning and development, policy development and service innovation, and quality and safety. This included meeting the need for consumer representatives to participate in a wider range of ACT Health committees. This trend reflected a positive recognition by the ACT Government of the value of consumer input into decision-making, informed by HCCA’s effective work in championing and demonstrating the value of consumer representation over many years. Growth in demand for consumers to participate in policy and planning committees also reflected ACT Health’s enhanced focus on infrastructure matters from the mid-2000s. During this time a Capital Asset Development Plan and a Master Plan for health system redesign were developed, both in anticipation of continued strong future growth in demand for health services in the ACT.

As was the case nation-wide, demographic shifts including an ageing population and increasing numbers of people living with chronic diseases drove changes in patterns of demand for health services in the ACT.[[13]](#footnote-13) There was widespread recognition from the ACT Government, ACT Health, health services and consumers that new models of care were required to respond to these shifts, and that the Territory’s ageing health infrastructure and ICT systems were no longer adequate. During this time HCCA’s work on health infrastructure involved provision of policy advice to government, and sharing information with consumers and the community about infrastructure planning processes through one-off consultation processes and member communications (including a newsletter and regular member forums). HCCA also supported consumer representatives to participate in ACT Health committees through our Consumer Representatives Program, which trained, nominated and supported consumer representatives.

New opportunities for consumer representation meant that HCCA consistently outperformed our contract obligations in this area. Our contract with ACT Health required HCCA to support 30 consumer representatives participating in 50 committees, however in 2005 HCCA supported 43 consumer representatives,[[14]](#footnote-14) and in 2006 the number had grown to 75 consumer representatives.[[15]](#footnote-15) While HCCA welcomed the growth in opportunities for consumer involvement, this situation also posed challenges for our organisation. Central to HCCA’s approach to consumer representation is our understanding that people must be appropriately trained and supported in order to participate effectively in committee work. HCCA also recognises that the pool of people with capacity to participate in healthcare committees is limited, and that community capacity to take part must be built and maintained over time through network building and information sharing.

From the mid-2000s our contract funding reports record the challenge that HCCA faced in sourcing, and supporting, a growing number of consumer representatives within the modest resources of the organisation and our Consumer Representatives Program.[[16]](#footnote-16) In response to this situation, HCCA put in place additional methods of inviting and supporting consumer representatives to participate. These methods included advertising in the networks of other community organisations and working with ACT Health agencies to identify potential consumer representatives. HCCA also established an e-mail list to share information with consumer representatives, as well as continuing to provide face-to-face workshops and forums to provide information, skills training and peer support. Nonetheless by the close of 2008, the CADP’s year of establishment, demand for consumer representatives outstripped HCCA’s ability to source sufficient numbers of consumer representatives and to appropriately support each representative to contribute effectively and confidently to their committee.[[17]](#footnote-17)

### *Summary: Consumer involvement in health infrastructure, prior to 2009*

* From the mid-2000s the ACT Government began to plan for major renewal and expansion of the Territory’s health infrastructure, and HCCA’s work in relation to health infrastructure grew steadily.
* Need and demand grew for HCCA-supported consumer representatives to take part in ACT Health committees. This created new opportunities for consumer involvement in important decisions about health infrastructure but also strained HCCA’s modest organisational resources.
* ACT Health funded HCCA to provide policy advice about health matters affecting consumers and to manage the Consumer Representatives Program (CRP). Through the CRP, HCCA trained, nominated and supported consumer representatives to participate on a minimum of 50 health decision-making committees at any time.

# Consumer involvement in the Capital Asset Development Program (CADP)

## 4.1. About the CADP

In 2008 the ACT Government established the CADP. This ambitious 10-year plan committed more than $1 billion to expand and modernise the ACT’s health system, taking in substantial capital works and redesign of existing services. The CADP aimed to reorient the ACT’s health system to better meet future healthcare needs,[[18]](#footnote-18) envisaging:

*“A high quality, integrated, efficient, accessible and safe network of tertiary, specialised and intermediary inpatient facilities that are supported by multidisciplinary hospital and community based ambulatory care zones/centres, appropriate technology, and strong primary care and population based prevention”.[[19]](#footnote-19)*

Taking in change across Models of Care, Technology, Workforce and Infrastructure[[20]](#footnote-20) the CADP had a particular focus on “better managing chronic disease and reducing the need for people to be admitted to hospital”.[[21]](#footnote-21) Thus the CADP oversaw planning for the construction of new or upgraded Community Health Centres (CHCs) in three town centres (Belconnen, Tuggeranong and Gungahlin), in addition to capital upgrades at both The Canberra Hospital and Calvary Public Hospital.

Specific aims of the CADP included to:

* Double the treatment spaces available to patients in the ACT;
* Almost double the beds in ACT public hospitals;
* Significantly upgrade mental health care;
* Provide improved and extended day surgery services;
* Transition as many non-acute services as possible out of the hospital setting and relocate these to convenient local health centres;
* Deliver improved and increased services through local health centres; and
* Ensure timely access to health services.[[22]](#footnote-22)

ACT Health engaged management consulting company THINC Health as the CADP project manager.[[23]](#footnote-23)

## 4.2. Commitment to consumer involvement

A feature of the CADP was the strong role envisaged for consumers. There was very senior support for consumer involvement in decision-making. For example, in the words of a consumer representative to the overarching CADP Redevelopment Committee, the then ACT Health Minister, Katy Gallagher MLA, demonstrated her:

*“Willingness to have dialogue with health consumers over a range of health priorities, and priority-setting and operations with health services was quite genuine. And [while] she may not have attended [Redevelopment Committee] meetings on a regular basis I’m sure she attended at least some of them….*

*[The meetings] were chaired by the Chief Executive of the Health Department and had significant commitment from senior-level people, not only within the Health Directorate [but also from Treasury and other areas of the ACT public service].” – Consumer Representative to the Redevelopment Committee[[24]](#footnote-24)*

This reflection highlights that consumers occupied an accepted role as partners in the governance of a major program of health infrastructure renewal. Representation at this level was essential to meaningful consumer involvement in decision-making, as HCCA’s HIP Consumer Coordinator observed:

*“It was very important for us to be at the governance level committees in order for the consumer perspective to be heard and inform debate. At lower levels there is a lack of understanding of the importance of the consumer voice. Having one or two reps involved at user group level is not an effective way to influence decisions. The clinical staff are seen as the experts at this level and consultants and architects defer to them for all decisions. Rep involvement at his level often felt tokenistic. Two of our reps that were on their own at user group level reported to us that they had felt patronised.”[[25]](#footnote-25)*

Involvement at the highest possible level of governance is recognised as enabling consumer representation to add value to health decision-making,[[26]](#footnote-26) and the CADP and HIP established structures that allowed this to occur.

## 4.3. HCCA’s work in support of consumer involvement in the CADP

HCCA’s work in support of consumer involvement in the CADP included providing policy advice to ACT Health, undertaking liaison with ACT Health and THINC Health, consulting with consumers and communities about the CADP and specific infrastructure projects, and sharing information about the CADP and infrastructure projects with the community and consumers. [[27]](#footnote-27) A focus of HCCA’s work was supporting consumer representatives participating in CADP committees, in particular in program and project governance committees. The modest capacity of our Consumer Representatives Program meant that we could not always meet demand for consumer representatives to participate in Working Group and User Group processes in the CADP, though our capacity to support this work did increase following the employment of a Consumer Coordinator in 2009.

Central to our approach to supporting consumer involvement, HCCA sought to work collaboratively with other community and consumer organisations to enhance consumer involvement. In particular HCCA maintained a strong relationship with the ACT Mental Health Consumer Network (MHCN), inviting members of the network to attend meetings with HCCA consumer representatives on CADP committees. HCCA and MCHN staff also met regularly to exchange information about consumer involvement in infrastructure projects.[[28]](#footnote-28) As a member organisation, HCCA worked closely with our membership to develop policy and advocacy positions related to health infrastructure.

Of the major projects begun under the CADP, HCCA supported particular consumer involvement in:

* The Village Creek Rehabilitation Centre;
* The Adult Mental Health Unit at The Canberra Hospital;
* The Belconnen and Gungahlin Community Health Centres;
* The PET/CT Scanning Suite at the Canberra Hospital; and
* The multi-storey Southern Car Park at The Canberra Hospital.

HCCA supported minimal consumer involvement in planning for the Centenary Hospital for Women and Children, a major infrastructure project begun under the CADP. In large part this reflected constraints on HCCA’s resources. ACT Health oversaw a specific consumer and community engagement process, sourcing consumer representatives from outside HCCA’s network. Notably, the neo-natal intensive care unit at the new hospital convened a parents’ group that provided significant input into the design of this service. This process identified a gap in the consumer representative demographic within HCCA, and in response HCCA convened a Maternity Services Consumer Reference Group which first met in 2013.[[29]](#footnote-29) This Reference Group continues to operate in 2016. HCCA’s minimal involvement in planning for the Centenary Hospital limited the consumer input that could be provided on the model of care delivered at this important new service.[[30]](#footnote-30)

## 4.4. The CADP committee structure

The CADP established several decision-making committees, each of which included a role for consumer representatives. These committees operated at different levels of decision-making, and their roles are detailed at Appendix C: [[31]](#footnote-31)

|  |  |
| --- | --- |
| **Committee name** | **Level of decision-making** |
| Redevelopment Committee  Strategic Implementation Groups  Project Control Groups | Program Oversight Committees |
| Executive Reference Groups | Project Oversight Committee |
| Working Groups  User Groups | Project Delivery Committees |

This structure established a role for consumers in program governance, in the governance of individual projects, and in project delivery committees (Working Groups and User Groups) tasked with practical decisions about the implementation of specific projects. As a Consumer Representative to the Redevelopment Committee observed, this committee structure reflected ACT Health’s commitment to partnering with consumers:

*“The commitment to having consumer and community input into decision-making about the major infrastructure projects was really quite obvious. And the mechanisms and the methodologies behind the whole process were well-formulated and so it was quite clear what the Redevelopment Committee was there for.” - Consumer Representative to the Redevelopment Committee[[32]](#footnote-32)*

While reflecting a positive commitment to consumer partnership, the CADP committee structure did bring with it some challenges for consumer participation, and these are discussed in the next section.

## 4.5. Consumer representatives’ contributions to infrastructure committees

Consumer representatives made substantial contributions of time, knowledge and consumer experience to CADP committees. Meetings, particularly of the program and project governance committees, demanded significant preparatory work from consumer representatives. These committees were tasked with decision-making in relation to complex health infrastructure and ACT Government processes (such as the Treasury budget cycle, capital works and procurement), and consumer representatives had to quickly develop a sound understanding of these processes in order to participate effectively in meetings. The complex subject matter made it difficult for a proxy to be brought up to speed on the issues, and the fast-paced decision-making processes that characterised many of the infrastructure projects made it difficult for consumer representatives to miss a meeting for fear of also missing an essential decision. This placed considerable pressure on consumer representatives, who take part in committee work as volunteers.

This situation was compounded by the varied quality of secretariat support offered to consumer representatives. As this account from a consumer representative to a Project Control Group makes clear, a combination of limited secretariat support and poor decision-making processes made the role of the consumer representative unnecessarily difficult:

*“They were poorly run meetings with no papers, with little or no scrutiny of items on the agenda as the norm. In fact we wrote to the chair of the committee saying, you know, we’re getting 65 papers two days before the meeting. What are we supposed to do?” – Consumer Representative to a Project Control Group[[33]](#footnote-33)*

HCCA’s Consumer Coordinator observed a culture of poor support for committee decision-making in the CADP and HIP:

*“There was a culture of late delivery of meeting papers as well as papers tabled at the meeting or sent out of session. This culture was very prevalent for many years and hindered the consideration of very important matters” – HCCA HIP Consumer Coordinator[[34]](#footnote-34)*

The quality of secretariat support and decision-making processes could also vary over the life of a committee. This consumer representative to the Redevelopment Committee recounts a shift from high levels of commitment to the committee at its inception, to reduced support and declining effectiveness over time:

*“It functioned well in the first instance, largely I think because the personnel involved from Health in putting stuff together was appropriately skilled and committed to the project.* *Developing papers, distributing, you know, in a timely way so we would get a chance to read them before meetings, and to come up with… you know, considered input into the decisions that was always heard with respect, [though] not always followed. But you expect that… Gradually, the level of servicing for the committee diminished. The level of attendance by senior representatives from other departments declined, the effectiveness of the committee in terms of making decisions reduced.” -Consumer Representative to the Redevelopment Committee.[[35]](#footnote-35)*

The challenges that consumer representatives experienced arose in part as a result of the time-urgency of CADP processes. As this consumer representative explains, time pressures on infrastructure projects and on committee decisions could be seen as one of the drivers of poor decision-making processes and variable support to consumer representatives:

*“From a healthcare consumer’s perspective, it was incredibly difficult to have any real influence. The background for that, to me, was that to me the health department was always hanging on by the skin of their teeth. I don’t know where the deadlines were coming from, but there were always deadlines. So you never really got a proper process. I think the staff did the best they could, but they’re just under the pump all the time.” - Consumer Representative to a Project Control Group.[[36]](#footnote-36)*

In summary consumer representatives’ ability to contribute to CADP governance committees was challenged by varied quality secretariat support, varied adherence to good decision-making processes, time-urgent decision-making, and the significant workloads that consumer representatives undertook as volunteers.

It is important to observe that consumer representatives had diverse experiences of support from secretariats, chairs and other committee members. Some consumer representatives reported that their role was well-understood and that they were welcomed by other committee members:

*“Immunology, oncology, all of them turned up, all their top people… And we [consumer representatives] were important, they accepted us.” – Consumer representative to a User Group[[37]](#footnote-37)*

These reflections from consumer representatives underscore the important role that committee members, and in particular Chairs, can play in supporting consumer representatives to participate as equal partners in decision-making.

Nonetheless consumer representatives were almost invariably the sole consumer members of their committees and consequently their perspectives were sometimes overlooked or dismissed. This was a particular issue for Working Groups and User Groups, which could count up to 30 members including just one or two consumer representatives working alongside health professionals. As HCCA’s Consumer Coordinator explained, when consumers are represented by just one or two voices in a process intended primarily to elicit the views of health professionals, the consumer perspective can readily be diluted:

*“Embedded and substantial consumer involvement in health infrastructure offers the opportunity to influence service design for the real end user of the health service being built. Traditionally this end user is seen as the clinical staff who work in that service. They make the decisions and are seen as knowing how things should be designed - speaking on behalf of patients and carers on what is best for them. This can be seen demonstrated in the traditional health infrastructure user group process where a consumer rep is often an afterthought or outsider rather than being seen as integral to the process for the unique and invaluable insights they offer to patient centred service design.” – HCCA HIP Consumer Coordinator[[38]](#footnote-38)*

The imbalanced representation of consumers as members of User Groups had particular implications for decisions about the design and layout of health services. Such decisions, for example about the location of nursing stations in hospital wards, tended to be driven by health professionals’ preferences and existing practices. Combined with the time pressures on User Group processes, the priority given to the expressed preferences of health service staff could unfortunately limit the possibilities for an evidence-based discussion of alternative models of care, and the design and layout of clinical areas. As a consumer representative to the Redevelopment Committee explained, decision-making could be:

*“sort of high-jacked by clinicians, clinicians who were wedded to existing models, rather than looking at what’s the most consumer-friendly.”[[39]](#footnote-39)*

One of the ways that HCCA supported consumer involvement in these decision-making processes was to gather and provide evidence to committees and ACT Health about good practice in consumer-oriented health service design. Our capacity to perform this role increased from 2009, when HCCA was successful in negotiating with ACT Health for funding to employ a Consumer Coordinator, increasing our capacity to undertake this work.

Despite the challenges they faced, consumer representatives succeeded in consistently raising priority consumer issues with key decision-makers. They brought a unique consumer perspective that would otherwise have been missing from deliberations about health infrastructure:

*“Consumer reps have lived experience and they have networks of other consumers who have experience of that service. So just the fact that they don’t have a health professional background they think differently. And their job is to wear the consumer hat. Often we get that whole, “Well, we’re all consumers” says the senior doctor. “Well, congratulations, I’m pleased you’ve made that jump in logic, but at this table, no. You’re here because you’re a senior staff specialist. I’m here because I’m representing a consumer perspective. Yes, of course we’re all health consumers.  But it’s about your role at that point in time.” - HCCA Executive Director[[40]](#footnote-40)*

As a part of their role, consumer representatives were able to highlight issues for consumers that would likely otherwise have been neglected by committees. For example, this consumer representative prompted other committee members to take a more patient-centred approach to planning for a new health service:

*“All the talk was about nurses… They're saying… ‘your patient arrives. They go here, then they go there’… I said, ‘hang on. Stop’. I said, ‘why are we having this patient go from here to here to here to here? Why aren't we stopping them at one of these places? If you left the patient in this one place [and had the staff and services come to them]… I got agreement [about that]”. Consumer representative involved in planning for the Capital Region Cancer Centre.[[41]](#footnote-41)*

In another example, this consumer representative suggested that a pharmacy dispensing counter should be accessible to people using wheelchairs or crutches, even though at that time it was not expected that this area would be attended by consumers:

*“I did question it… It was right where this little bit of reception area and the desk, the counter thing was going to be, and I thought, if someone in a wheelchair’s being brought around here, where are they going to leave them if there’s a doorway right there? …Someone on crutches or something, and they probably assume, we’ll be visiting the other side [of the counter]. Who knows, you know? They don’t know either [how the space will eventually be used by consumers and staff].” - Consumer representative to a User Group[[42]](#footnote-42)*

These examples draw attention to the important role that consumers played in bringing issues that would otherwise have been overlooked to committees’ attention, and influencing decisions that better reflected consumer needs.

Infrastructure design is an iterative process. The physical layout of buildings could change multiple times in a design process, as architects revised plans based on feedback from User Group members. This consumer representative recalled that plans could “totally change” as they evolved during a User Group process:

“*There was a range of people who obviously had to attend all those things and to overview various stuff, so in the very early days they did have a plan when they talked about what was happening, so by the third meeting, that plan had changed, obviously, but by the next one it had – pathology had totally changed location into a different place altogether. So it was interesting to see how it evolved. Yes, and the final pharmacy layout thing was quite different from the initial – absolutely.” – Consumer representative to a User Group[[43]](#footnote-43)*

Consequently, consistent consumer participation in User Group processes was valuable because it helped to ensure that consumer needs and priorities remained ‘on the table’ as design plans evolved.

### *Summary: Consumer representation – challenges and achievements*

* The CADP established a clear role for consumer representatives at every level of governance;
* Consumer representatives made substantial and valuable contributions of time, knowledge and skill to their committee work;
* Consumer representatives ensured that consumer perspectives, priorities and concerns were consistently articulated and considered by decision-making committees; raised consumer issues that would otherwise have been overlooked; and ensured consumer issues stayed ‘on the table’ as iterative infrastructure design processes evolved over time. They brought a unique consumer perspective to deliberations; helped committee members to make decisions that put patients and consumers closer to the centre of their considerations; and shaped decisions that better met consumer expectations and needs.
* Consumer representatives made these contributions despite obstacles including variable secretariat support, rushed decision-making processes, in some cases very high committee workloads, and the power differential that existed between the consumer representative role and the professional members of their committees, and in some cases being marginalised or having their perspectives overlooked.
* The welcome and support extended by some Chairs, committee members and secretariat staff made a significant difference to the experience of consumer representatives and to their ability to contribute effectively.

## 4.6. HCCA support to consumer representatives

HCCA supported consumer representatives to contribute effectively to their committees. We did this by providing regular opportunities for consumer representatives to meet with one another, share experiences, and receive training and information relevant to their committee roles. Through the CRP HCCA also provided personalised practical support to consumer representatives. This could range from research assistance to obtaining and printing meeting materials, and helping to arrange access to buildings to attend meetings. As this consumer representative to a User Group explained, it could be difficult to locate meeting rooms in the absence of clear directions:

*Yes, it was fine for me, just had to get to the right place. The Canberra Hospital site, it’s interesting, you know – find building 24 and then you find out it’s been moved to building 25, which is not next door. It’s somewhere else altogether or something, whatever it is. Anyway, it’s good exercise. There was one meeting where there was a few of us. A few of us were standing and someone said, look. I think it’s upstairs. I’ll take you upstairs. None of [our committee] were there. That was something else, so you’d got two meeting rooms that were busy. When they said meeting room three and this was meeting room one and two, we had no idea it was upstairs, down a corridor, behind a locked door. It was funny.” – Consumer representative to a User Group[[44]](#footnote-44)*

The administrative liaison work that HCCA undertook in support of consumer representatives was time-consuming but essential to supporting effective consumer participation. Tasks such as providing hard copies of meeting materials and arranging building access could have been performed by committee secretariats within ACT Health or by THINC Health employees, and HCCA’s active role in this area may reflect the ‘outsider’ status of consumer representatives. The only non-ACT Government (or THINC Health) members of these committees, consumer representatives sat outside the established lines of communication between ACT Health staff participating in or supporting committee work. This situation also reflects the variable familiarity and understanding that committee members and secretariat staff had of the role of consumer representatives. A specific issue that arose for consumer representation in the CADP was that ACT Health and THINC Health employees were not always clear on the distinction between the role of consumer representatives (namely, to represent the broad issues for health consumers), and HCCA organisational representatives (who unlike consumer representatives, speak for HCCA’s position on a given issue). On occasion this led to confused expectations of consumer representatives. This underscores the value of education for committee secretariats and health professionals involved in committee work about the role, and support requirements, of consumer representatives.

HCCA sought to ensure that consumer representatives had access to the information and support they needed to undertake their roles confidently and well. For example HCCA successfully advocated to ACT Health to include consumer representatives in important briefings arranged for the Directorate’s staff.[[45]](#footnote-45) Through the CRP, HCCA provided a bi-monthly forum for all consumer representatives, and an additional bi-monthly Health Issues Group on topics of interest to consumer representatives. The CRP also provided training and support to consumer representatives around meeting procedures and decision-making processes, including ensuring that meeting minutes accurately reflected decisions:

*“Don't make assumptions that the minutes reflect the decisions taken at the meeting. And we teach people that in reps training, pay attention to the minutes. The minutes write history, you've got to make sure that they're correct. Sometimes they're junior staff doing the minutes. In fact, in almost all occasions it’s junior staff who take the minutes. It’s unfair to think that they have the content or the skills to capture, in a way, quite complex issues. And it’s not a deficiency of theirs, we can't see it as a deficiency. It’s our role as committee members on those high level committees, to make sure that we help them craft the words to capture that.” – HCCA Executive Director.[[46]](#footnote-46)*

In response to requests from consumer representatives, HCCA also established the CADP Consumer Reps Network as a quarterly forum for networking and support specifically for representatives to health infrastructure committees. Advice provided to Network members included how to read architectural plans, advice about what the CADP process was, and what decisions could be taken at different decision-making levels.[[47]](#footnote-47) As Appendices C to E illustrate, the CADP governance arrangements and decision-making processes were complex.

CADP Consumer Reps Network meetings were attended by consumer representatives, HCCA’s Executive Director, and senior ACT Health representatives including the Executive Officer, Government Relations and Planning. This senior representation meant that the Network meetings were an opportunity for information to flow not only between consumer representatives on the different CADP committees, but also between consumer representatives, HCCA and the ACT Health executive. This was important, as one of the significant challenges of CADP (and later HIP) committee work related to disjointed information flow between the different committee levels. A consumer representative to the Redevelopment Committee outlined this challenge:

*“There were consumers on subordinate groups, we couldn’t just rely on our own expertise. Perhaps [we] didn’t have as good a flow of information from the consumers who were directing issues at the subordinate levels, as would be desirable”. - Consumer Representative to Redevelopment Committee.[[48]](#footnote-48)*

HCCA established peer networking, training and information sharing opportunities in order to minimise and overcome the challenges created by the CADP’s multi-tiered governance structure. In addition to opportunities for information sharing and networking through the CADP Consumer Representatives Committee, HCCA maintained an email distribution list specifically for CADP committee representatives, providing a link outside of meeting times.

## 4.7. HCCA resourcing to support consumer involvement in the CADP

As the numbers of consumer representatives contributing to CADP committees grew so too did the demands on HCCA resources. [[49]](#footnote-49) In addition the CADP brought with it increased demand for HCCA to provide detailed comment on ACT Health plans and policies related to health infrastructure. From the outset of the CADP in 2008 HCCA identified the challenge of supporting consumer representatives on CADP committees:

“We have identified a strong need for more consumer representatives to support the Capital Asset Development Program. This is a very intensive process that has increasingly taken the resources of HCCA staff and consumer representatives and at times compromised our capacity to meet other commitments. We consider that there is a need for consumer representatives to be involved in the development of the models of care than underpin much of the service planning for the CADP. Consumer representatives are involved in the Project Control Group and Redevelopment Committee and most of the Health Service Planning committees. This continues to be a challenge for HCCA and we look forward to further discussion with ACT Health around how best we can support the CADP”.[[50]](#footnote-50)

In addition to the challenge of sourcing and supporting consumer representatives, this excerpt from the contract report identifies the need for consumers to be involved in shaping the models of care that were to be delivered in new infrastructure developments. The tendency for infrastructure planning to prioritise questions associated with the physical design of health services, while attending less closely to matters related to models of care, would become a recurring theme in consumer involvement in health infrastructure planning in the ACT.

In March 2009 HCCA wrote to the Executive Director, ACT Health Government Relations and Planning, outlining the ongoing challenge of supporting consumer representative activity within existing organisational resources and detailing the need for an increase in funding to support consumer involvement in the CADP.[[51]](#footnote-51) Following negotiations with ACT Health HCCA was successful in negotiating an amendment to our Service Funding Agreement, under which ACT Health provided 12 months of non-ongoing funding for activities “to sustain consumer input to the CADP”. The activities funded under this one year agreement (June 2009 – June 2010) were to:

1. *Provide and coordinate consumer representation*
2. *Report on activities related to liaison with the Territory*
3. *Report on emerging issues in consumer representation[[52]](#footnote-52)*

This funding enabled HCCA to employ a 0.4TFE Consumer Coordinator from April 2009 to June 2010 to work specifically on the CADP. The Coordinator’s role was to:

* network with consumer and community groups to further consumer involvement in decisions regarding the CADP;
* liaise with ACT Government about opportunities for consumer involvement in CADP activities;
* work closely with Consumer Representatives Coordinator to ensure opportunities for input from consumer representatives;
* identify training needs of consumer representatives involved with the CADP and work with ACT Health to provide training; and
* network and develop interest in consumer participation with consumers and community organisations to support the User Groups.[[53]](#footnote-53)

The Consumer Coordinator role provided a clear liaison point for consumer representatives, ACT Health staff and THINC Health employees, and was in frequent contact with each of these groups. The role also provided increased support to consumer representatives, and allowed HCCA to more actively engage in strategic policy development and consumer engagement work. This included promoting opportunities for consumer participation in addition to committee representation, reflecting HCCA’s awareness of the need for multiple methods of consumer involvement in health infrastructure projects.[[54]](#footnote-54)

Creation of the Consumer Coordinator role allowed HCCA to more actively engage with other consumer and community organisations, and with ACT Health. The Consumer Coordinator met regularly with consumer and community organisations to provide information and seek input on health infrastructure matters. This role also supported opportunities for ACT Health staff to share information with HCCA’s network of consumer representatives, for example by presenting to the CADP Consumer Representatives Network on infrastructure initiatives. There was close coordination between the Consumer Coordinator and the HCCA Consumer Representatives Program, which continued to provide support to CADP consumer representatives by undertaking selection and endorsement of consumer representatives, and providing personalised support as well as networking and training opportunities.[[55]](#footnote-55)

The scope of the Consumer Coordinator role expanded rapidly during this year of work. As a result in early 2010 HCCA increased the position from 0.4 EFT to 0.5 EFT, and employed an administrative assistant for five hours per week to support consumer involvement in the CADP.[[56]](#footnote-56) This increase was funded from organisational reserves. Following negotiations with ACT Health, a second year of time-limited funding for the Consumer Coordinator role was secured for 2010-2011. This can be understood as reflecting the value ACT Health placed on this work.

## 4.8. Case study: The Village Creek Centre

The ACT Health Village Creek Centre was an early CADP project that provided important learning about consumer involvement in health infrastructure. In particular this project highlighted the benefits of consumer involvement in site selection, developing models of care, and in post-occupancy evaluation (POE). The Village Creek project relocated a number of ACT Health rehabilitation, assistive technology and aged care services[[57]](#footnote-57) from The Canberra Hospital and the Weston Creek Community Health Centre to the former Village Creek School site in the south Canberra suburb of Kambah. This included relocating several rehabilitation services from Building 3 at The Canberra Hospital, in readiness to prepare this site for a new clinical services building, which was planned for but has not progressed following an ACT Government decision to postpone this project. Initially the ACT Government also proposed to relocate the Independent Living Centre (ILC) – a key provider of assistive technology in the ACT - to Village Creek. The decision to relocate and co-locate these services in Kambah was taken by the ACT Health Minister without input from HCCA or other consumers.

Early in the planning process HCCA, along with other consumer and community organisations, raised concerns about the difficulty consumers would face in accessing services at Village Creek. The centre was to house services for people with limited mobility, yet it was located in a suburban area that was not on a main transport corridor and was isolated other services. Associated with this overarching concern were:

* The distance between Village Creek and The Canberra Hospital and Calvary Public Hospital (from which consumers would often be referred);
* Increased travel time and distance for people travelling from Canberra’s north;
* Increased cost for people travelling to the service by taxi, especially from north Canberra locations;
* Limited public transport services and lack of direct services from many locations in the ACT;
* Lack of accessible public transport services to Village Creek, especially concerning given the provision of rehabilitation and aged care services at the centre; and
* The inaccessible physical design of the Village Creek building and surrounds for people with disabilities or requiring rehabilitation services.

HCCA also recognised that the ILC had an appropriate location at the Weston Creek Community Health Centre, and that the move to Kambah would be to the detriment of current and future users of this service. As a result of these concerns, HCCA did not support the selection of Village Creek as the new site.

Following strong opposition to the relocation of the ILC from organisations representing people with disabilities, and with the ACT Human Rights Commission investigating the impact of the move on people with disabilities[[58]](#footnote-58), in September 2009 the ACT Health Minister was quoted in the Canberra Times as saying that the community was being consulted about which services should relocate to Village Creek.[[59]](#footnote-59) Ultimately, the ILC remained in Weston Creek, while the relocation of other services to Village Creek continued. The reversal of the decision to relocate the ILC, and the very challenging process of minimising the access barriers created by the selection of the site, underscore the value of early consultation with consumers and the community about the selection of appropriate sites for new and relocated health services in the future.

HCCA supported consumer involvement in addressing the significant access issues created by the selection of the Village Creek site. In July 2009 HCCA liaised with ACT Health to organise a consumer site visit that allowed consumers to hear from ACT Health representatives about plans for the site, and to test the access issues first hand. This was an opportunity for consumers to identify ways to minimise access barriers, including by stressing the need for regular accessible bus services to Village Creek. Ultimately, consumers successfully advocated for improvements including bus stop upgrades and the construction of an appropriate path from the closest bus stop to the centre’s entrance.[[60]](#footnote-60) These initiatives minimised the access challenges but do not detract from the fact that early consumer involvement in site selection would likely have identified a more suitable location for this service.

HCCA also supported consumer involvement in the development of the model of care to operate from the relocated services. This included convening a consumer workshop in September 2009 at which participants provided a ‘consumer scorecard’ on the proposed model of care. Among other issues this process highlighted the unresolved access challenges at the site, and identified the lack of a plan to guide delivery of consumer-appropriate information about the services at Village Creek or the relocation process.[[61]](#footnote-61)

HCCA successfully advocated for consumer involvement in developing an approach to POE at Village Creek. In July 2009 the Executive Director, ACT Health Aged Care and Rehabilitation Service (ACRS), wrote to HCCA acknowledging that:

*“There remain some concerns, particularly from consumers, regarding this relocation. Equally, I would like to acknowledge that I consider you and I have established a committed and constructive relationship to provide and ensure effective communication lines and strategies are maintained during the development, design and transition phases of service establishment at Village Creek… Your suggestion of the development of an evaluation framework… is one of the major pieces of work for us over the coming weeks. We agree with you that a consumer perspective is critical during the development and the entire project team are keen to progress this further.”[[62]](#footnote-62)*

ACT Health provided one-off funding to support HCCA to convene two consumer workshops to develop and propose POE indicators. The indicators agreed at these workshops included:

* Consumer involvement in the development of service models for the relocated services, and in the development of a communication strategy for the relocation;
* Access to affordable and appropriate transport to Village Creek;
* Safety while waiting for transport at the site; and
* Protection of personal information, and integration of services at the site.[[63]](#footnote-63)

This process ensured that key issues of concern to consumers were captured in the POE framework, and informed the relocation process. These outcomes were possible in part because of the “committed and constructive” relationship that HCCA established over time with key decision-makers within ACT Health, as indicated above in the excerpt from correspondence from the ACRS Executive Director. [[64]](#footnote-64)

The Village Creek project was one of the first CADP projects to employ multi-disciplinary working groups (later called User Groups) as a structure and approach to decision-making about models of care, and the design and layout of new health services. As with later CADP and HIP projects, these working groups met intensively over a time-limited period to make crucial decisions about how new services would operate and their physical design, bringing together the staff who would work in the new services, ACT Health policy specialists, and one or two consumer representatives. HCCA nominated and supported consumer representatives to the Administrative Services, Models of Care and Independent Living Unit Working Groups.[[65]](#footnote-65) Representatives of these working groups reported to the Village Creek Steering Committee, which provided project oversight and included HCCA’s Executive Director among its members. HCCA successfully advocated for a consumer representative to be nominated by People with Disabilities ACT (PWD ACT) to join the Steering Committee in July 2009. HCCA saw this as ensuring that a key consumer group that would use the services at Village Creek would be represented in strategic decision-making about the relocation, including in relation to decisions about access issues at the site. The PWD ACT representative urged consideration of design issues such as the provision of hearing loops and appropriate signage for vision and hearing impaired people, the dimensions of wheelchair turning spaces, the height of power points, and the path of travel from kerbside to the building entrance.[[66]](#footnote-66) HCCA also advocated for the inclusion of a representative of Disability ACT as a member of the Village Creek Steering Committee, given the importance of the Village Creek service to health consumers with disabilities.

The example of Village Creek highlights the active role HCCA played in support of the involvement of consumers most affected by health infrastructure changes, the effective working relationships HCCA established with key decision-makers within ACT Health, and our successful advocacy in support of meaningful consumer involvement in POE. The ongoing access challenges at Village Creek were in large part a direct consequence of the lack of early consumer consultation around site selection. However, HCCA played a role in ensuring ongoing consumer involvement in responding to these challenges, including by supporting the involvement of organisations representing the consumers most affected by proposed changes. The Village Creek project established a process for meaningful consumer involvement in POE, including in designing evaluation criteria. Unfortunately, this successful model for consumer involvement in POE was not replicated in later CADP and HIP projects.

## 4.9. Case study: Consumer involvement in planning for Community Health Centres

HCCA supported consumer involvement in the oversight of plans to construct new or substantially refurbished Community Health Centres in Belconnen, Gungahlin and Tuggeranong. Consumer representatives involved in planning for the CHCs played an essential role in articulating consumer priorities for and expectations of these new services. Reflecting the broader experience across CADP and HIP projects, consumer representatives consistently highlighted access issues. For example, consumer representatives highlighted the importance of accessible parking and good connections to public transport. This consumer representative explained how important these issues were in planning for the Belconnen CHC:

*“[At one meeting, the Chairperson] said to everybody, what's your wildest dream? What would you put forward? I'm an introvert, so I need to think before I can talk, but I think the next day I thought I should have said, unlimited parking... unlimited free parking for everybody. As parking is a big issue in Canberra and there is lots of consumer input on this issue, particularly if you are frail and/or disabled. In the end we got free parking for the people on dialysis, underneath [the building].*

*But the [idea to construct a] walk-in centre idea came halfway through the development of the health centre. I've mixed with a number of my contemporaries, you know, people in their 70s and 80s who have had problems going to that walk-in centre because the parking is so [difficult]... And they had no idea that you can park underneath. The first time they go, they have this trouble, and then they hear that there is parking underneath and you can use it, but... We didn't do well with the parking. It really is a problem. I don't think that's something that professionals recognise.” - Consumer representative involved in planning for the Belconnen CHC[[67]](#footnote-67)*

This example highlights a challenge often encountered by consumer representatives to infrastructure committees, namely that plans for new or redesigned health services could change – sometimes dramatically – during the planning phase. In this instance plans to co-locate a nurse-led walk-in centre with the CHC emerged mid-way through planning, placing additional pressure on the limited free on-site parking that had been set aside for CHC consumers.

The example of the Gungahlin CHC illustrates the way in which HCCA and consumer representatives were able to support, and raise the priority, of particular initiatives being considered by ACT Health. In this case HCCA and the consumer representative strongly supported ACT Health’s consideration of basing a Community Development Officer at the CHC. The consumer representative explained:

*“Gungahlin was supposed to have some rooms for community groups, and it was supposed to have a community development officer, which are things that I really supported. But the community development officer kind of got lost by the time it was opened. I think there was a shortage of money, but I’m really pleased now that, in the last year, they’ve resurrected that. We supported them [ACT Health, in the proposal to employ a Community Development Officer] and it was really important that we did support them, because they certainly were low priority, as you can see, because they started off with it not being there.” - Consumer representative involved in planning for the Gungahlin CHC.[[68]](#footnote-68)*

HCCA’s Multicultural Liaison Officer was involved in initial discussion of the proposal to employ a Community Development Officer. She described her frustration when these plans appeared abandoned, and her surprise when a Community Development Officer was employed after years had elapsed:

*“They were looking for a community development worker, to hire one at that time… That was four, five years ago. [I gave] a small presentation about… how different is a community development worker from a social worker… It was good that they knew what they wanted and how they wanted it and what skills they have and what they do… But they didn’t do it. It is frustrating when you present it and nothing happens and nothing moves on. They didn’t do it until this year. I was really surprised when they said they had done it! And then, the community development worker contacted me to see about meeting and talking. And now we’re working together and doing things together.” – HCCA Multicultural Liaison Officer[[69]](#footnote-69)*

This example highlights the valuable role that consumer representatives and HCCA played in articulating consumer support for particular ACT Health proposals. It also draws attention to the importance of HCCA’s long-term consumer advocacy and relationship-building. As this example demonstrates, a long-term approach can deliver unexpected positive outcomes over time.

### *Summary: Consumer involvement in the CADP*

In line with our existing partnership with the ACT Government, HCCA was involved in the CADP from its inception in 2008, providing policy advice and liaison with ACT Health, undertaking consultation and information sharing with consumers and the community, and supporting consumer representatives.

Following negotiation with ACT Health, HCCA’s resources to support consumer involvement in the CADP were increased in June 2009. Our Service Funding Agreement was amended to include a new Schedule (2B), under which modest, time-limited, resources were provided to enable HCCA to employ a 0.4FTE Consumer Coordinator for 12 months to support consumer involvement in the CADP. This made it possible for HCCA to meet the growing need for appropriately supported consumer representatives to ACT Health infrastructure committees, and to consult and share information more widely and effectively with consumers and communities.

In early 2010 HCCA increased the Consumer Coordinator role to 0.5FTE in recognition of the growing scope of the work it entailed. This was funded from organisational reserves, reflecting the importance of infrastructure planning matters to HCCA and to healthcare consumers. An administrative assistant was also employed at this time for five hours a week to support consumer involvement in the CADP.

Following negotiation with the ACT Government a further year of time-limited funding to continue the part-time Consumer Coordinator role was secured for 2010-11.

Major CADP projects to which consumers provided input with HCCA support included the Village Creek Rehabilitation Centre; the Adult Mental Health Unit at the Canberra Hospital; the Belconnen and Gungahlin Community Health Centres; the PET/CT Scanning Suite at the Canberra Hospital; and a new multi-storey Southern Car Park at The Canberra Hospital. A number of these projects were in the planning and development stages under the CADP but were completed after the program changed name to HIP in 2012.

Under the CADP, HCCA established sound processes and systems for supporting consumer representatives, who occupied an accepted place in the governance of the CADP and its projects.

# Consumer involvement in the Health Infrastructure Program (HIP)

## 5.1. About the HIP

In 2012 the CADP name was changed to the Health Infrastructure Program (HIP). At this time ACT Health took over the project management role from THINC Health[[70]](#footnote-70) and the ACT Government extended the Program to 2022.[[71]](#footnote-71) The HIP retained the multi-tiered governance structure established under the CAPD, and consumers continued to be represented on key governance committees:

* Health Infrastructure Program Steering Committee (formerly the Redevelopment Committee);
* Executive Steering Committee (formerly Project Control Group)
* Project Control Group (formerly Executive Reference Group)
* User Groups (formerly Reference Groups).[[72]](#footnote-72)

The roles of these committees are detailed at Appendix C.

In addition HCCA supported consumer representation to preliminary and final sketch plan processes (PSP and FSP) and risk workshops for various projects undertaken under the HIP.

There continued to be high-level support for consumer involvement in infrastructure governance, and an understanding of HCCA’s role in support of effective consumer participation. In 2012 the then ACT Chief Minister and ACT Health Minister Katy Gallagher MLA expressed this view:

*“Health Care Consumers Association has always been a very strong organisation, so they’ve always taken part in things like budget processes and community consultation and government − the machinery of government. ... They really are involved in almost everything the Health Directorate does, whether it’s looking at models of care, designing buildings, sitting on the Health Council, sitting on the local hospital network, policy, service delivery ... I think the consumer movement in health is essential because consumers look at things differently ... and it’s enormously powerful to be sitting there talking about patient experience as opposed to clinical outcome and weighting those equally.”* [[73]](#footnote-73)

HCCA welcomed the opportunity to continue to support consumer involvement in infrastructure governance and planning. In mid-2012 HCCA observed in a contract report to ACT Health that:

“The Health Infrastructure Program (HIP) is a significant body of work for the ACT Government and has great potential to bring about structural changes to clinical practice, and to improve efficiencies as well as health outcomes for consumers. There is a great need for strong, effective consumer input to this Program to assist in developing solutions to intractable problems in our health system. We are committed to continuing our work with the ACT Government to improve the quality of health services. Our commitment is reflected in the significant increases in activity, providing consumer perspectives on committees and consultation fora, and responding to service plans and polices in recent years.”[[74]](#footnote-74)

While welcoming the opportunity for continued consumer involvement, HCCA also identified the associated challenge of building community capacity to participate in HIP committees. HCCA’s commitment to appropriately supporting consumer representatives, along with the need for new consumer representatives to join growing numbers of User Groups, contributed to a very high workload for the part-time Consumer Coordinator. This prompted an internal review of HCCA’s staffing in 2012. The review formalised HCCA’s recognition that the organisation required additional employees in order to support effective consumer involvement in health infrastructure. HCCA also identified the specific need for greater involvement of culturally and linguistically diverse communities in the planning and design of healthcare services in the ACT.[[75]](#footnote-75)

In 2012 HCCA successfully negotiated with ACT Health to obtain an additional year of non-ongoing funding to support consumer involvement in health infrastructure projects. This allowed HCCA to continue the employment of the Consumer Coordinator, and to employ a 0.5 EFT Multicultural Liaison Officer (MLO) to support culturally and linguistically diverse (CALD) community involvement in health infrastructure planning. Working to “sustain consumer input to the HIP”, HCCA’s contracted performance indicators in this period were:

*(i) Identification of consumer need through consumer consultation including outreach to marginalised and vulnerable communities;*

*(ii) Raising awareness of the HIP within consumer and community organisations;*

*(iii) Creating new opportunities for training and support for consumer representation, including further developing health literacy; and*

*(iv) Monitoring how consumer input is used to have a real impact on the outcome of HIP.[[76]](#footnote-76)*

Work under this contract began in August 2012, with the appointment of the MLO and a focus on engaging marginalised and vulnerable communities in providing input into infrastructure projects.

## 5.2. CALD community engagement

HCCA established an effective model of CALD engagement, which prioritised relationship-building, clear communication about HCCA and our role in infrastructure planning, and understanding CALD community members’ healthcare experiences, needs and priorities. The importance of taking time to build relationships with CALD community leaders and members was an early and important learning from this work. HCCA’s contract report to ACT Health in December 2012 observed that:

Relationship building takes time, often out of regular 9am-5pm office hours. In addition, the identification of community leaders is often not straightforward and requires investigation and forging personal connections with members of CALD communities themselves, before they are willing to open up their networks.[[77]](#footnote-77)

Forging trust with community members and leaders was essential to success of this approach. Trust building required clear communication about HCCA and our role, and hinged on HCCA reporting back to community members about the outcomes of their involvement. HCCA’s MLO described the challenge of building trust:

*“There I was, going around and trying to get in touch with a lot of people, different organisations. I made a lot of calls and a lot of doors closed. They didn’t open because they didn’t know you. They didn’t know me, they didn’t know what we were doing, or who our organisation, HCCA, is.*

*The first question they asked is, ‘Are you from the government?’ So that’s when I realised that there were issues with the government. And also, the issues that members of the communities have had accessing health services. There have been problems and no one has been able to address them, or nothing has happened. So I think that’s why they didn’t want anyone else [to engage them in health matters]. We had to put, upfront, a strategy for what to say, that we were funded by the government, but we’re not the government...*

*You have to prove yourself to be let in. There are many reasons for that: they still don’t trust who you are, even though they know you; they think the information I provide is not important for them, they think they don’t need it, they think that… [HCCA is] just going to come and ‘blah, blah, blah’ and nothing’s going to happen. I understand their point of view, only because I come from that migrant background. I experienced a lot of issues when I arrived. I was never offered an interpreter.*

*But then, the good thing is if a change happens… just to give you an example, the emergency paediatric [project at the Canberra Hospital]. We had a consultation, and… [one of the participants] was very vocal, and she suggested a few things. And one or two of those things happened. You have to get back to them and let them know this kind of thing. It’s good. They feel that it’s worth doing, and that you are listened to.” – HCCA Multicultural Liaison Officer[[78]](#footnote-78)*

As the MLO’s description of her work illustrates, many CALD community members have had negative experiences of health services which may predispose them to disengage from feedback and consultation processes.[[79]](#footnote-79) It is essential to recognise that in this context it can take considerable time to establish the person-to-person and organisational relationships that are a necessary aspect of community engagement.

Initially HCCA obtained just one year of funding to employ the MLO. In this context it was necessary for both HCCA and ACT Health to remain mindful of the barriers to CALD engagement in infrastructure planning, and the time involved in establishing consultative relationships. In consultation with CALD communities it became apparent that many people had very limited knowledge of the HIP and its projects. As a result, HCCA focused on supporting basic health literacy and providing information about the health services available in the ACT. From this basis the MLO would then introduce information about the HIP and invite more specific community feedback related to infrastructure projects. Using this approach, HCCA convened consultations with a variety of consumer and community organisations. This work identified core issues of importance to CALD consumers including:

* The value of cultural awareness and sensitivity on the part of clinicians;
* Widespread uncertainly among CALD consumers of what health services are available and how to access them (including eligibility criteria);
* The lack of sufficient written information available in different languages;
* Lack of awareness of, or access to, interpreter services, especially in public hospital Emergency Departments;
* Limited access to dental care; and
* Transport as a barrier to accessing services[[80]](#footnote-80)

In short, HCCA’s approach to community consultation was designed to reflect the needs of the CALD communities with which the MLO worked. This successful model sought to understand the experiences and priorities of CALD community members, and to support health literacy alongside and as a necessary precursor to engagement about infrastructure projects.[[81]](#footnote-81)

## 5.3. 2013-2016 Service Funding Agreement

In 2013, HCCA renegotiated a new three-year Service Funding Agreement (2013-16) with ACT Health. HCCA had long advocated for a comprehensive approach to communications and consumer and community engagement related to infrastructure. This Agreement provided the opportunity to develop these processes. HCCA’s Executive Director described the importance of an overarching approach to consumer involvement as follows:

*“You… need to have really clear expectations. Now, as an advocacy organisation, we need to have clear expectations of our consumer reps and what they can do; of the staff and their roles, but also of the [Health] Department. We need to... be clear about their expectations of what they need us to do. Any time there’s a lack of clarity around that, there are moments of tension. That was why the Service Funding Agreement between 2013 and 2016 was so important, because we were finally going to get to the point where we mapped a process. So, every time we started a project, we then didn't have to prosecute the same case and argue for consumers to be part of it, there was already a programme... or a model, that we had agreed to.” - HCCA Executive Director.[[82]](#footnote-82)*

The 2013-16 SFA focused on consumer involvement and building community awareness and understanding of the HIP. Activities that fell under this agreement included community development, liaison with other health and community organisations, development of consumer information, promoting the involvement of marginalised and disadvantaged consumers in HIP projects, and supporting consumer representatives to be effective in their roles.[[83]](#footnote-83)

The performance indicators negotiated under the 2013-16 SFA were:

*(a) Coordinate and support consumer representation in HIP committees and activities and develop and deliver training to support consumer representatives;*

*(b) Develop and implement a consumer and carer participation plan for each new HIP project, in collaboration with the project Executive Reference Group;*

*(c) Develop and implement an annual plan that is endorsed by the Executive Director Service and Capital Planning to consult with consumers and target groups on informing HIP decisions on specific matters such as signage and way finding, patient flows and models of care;*

*(d) Identify and document consumer needs through consumer consultation, including outreach to marginalised and vulnerable communities; and*

*(e) Report on emerging issues in consumer representation, policy development, participation in projects and organisational development with regard to the HIP.[[84]](#footnote-84)*

Performance indicators (a), (b), and (e) describe HCCA’s ongoing and well-established work in consumer representation, policy development and consultation. Indicators (b) and (c) reflected HCCA and ACT Health’s agreement to undertake joint planning processes to identify and address priority consumer involvement issues in each major infrastructure project (b), and through an annual plan to focus on specific consumer issues (c).[[85]](#footnote-85) Unfortunately, these joint planning processes did not take place. It is HCCA’s view that these processes would have supported a holistic approach to consumer involvement, and that consumer involvement in health infrastructure could have been better supported had they occurred.

Funding for HCCA’s work in support of consumer involvement in infrastructure increased under the SFA. From 2013 HCCA’s HIP Project Team comprised a Consumer Coordinator, a Project Officer and a Multicultural Liaison Officer (2.5 EFT staff positions). As a result of this increase in staff HCCA was able to significantly increase our activity in support of consumer involvement in health infrastructure projects. From July 2013 to June 2016, HCCA:

* Supported consumer representatives on 131 ACT Health HIP committees, who contributed 904 meeting hours and 1,223 preparation hours;
* Undertook 23 community consultations;
* Shared 78 articles on HIP in the HCCA e-newsletter Consumer Bites (for example about HIP projects, openings, and changes to access due to construction); and
* Provided 107 community information sessions or presentations on new services and facilities.[[86]](#footnote-86)

This expansion of our work would not have been possible without the increased resources provided under the 2013-2016 SFA.

## 5.4. Consumer and community consultation

Continued funding for a Multicultural Liaison Officer between 2013 and 2016 allowed HCCA to strengthen our engagement with CALD community organisations and networks, an important aspect of our co-operation with ACT community groups and organisations. Issues raised in meetings, workshops and other discussion fora were fed back to the Health Directorate, with every effort made to obtain responses that could be provided to the groups which raised the issues. HIP team members also attended numerous community events and used appropriate media such as multicultural community radio broadcasting to provide information about the HIP to diverse community and consumer groups. The MLO maintained existing relationships and worked to establish connections with a variety of consumer organisations and networks, including by working with multicultural groups supported by Carers ACT and community service organisations.[[87]](#footnote-87)

HCCA’s increased staffing profile between 2013 and 2016 allowed us to extend our consumer consultation and engagement work. From 2013 we undertook significant community engagement, meeting with every ACT Community Council and the Queanbeyan (NSW) Community Council to discuss and seek community input on the HIP and its projects. HCCA worked collaboratively with consumer organisations including the Mental Health Consumers Network, Carers ACT, the Multicultural Mental Health Network and HCCA’s Aged Care Consumer Reference Group and Maternity Services Consumer Reference Group. HCCA also convened consumer consultations in such projects as Paediatric Streaming in the upgrade of The Canberra Hospital Emergency Department, the planned refurbishment of The Canberra Hospital Outpatients’ Department, and the refurbishment of a Pathology unit at The Canberra Hospital.[[88]](#footnote-88) In particular, HCCA supported consumer involvement in the design of shared spaces such as waiting rooms and reception areas; and worked to bring evidence about best practice to decisions about the design of in-patient areas and family rooms, and the selection of furniture, fixtures and equipment. In this last area HCCA had variable success: consumer representatives were not involved in the selection of fixtures, furniture or equipment for the University of Canberra Public Hospital but did have some input in this area during the design of Paediatric Streaming at The Canberra Hospital Emergency Department, particularly in relation to seating.[[89]](#footnote-89)

Supporting ACT Health to communicate with consumers and the community about infrastructure projects continued to be a significant focus for HCCA during this time, and we undertook considerable work in support of improved signage and wayfinding during infrastructure projects. We liaised with key ACT Government partners including the ACT Health Multicultural Health Policy Unit and ACT Health Communications team.

HCCA staff also undertook several tours of health infrastructure projects in other jurisdictions. This was an investment in HCCA’s understanding of good practice in consumer-engaged healthcare redesign and enhanced our ability to promote good practice in discussions with ACT Health. For example, HCCA’s Consumer Coordinator was invited to address ACT Health staff on interstate developments in healthcare ICT.

## 5.5. Consumer representation

### 5.5.1. HCCA support for consumer representatives

Identifying, training and supporting consumer representatives remained a focus of HCCA’s work under the HIP. During this period HCCA consolidated the support we provided to consumer representatives on HIP committees. The CADP Reps Network became the HIP Reps Network and moved to more frequent meetings (monthly), with a structured agenda. This provided a regular opportunity for consumer representatives to report on their committee work, share issues and common concerns, and to obtain information. It played an important function in helping consumer representatives to see their committee work in a broader perspective:

*“If you’re only just in that little small bit [of the User Group you are member of]... Well, it gave me the, widened my horizons, I suppose, and understanding what it was about and awareness of concerns people had been raising in terms of what was going on at The Canberra Hospital”. – Consumer Representative to a UCPH User Group.[[90]](#footnote-90)*

HCCA staff provided an update on all HIP projects to each HIP Reps Network meeting, and speakers including ACT Health representatives regularly attended to present on issues of interest.[[91]](#footnote-91) Under the HIP ACT Health employed approaches to procurement that were unfamiliar to many consumer representatives, such as Public Private Partnerships and Design Construct Maintain contracts. One area of focus for the HIP Reps Network was ensuring consumer representatives understood these approaches and could participate confidently in processes shaped by them.

This stage of the HIP involved consideration of a new Clinical Services Building at the Canberra Hospital, and a subacute hospital on the site of the University of Canberra. Both facilities would require significant appropriation from the ACT Government Budget, and it was important for consumer representatives to understand the financial and commercial constraints that this context placed on the HIP. This was essential information for HCCA and consumer representatives to understand as this context, along with complex procurement and contracting approaches, shaped the infrastructure planning process and determined key decision-points and opportunities for consumer input. The HIP Reps Network provided an important structure for discussion of these issues.

HCCA continued to provide personalised support to consumer representatives, for example policy and research support, printing meeting documents and liaising with committee secretariats when appropriate. HIP consumer representatives were also provided with folders containing an *Introduction to HIP* booklet, Models of Care documents, HIP timelines and other relevant information. Items of interest (such as meeting reports, articles, podcasts, conference presentations) were also shared with the HIP Reps Network out of session by email.[[92]](#footnote-92) HCCA provided these forms of support in order to ensure that consumer representatives received at least a basic orientation to the HIP and its processes prior to beginning their roles, as well as ongoing assistance from HCCA and the HIP Reps Network. This responded to one of the ongoing challenges for consumer representation to the HIP, namely ad-hoc and time-urgent committee processes. Particularly at the User Group level committee members were often unclear about their roles and responsibilities, and the scope of their decision-making. In the absence of documentation about these matters, HCCA developed this material for consumer representatives.[[93]](#footnote-93)

### 5.5.2. Probity standards and commercial-in-confidence requirements

CADP and HIP committees worked in a context in which probity standards and commercial-in-confidence requirements were of paramount importance. Like all members of CADP and HIP committees, consumer representatives were required signed a confidentiality agreement. While all HCCA-supported consumer representatives sign a confidentiality agreement prior to commencing committee work, in the CADP and HIP context ACT Health officials placed a particular importance on these agreements: in governance committee meetings it would not be unusual for a Chair to ensure that every committee member attending had signed this agreement before proceeding with the meeting. HCCA explained the confidentiality, probity and commercial-in-confidence requirements to all consumer representatives, and ensured that consumer representatives had opportunities to ask questions and discuss the confidentiality agreement before they signed it.

While HCCA understood the importance of confidentiality and probity, we also recognised that it was essential for consumer representatives to be able to discuss their committee work with one another and with HCCA. HCCA negotiated with ACT Health to ensure that the confidentiality agreement stated that consumer representatives were permitted to discuss their committee work with one another and with HCCA employees, so long as all the consumer representatives involved in discussion had signed the agreement. HCCA’s Executive Director explained that:

*“The HIP Reps Network was valuable as all the members of that group had signed the confidentiality agreements, so we could share openly.” – HCCA Executive Director[[94]](#footnote-94)*

The confidential nature of discussions in CADP and HIP committees also created challenges for the way in which HCCA could share information and seek input from our membership. HCCA’s Executive Director describes how HCCA responded to this situation:

*“The confidential nature of the content was a challenge. It limited the way we could talk to our broader membership and networks. We had to develop new approaches to consultation and focus on principles and draw on examples from other services or describe concepts because we couldn’t talk about specific proposals in the HIP projects. So it was challenging in ensuring our input was representative of a variety of consumer experiences. I’m confident we got there in the end.” – HCCA Executive Director[[95]](#footnote-95)*

HCCA worked sensitively to ensure that consumer representatives and HCCA could share information without compromising probity and commercial-in-confidence requirements.

### 5.5.3. A changed model of consumer engagement in committee work

Under the HIP HCCA established a new way of approaching consumer representation to infrastructure committees. Under this engagement model, consumer representatives took part in User Groups, while HCCA staff took on roles on the governance committees. This division of roles was a significant change from HCCA’s longstanding position that the role of employees is to support consumer representatives at all levels of decision-making. Departure from this position took place in the context of a shift in attitude by ACT Health HIP executive staff, who communicated to HCCA their preference that an organisational representative rather than a consumer representative contribute to the HIP governance committees.[[96]](#footnote-96)

HCCA was also mindful of the significant challenges that consumer representatives continued to encounter on the governance committees. Among these were:

* The very tight timeframes available to committee members to consider decisions with significant ramifications for ACT health consumers;
* The breadth and depth of health service and system knowledge, and skills and knowledge specific to health infrastructure (including of complex procurement and budget cycle processes), required to participate effectively;
* Over-reliance on single committee members to participate in complex committee work, meaning that committee members could in effect not miss a meeting for fear of being unable to contribute to essential decisions;
* The near impossibility of supporting an adequately-informed proxy to attend meetings, particularly at short notice, due to the complex background knowledge required;
* The very substantial amount of pre-reading and preparation required in order to understand the meeting papers, combined with the necessity of understanding the full meeting papers;
* Ongoing confusion on the part of some committee Secretariats and Chairs in relation to the distinction between the role of consumer representatives, and HCCA organisational representatives;
* Insufficient time for consumer representatives to consult with HCCA and/or consumer networks to inform their decision-making;
* Variable secretariat support and meeting procedures, with late receipt of large volumes of meeting papers and inadequate orientation to HIP decision-making processes common experiences for consumer representatives; and
* Isolation and dilution of the consumer perspective as the lone consumer representative to a committee.

As HCCA’s President and consumer representative observed, consumer representatives faced these challenges as the sole voluntary members of committees:

*"Many ACTH bureaucrats and service providers (and in the case of the HIP, the commercial partners) often don’t understand that the consumer reps sitting at the table are volunteers.  It’s challenging enough for consumer reps to establish themselves in this milieu as authoritative participants in these very complex processes. Some appreciation of the time and commitment that we put into preparing and contributing at all levels would further support positive working relationships (a broader issue than just a reimbursement for attending a meeting, however important that is)" – HCCA President[[97]](#footnote-97)*

These challenges for consumer representatives were essential factors driving HCCA’s adoption of a changed approach to representation.

Monthly meetings of the HIP Reps Network ensured information flowed between consumer representatives to the User Groups and the HCCA staff taking part in governance committees. This meant that HCCA was well-placed to escalate issues encountered in the User Groups to the project and program governance committees, or to raise these directly with ACT Health executive staff. Though this new process did help to improve the flow of information from User Groups to the governance committees, this remained a challenge for the multi-tiered HIP governance structure. A consumer representative to a governance committee described the issue:

*“There were working groups below us, but we weren’t getting [information] directly… from the working group. There probably should have been better coordination between myself… and the people on the working group. But there were so many working groups, even that was hard to do.” Consumer Representative to a Project Control Group.[[98]](#footnote-98)*

The changed model of consumer representation required HCCA to put in place processes to ensure HCCA employees remained accountable to consumer representatives and to HCCA’s members. Regular reporting to the HIP Reps Network was the most important of these. HCCA’s Executive Director described the challenge of co-option that attended our partnership with ACT Health:

*You… run the risk of co-option, because… when you’re around the table [with health professionals and bureaucrats] you want to make friends with the people, you’ve got to have good working relationships. But unless you are accountable to your members you can sort of lose your anchor and you can get swept along with it. Which is why, with our reps… they get together [every month] to talk about what’s the work of their committee so they can report back. That’s why we have - the staff have to report to their members, so we’re not doing anything without thinking about it… Co-option is a real - it’s a tension, a real tension, but I think we’ve got processes in place and a culture that is aware of it and prevents it.” HCCA Executive Director[[99]](#footnote-99)*

This changed approach to consumer representation responded to longstanding challenges that consumer representatives had experienced on the CADP and HIP governance committees. The HIP Reps Network supported information flow between User Groups and the governance committees, and provided a forum for accountability by HCCA staff to consumer representatives.

### 5.5.4. Supporting consumer input into complex processes

Health infrastructure development is complex. The CADP and HIP had multiple layers of governance, and involved complex budget cycle, planning, design, procurement, construction and contract management processes. These were often unfamiliar to consumers. (Indeed, they were likely also unfamiliar to many of the ACT Health professionals involved in rolling out these programs - as evidenced in the production of ‘how-to’ guides designed to explain the infrastructure development process to ACT public servants.[[100]](#footnote-100)) The complexity of CADP and HIP processes was such that it was often unclear at which points in the planning and design process consumer input should, or could, be usefully provided. Additionally, pressures of time often limited the quality and effectiveness of consumer involvement, as this consumer representative explained:

*“The meeting frequency of some User Groups was like, within a fortnight. Things were happening in which those particular consumer representatives [to the User Groups] were consulting us before being asked to contribute. Often you know, issues either arose without due consideration, and by the time they got up to the senior committee it was too late. This particularly goes to the model of care development.” Consumer Representative to the Redevelopment Committee.[[101]](#footnote-101)*

To respond to these challenge, in 2013 HCCA developed an Indicative Process Diagram. This document outlined a generic HIP process from service planning to POE, and clearly identified the points in this process at which consumer input was necessary and important. It also set out the roles of HCCA, consumer representatives and the general community in the provision of input into health infrastructure projects. The Indicative Process Diagram (Appendix F) was intended to provide clear and easy to implement advice to ACT Health and other professionals working on the HIP, about the points in the process where consumer input is required and can make a practical difference to decisions and outcomes. While the Indicative Process Diagram was unfortunately never formally accepted by ACT Health, it remains a useful reference for organisations looking to understand the key points in health infrastructure projects at which consumer involvement is essential.

## Communication and language in health infrastructure

Communication issues were a focus of HCCA’s advocacy in the CADP and HIP. Consumer feedback consistently demonstrated limited public awareness of major health infrastructure projects or the CADP and HIP. HCCA’s Consumer Coordinator described the limited community awareness of infrastructure projects that HCCA encountered when conducting information sessions:

*“When we did presentations on what was happening in the Health Infrastructure Program to all the Community Councils and to other peak organisations it was very apparent that there was little to no understanding in the ACT community about HIP projects. We reported this back to ACT Health reflecting that this was a missed opportunity to celebrate the substantial work and money involved in upgrading and building new faculties. There was very little involvement of the community in projects which meant the community feels no ownership but rather a scepticism at what's being done with their taxpayer dollars. At one stage I offered a list of consumers who were happy to provide good news stories for the purpose of promoting HIP but it wasn’t taken up. This meant there was very little to counteract the negatively focused stories that made it into the Canberra Times regularly.” – HCCA HIP Consumer Coordinator[[102]](#footnote-102)*

In addition the language of infrastructure development is often highly technical and is rarely consumer-oriented. This posed challenges for consumer representatives. One of the consumer representatives on the UCPH user groups spoke about the challenge of jargon in her committee work, commenting that:

“*Body holding – that sounds like the sort of apparatus and policies and things they have in terms of how they move people. Is that what you think? Do you know what it means? It’s how you care for dead bodies. The holding of bodies so the provision of how you do that if someone has died onsite. It was a big learning curve for me, so there you are, there’s the official expression.” – Consumer representative to UCPH User Group[[103]](#footnote-103)*

HCCA regarded jargon-free, consumer-friendly information about infrastructure projects as essential to consumer awareness of health infrastructure projects and opportunities to be involved.

HCCA sought to model consumer-friendly language in our own communication with consumers. HCCA’s Executive Director explained:

*“You get so caught up in government processes and their procurement models and the probity, commercial in confidence, you start talking like the bureaucrats; you assume their acronyms and the jargon. Over seven years you learn so much, and you've got to remember to go and talk to everyday people. So, for example, UCPH rolls off the tongue. Most people have no idea what it is, nor should they. So we deliberately try and say: University of Canberra Public Hospital. Or the rehabilitation hospital.” - HCCA Executive Director[[104]](#footnote-104)*

HCCA’s use of plain English in our communication with members and consumers supported consumer awareness of and involvement in health infrastructure projects. As the quote above illustrates, our use of consumer-oriented language was an important aspect of our identity as a consumer organisation and a strength that we brought to our partnership with ACT Health.

HCCA also worked to ensure that consumer perspectives and experiences informed ACT Health discussions about appropriate terminology. HCCA’s Executive Director describes how HCCA undertook this work:

*“I did one yesterday with a senior bureaucrat around this health infrastructure program, on a term called Model of Care, compared to Model of Service. They’ve got their own confusion around the term and they’re wanting to move to model of service, because they think it’s more inclusive. But we actually prefer the term model of care, because at the heart of the health service is caring for people. Caring for staff, caring for consumers and family, so what’s wrong with it? If you move it to model of service, well, that could be a fast food restaurant. What’s intrinsic to the health service is there’s an element of care with all human services…*

*“What we do, as an organisation, is that we take the lived experience of consumers and then translate that in a way that bureaucrats and policy makers can understand… The more we package things in a way they understand, the more hope we have of changing their minds, changing their views and challenging their thinking.”[[105]](#footnote-105)*

This example highlights the role HCCA played in bringing consumer perspectives to ACT Health deliberations, in ways that could be understood and acted on by decision-makers.

HCCA also worked to overcome communication and language challenges in the CADP and HIP by:

* Advocating to ACT Health for improved public information about major infrastructure projects and opportunities for consumer and community involvement;
* Providing advice and support to ACT Health around communication with the public; and
* Undertaking consumer and community consultation and information sessions about major infrastructure projects.

While clearly further work could have been done, HCCA’s consumer and community engagement increased community understanding of the CADP and HIP and the opportunities that existed to be involved.

## 5.7. Case study: University of Canberra Public Hospital

### 5.7.1. Consumer involvement in UCPH

The University of Canberra Public Hospital (UCPH) is a major HIP project, expected to be complete in 2018. Located on the University of Canberra campus in Canberra’s north, UCPH will be a sub-acute hospital with a focus on rehabilitation services. HCCA was an important partner in the decision to construct a sub-acute hospital, having long advocated the benefits of a sub-acute facility in meeting consumer needs as well as offering cost saving to government by offering opportunities to heal without the high cost of a long stay in an acute hospital environment.[[106]](#footnote-106) While UCPH is one of the later projects to be delivered under the HIP, the purpose and role of the new hospital had been under debate from early in the CADP:

*“Very much the views we took as healthcare consumers and as representatives of users of services is that services should be provided in the appropriate place using appropriate clinicians at the appropriate time. I think that it was a significant achievement not to give in to the people saying we just need a new hospital, which would have replicated [services already available at existing ACT public hospitals]. The deficiency that we kept pointing out was this ability to cope with the subacute, the rehabilitation of people who were not ready to go back into the community but did not need to occupy subacute beds. And the step-up facility of people who may be needed assessment and work, but wouldn’t get seen within the emergency department.” Consumer Representative to the CADP Redevelopment Committee.[[107]](#footnote-107)*

HCCA supported consumer representatives on the overarching HIP committees, the UPCH Project Control Group and on User Groups tasked with decision-making in relation to the design of different areas of the new hospital, and the models of care to operate from these areas. In later stages HCCA supported consumer representatives to Operational Commissioning Working Groups. HCCA also undertook significant member and community consultation to inform our advice to ACT Government in regard to planning for the new hospital. Our focus on this work reflects the importance of this project to ACT health consumers. UPCH is also an important case study in consumer involvement in infrastructure projects, because HCCA was involved in this major project from inception through to final design decisions, and had the staffing levels and resources to allow consistent engagement in the process.[[108]](#footnote-108)

### 5.7.2. Access issues at UCPH

Reflecting the priority consumers placed on access as an issue across all CAPD and HIP projects, HCCA and consumer representatives consistently drew attention to barriers to consumer access to the new hospital. One of the primary concerns related to the proposal to provide only limited accessible parking:

*Parking can often be dismissed as a trivial issue but it is hugely important for consumers and the community… The provision of only three accessible parking places located on the site of UCPH needs reconsideration as we do not see that this is adequate. A rehabilitation hospital will have a high need for easy access and part of easy access is to provide ample onsite parking for those who need it most.[[109]](#footnote-109)*

Consumers consulted by HCCA also saw the proposal in the 2015 Reference Design Plan to provide a total of 30 accessible parking spaces in a main car park located some distance from the hospital as insufficient. Given that demand for accessible parking could be expected to be high in a rehabilitation facility, HCCA advocated for a larger number of accessible parks and for car parks slightly larger than usual to allow for the limited mobility that many visitors to the hospital could be expected to have. HCCA also advocated for clarity around the location of the main UCPH car park, which was to be located away from the hospital rather than alongside or underneath the building. Ultimately a decision was made to incorporate 250 carparks under the UCPH building.[[110]](#footnote-110) HCCA also advocated that bus stops, taxi stands and carparks be located in such a way that patients would not need to navigate a slope to and from the hospital. As HCCA’s Consumer Coordinator described, several of the access challenges that consumer representatives and HCCA drew attention to were addressed as the design of UPCH progressed:

*“We had a real win with disability access parking. We managed to get a lot more than what the regulation was, because we really pushed for it. I think we’ve had a win with the bus... [the] ACTION bus stop is right outside the entrance. I think the carpark being underground, incredibly good. I think there’s really good element to the access of it, and it’s going to be flat. A lot of the day services in the high use areas, the hydro therapy, will have flat access from drop off or from underneath, which I think is great.” HCCA HIP Consumer Coordinator[[111]](#footnote-111)*

While these are positive outcomes for consumers, a major transport issue that remains outstanding is the insufficient provision of community transport to the new hospital.[[112]](#footnote-112)

### 5.7.3. Consumer priorities for UPCH

HCCA and consumer representatives ensured that consumer priorities and perspectives were articulated and considered during planning for the UCPH model of care. In particular, consumer representatives and HCCA advocated for:

* Provision of palliative care as an aspect of the model of care provided at UCPH;
* Active support for advanced care planning by patients in the hospital;
* Extended operating hours for the facility and the rehabilitation services it offers, to reduce the time of stay in hospital and provide a person-centred model of care;
* Community access to hydrotherapy facilities at the hospital, meeting a priority consumer need for this service;
* A clearly articulated role for volunteers, and unpaid caregivers and family members; and
* Adequate space to allow family and friends to be involved in caring for people in inpatient areas.

A consumer representative involved in planning for UCPH described how she raised end-of-life issues and advocated for provision of palliative care services at the new rehabilitation hospital:

*“I said we want palliative care beds and palliative care services, because these people, if they deteriorate, they shouldn't have to go back to the [acute] hospital to die…*

*I advocated in the model of care that we should offer everybody who is to be transferred there a chance to do an advanced care plan.[[113]](#footnote-113)*

This example demonstrates that HCCA-supported consumer representatives ensured that important consumer issues were raised and heard by decision-makers.

HCCA also advocated with reasonable success for the inclusion of design features that will deliver patient control of in-patient areas and provide a home-like environment.[[114]](#footnote-114) Patient control of inpatient areas was a priority for HCCA:

*“Things like natural light, control over your own inpatient area, and this is particularly around University of Canberra Public Hospital – were non-negotiables. We wanted openable windows. If this was to be a homelike environment, at home you’d have control over your environment.” - HCCA Executive Director[[115]](#footnote-115)*

*“Natural views, lights, and courtyards… I think that’s going to be very good… But, courtyards are going to be totally shaded in winter, so not good when people want to sit in the sun. That’s one of the things I escalated to a very high level, because they didn't know that. So they said: okay, well, we’ll make sure that we have seating and areas just outside the door that will be in sun… I think the inpatient area, I'm a bit disappointed, because when I look... I think it’s a missed opportunity to have had some rooms with a carer bed and a carer zone.” - HCCA HIP Consumer Coordinator[[116]](#footnote-116)*

HCCA succeeded in drawing attention to the essential importance of natural light and windows that open – two aspects of patient control in which the in-patient areas are likely to perform well overall. However we were less successful in advocating for design features that would have better supported the involvement of unpaid caregivers.

A focus for HCCA’s work in relation to UCPH was to gather evidence about the benefits of a high ratio of single bed rooms. HCCA advocated for an 80%-20% ratio of single bed to multi bed rooms on the grounds that a higher ration of single bed rooms offers privacy, better infection control, error reduction and patient safety, improved patient flow and cost effective delivery of care.[[117]](#footnote-117) Ultimately the decision was that the ratio of single to shared rooms would be 60%.[[118]](#footnote-118) It is probable that a lower ratio of single bed rooms would have been delivered without HCCA’s advocacy. HCCA’s Consumer Coordinator explained:

*“Yes, we wanted 80 [per cent] and there’s an argument for 80 [per cent]... We listened to our reps, and some of our older reps said, and there’ll be a lot of older people here, we actually like to share rooms. We might think that that’s, you know, [not] evidence based, but there’s a lot of people that like the social interaction… So, we shot for 80 and we got 60 [per cent]. Had we not been there though, we definitely would have gotten 40 [per cent]”. – HCCA HIP Consumer Coordinator[[119]](#footnote-119)*

HCCA continues to advocate for a higher ratio of single bed rooms at UCPH.

Though not all of HCCA’s advocacy goals in relation to UCPH were achieved, our support of consumer involvement ensured that consumer priorities were articulated to and understood by decision-makers. One issue that was a source of discussion at UCPH was the provision of entertainment in the inpatient rooms. One consumer representative shared her experience:

*“When [HCCA’s Consumer Coordinator] and I were first on a committee with [one of the clinicians] about UCPH, they were talking about TVs, and he said, no, we don't want any TVs in the room, because the patients will sit there and watch the TVs instead of coming out and doing their rehab… We consumers protested. And I thought, it's okay for you, mate. You go home at 5 o'clock. I'm there after 5 o’clock. Do I have to go to the community room and watch a TV with ads when I only watch the ABC at home? No, no way.” Anyway, after some negotiated humour and email exchanges, it was agreed that patient rooms will have TVs.”[[120]](#footnote-120)*

HCCA also gathered and presented the evidence for incorporation of a Patient Information and Entertainment System at UCPH. In this way, HCCA and consumer representatives ensured that consumer experiences and priorities in relation to entertainment in inpatient rooms were articulated to decision-makers and informed decisions.

It was necessary for HCCA to compromise on some of our goals for UCPH. For example, based on feedback from consumers HCCA advocated strongly but ultimately unsuccessfully for a change of name for this sub-acute facility. Consumers and HCCA members consistently said that the “University of Canberra Public Hospital”, as a name, communicated little about the new facility’s purpose.[[121]](#footnote-121) HCCA’s Executive Director described the importance of retaining perspective in discussions about major infrastructure projects such as UCPH:

*“Remember the big picture: so often you get caught up in a battle over a particular way a waiting room is structured, or whether, in fact, a doorway is hung left or right, or a type of en-suite. Or even if there’s going to be boards, information boards in waiting rooms. You've just got to take a step back and remember: is, in fact, this meeting the needs of the community? Are the decisions that we’re taking going to deliver better access to services? And sometimes you have to take a hit, but, as long as you understand that every decision you're taking is getting you closer to that end point, it’s okay. That’s actually harder to do than say. When you feel quite passionate about something, you can see the logic in it, whether it’s about having, for example, computers in all of the family resource rooms.”[[122]](#footnote-122) HCCA Executive Director*

The example of UCPH highlights the value of consumer involvement in major infrastructure projects, and the ‘give and take’ required in a partnership between consumers and government. HCCA’s Consumer Coordinator described the overall positive impact of consumer involvement:

*“There’s always going to be major issues with a new build. Nothing’s going to be perfect, but yes, I think... of course it’s better if we’re there.” – HCCA HIP Consumer Coordinator[[123]](#footnote-123)*

HCCA’s support of consumer involvement at UCPH delivered tangible outcomes including more natural light, openable windows, a higher ratio of single bed rooms, more on-site car parking, better public transport access, and greater number of accessible car spaces than would otherwise likely have been achieved. While not all of the consumer priorities for the new hospital were achieved, these are important outcomes of our involvement in this major project.

### *Summary: Consumer involvement in the HIP*

* In 2012 the ACT Government changed the name of the CADP to the Health Infrastructure Program, took on the role of project manager that had previously been performed by THINC Health, and extended the timeframe of the Program to 2022.
* HCCA was successful in negotiating with ACT Health to obtain additional resources to support consumer and community engagement in health infrastructure decision-making, with a renegotiated Service Funding Agreement (2013-16) allowing HCCA to employ a 2.5 FTE staff team to undertake community and consumer engagement, support consumer representatives, and share information with and provide policy advice to ACT Health.
* With dedicated funding for a part-time Consumer Coordinator from 2009, a part-time Multicultural Liaison Officer from 2012 and a further increase in the HIP staffing profile to 2.5 EFT between 2013 and 2016, HCCA was able to provide enhanced support to consumer representatives, expand our consumer and community consultation, and provide, and consolidate our approach to consumer involvement in major infrastructure projects.
* Major projects to which HCCA provided input under the HIP included:
  + Expansion and refurbishment of the Tuggeranong CHC;
  + Canberra Regional Cancer Centre;
  + Calvary Public Hospital Car Park;
  + Central Outpatients Refurbishment, The Canberra Hospital;
  + Duhlwa Secure Mental Health Unit (expected completion 2016);
  + Expansion of the Emergency Department and Paediatric Streaming, The Canberra Hospital
  + Intensive Care Unit Extension, The Canberra Hospital (expected completion 2017);
  + University of Canberra Public Hospital (expected completion 2018);
  + Ngunnawal Bush Healing Farm (yet to be completed); and
  + Clinical Services Building 2/3, The Canberra Hospital (yet to progress beyond initial planning).

# Key elements of HCCA’s work on health infrastructure, 2009-2016

HCCA’s activities in support of consumer involvement in health infrastructure evolved and were consolidated over seven years of funded work in this area. The key elements of our work are described below.

### 6.1. Supporting consumer representatives to be effective in their roles

HCCA supported consumer representatives contributing to decision-making committees, including at the highest level of program governance. HCCA’s support was tailored to individuals’ needs and included assisting with meeting preparation, printing meeting materials, arranging room access, providing research and policy advice, liaising with committee Secretariats and in some instances individual mentoring. The support provided to all consumer representatives through the HCCA Consumer Representatives Program, including through initial and ongoing training and a peer-led selection process, also benefited CADP and HIP consumer representatives. HCCA established the CADP Reps Network, which later became the HIP Reps Network, as a regular forum for information sharing, networking, learning and skills development. Essential training topics included procurement and contract management, understanding the ACT budget cycle, CADP and HIP governance arrangements, reading architectural plans, and probity and commercial-in-confidence requirements. The CADP and HIP Reps Network were also valuable forums consumer representatives working at different levels of governance to share information with one another; and with HCCA.

### 6.2. Community engagement and consultation

HCCA undertook consumer and community consultation through forums, workshops and meetings. We raised consumer and community awareness of health infrastructure projects and opportunities to contribute to infrastructure planning, by conducting information and feedback sessions. This included by liaising with consumer, carer and community organisations, Community Councils, peak organisations and self-help and support groups. HCCA had a particular focus on CALD consumer and community engagement, building relationships with CALD community leaders and networks in order to promote health literacy and understand consumer priorities as an essential precursor to supporting CALD participation in infrastructure planning. As a membership organisation, HCCA also consulted closely with our membership when developing policy positions and advocacy priorities related to health infrastructure. We worked collaboratively with key consumer organisations including the Mental Health Consumer Network in order to support the involvement of key consumer perspectives in decision-making. This collaborative work involved regular liaison and information sharing, and on occasion advocating for the inclusion of representatives of key consumer organisations in decision-making forums. HCCA prioritised the principles of meeting consumers at times and places that suited them, and providing feedback about the outcomes or consequences of consumer involvement.

### 6.3. Feedback and advocacy in relation to ACT Health communications material

HCCA provided feedback on public communications materials produced by ACT Health about infrastructure projects and the CADP and HIP, and advocated for improved public communication (including information about when the changes would happen and interim or transition arrangements, and transport options). HCCA promoted public awareness of the CADP and HIP through consumer consultation and engagement. We also played a role in translating the technical language of infrastructure development into consumer-friendly language; modelled consumer-appropriate language; and provided advice to ACT Health about appropriate terminology.

### 6.4. Liaison, information sharing and relationship building with ACT Health

HCCA liaised regularly, and shared information, with key areas within ACT Health including the ACT Health Multicultural Health Policy Unit and ACT Health Communications team. HCCA established strong relationships with decision-makers within the Directorate and these were important to the success of our partnership. When necessary HCCA elevated issues to senior decision-makers within ACT Health to be addressed. HCCA also invited ACT Health officials to present on topics of interest to the CADP Reps Network and HIP Reps Network; and arranged for consumer representatives to be invited to attend key ACT Health meetings in which executive staff shared information about the CADP and HIP.

*“Reflecting on what we’ve learnt from our time with the health infrastructure, I think the biggest lesson has been that it’s all about relationships. Just like healthcare is all about relationships, so is any time you're working closely with people – that was lesson one.” HCCA Executive Director[[124]](#footnote-124)*

The CADP and HIP aimed to deliver safe, high quality health services to consumers, but there were times when the priorities identified by HCCA were not supported by ACT Health. For example, HCCA’s position on the preferred ratio of single bed rooms at UCPH was not accepted. Though our advice on the benefits of a high single bed ratio was generally supported, financial constraints meant that compromises had to be made in the design phase. Construction of health facilities is very expensive, and the ACT Government does not have unlimited funds.

*“I mean, right at the very beginning of the negotiations, you know, I was told by [an ACT Health executive]: look, you know… no one’s arguing that this is the best, but we’re a small jurisdiction with a small tax base. And we have to compromise, and you have to compromise too. And so, it’s been a compromise.” – HCCA HIP Consumer Coordinator[[125]](#footnote-125)*

Discussions between HCCA and ACT Health had the potential to be heated and divisive. However having strong working relationships based on respect, and both parties committed to delivering high quality and safe health facilities, softened the impact of disagreements and ensured relationships withstood differences in viewpoints and priorities.

### 6.5. Sharing and promoting good practice in consumer engagement

HCCA invested in learning about evidence-based design, and good practice in patient- and person-centred health infrastructure development. This included by organising site visits for key HCCA personnel to infrastructure projects in other Australian jurisdictions. As a result HCCA was able to bring an understanding of good practice to discussions about major infrastructure projects in the ACT. However, as HCCA’s Consumer Coordinator described, outcomes were never assured:

*"In my opinion, the once in a lifetime opportunities that arose from the Health Infrastructure Program were not realized due in part to the lack of knowledge of contemporary evidence based design of those around the table where these crucial decisions were being made. As a result especially at user group level designs were often based on staff preference rather than current best practice. It often seemed like I was the one who knew more about what was happening in other jurisdictions due to the fact that we invested in this whilst ACT Health staff were too busy with their full time clinical or managerial loads. I feel disappointed as I think more could have been made of the opportunity to build in workflow efficiencies and create designs focused on patient quality and safety” – HCCA HIP Consumer Coordinator[[126]](#footnote-126)*

HCCA shared up-to-date evidence about patient and person-centred infrastructure design with ACT Health, for example by conducting research on patient experiences of single versus multi-bed hospital units and tabling relevant reports at strategic governance committee meetings. Recognising HCCA’s knowledge of inter-state developments in health infrastructure, HCCA’s Consumer Coordinator was invited to speak to ACT Health executive staff about recent developments in health ICT across Australia. HCCA’s investment in learning and research built our staff capacity in this area, and created opportunities to share our learning with ACT Health.

### 6.6. Consumer involvement in design and governance of health infrastructure

HCCA supported consumer involvement in both the design, and the governance, of health infrastructure projects and programs. This took in consumer input into the physical layout of buildings and areas, with a focus on the design of in-patient areas and shared areas such as reception and waiting areas as well as furniture, fixtures and equipment. A distinguishing feature of the work ACT Health funded HCCA to undertake was our support of consumer involvement in program and project governance. Importantly, HCCA supported consumer involvement in developing the models of care and models of service to operate from these services. In our experience this was an area of health infrastructure development that could be overlooked in a process focused on design and construction.

A number of issues for consumer recurred in the major infrastructure projects in which HCCA was involved, and these were a focus of our work and advocacy. These included:

* Promoting early involvement of consumers in infrastructure projects, including in site selection;
* Working with health services to identify and rectify barriers to consumer access, including in relation to provision of appropriate transport options;
* Working with consumers and health services to improve signage and way finding assistance both in new buildings and during construction processes;
* Involving consumers in the design of shared spaces (e.g. waiting rooms and reception areas);
* Involving consumers in the selection of furniture, fixtures and equipment;
* Involving consumers in the design of in-patient areas; and
* Promoting evidence-based consideration of models of care.

### 6.7 Consumer involvement in post-occupancy evaluation

HCCA consistently promoted the value of consumer involvement in POE. Unfortunately, over the course of the CADP and HIP there was limited consumer involvement in this area. The Village Creek project established a strong model for consumer involvement in POE, with consumers involved in identifying evaluation criteria. Unfortunately this model was not replicated in any later projects. Overall the approach to POE in HIP and CADP appeared ad-hoc. Three approaches to POE were piloted in evaluations of the Gungahlin CHC, the Adult Mental Health Assessment Unit and the Adult Mental Health Unit. It is however unclear to HCCA how evaluation of the three pilot approaches informed later POE processes. To HCCA’s knowledge, there has been no POE undertaken for many of the infrastructure projects undertaken since 2009. The lack of information sharing with regard to the findings of POE has been also been a significant barrier to quality improvement. As an example, planning for UCPH would have been aided by access to information gathered through POE of the Centenary Hospital for Women and Children. The HIP Consumer Coordinator observed that:

“It was disappointing as we learnt so much from post occupancy evaluations from interstate health infrastructure projects not ACT Health ones. In fact there were occasions where incorrect assumptions were made form past ACT Health projects and why things did or didn’t work which meant that there were risks of repeating the same mistakes because no formal evaluation had taken place”[[127]](#footnote-127)

The lack of POE for HIP projects represents a significant missed opportunity to apply insights and lessons learnt from previous projects in order to improve design quality and achieve greater value for money through the building of innovative health facilities that will be fit for purpose for now and into the future.

### 6.8 Documenting consumer issues in health infrastructure

One of the key elements of HCCA’s work was to document the consumer issues that recurred over seven years of health infrastructure development. Under the HIP HCCA formalised our approach in this area, developing an Issues Register to document and track issues raised by consumer representatives and HCCA staff. HCCA also maintained a separate UCPH Issues Register, reflecting the scale of this project and our level of involvement. These Issues Registers allowed HCCA to track recurring issues and progress (or lack of progress) of issues toward resolution over time. The key issues that were logged in the Register included matters related to:

* Safety (including after-hours security for staff and patients at various facilities);
* Signage and Wayfinding;
* Waiting Areas;
* Reception Areas;
* Project Governance;
* Amenities/Furniture/Fixtures;
* ACT Health communication with consumers; and
* Models of Care.

### 6.9. Building HCCA organisational capacity and networks

Over seven years of funded involvement in health infrastructure, HCCA developed the capacity and capability of its staff to contribute to infrastructure decision-making. This included by supporting staff to attend conferences and interstate site visits. As an organisation HCCA developed systems and processes for supporting consumer involvement in health infrastructure, and extended and strengthened our networks with consumers and community organisations. HCCA also developed collaborative working relationships with consumer and community organisations and networks through the course of our involvement with the CADP and HIP, to support consumer involvement in health infrastructure governance and design.

# Key outcomes for consumers

HCCA’s work, and the ACT’s approach to consumer involvement in health infrastructure between 2009 and 2016, delivered positive outcomes for healthcare consumers. Some of the specific outcomes delivered by consumer involvement in the CADP and HIP are tangible, relating to the built form, design and accessibility of new or redesigned health services. Other outcomes are less tangible but no less important, and relate to the knowledge, relationships and networks that HCCA sustained and strengthened over seven years of supporting consumer involvement in health infrastructure. Further outcomes have to do with the structures and processes for consumer involvement that were established, and added value to decision-making, through the CADP and HIP.

7.1. Skilled and knowledgeable consumer representativesConsumer representatives supported by HCCA acquired substantial practical knowledge of health infrastructure planning, design and governance. As a result the consumer network that HCCA supports has an enhanced capacity to contribute to and to positively influence future strategic health decision-making. Specific areas of knowledge and skill developed by consumer representatives include:

* The ability to interject consumer issues into complex, fast-paced and sometimes unclear infrastructure decision-making processes;
* Knowledge of ACT Government and ACT Health processes including Treasury budget cycle, procurement and contracting;
* Knowledge of infrastructure development processes and skills such as reading architectural drawings and technical plans;
* Ability to build good working relationships with health professionals at all levels; and
* Capacity to articulate consumer issues and ensure that these are considered by professional committees that may otherwise overlook these issues.

7.2. A networked and knowledgeable health consumer organisationAs a result of our sustained work in support of consumer involvement in the CADP and HIP, HCCA has strengthened our relationships, networks, knowledge and expertise relevant to health infrastructure planning and governance. These outcomes make a positive contribution to the capacity of consumers in the ACT to contribute to future decision-making about the delivery of health services. Specific areas in which HCCA has enhanced our capacity include:

* Stronger partnerships with consumer and community organisations which were hitherto less involved in health infrastructure decision-making;
* Demonstrated ability to broker the involvement of consumer groups who can make a priority contribution to service design and planning;
* Established processes for consumer and community consultation and information sharing to build public awareness of health infrastructure and opportunities to be involved;
* Stronger relationships with and appropriate processes to support the involvement of CALD consumers in health decision-making;
* Knowledge and ability to influence health infrastructure processes in the interests of better consumer outcomes; and
* Respectful relationships with clinical decision-makers and health policy-makers, which can withstand disagreement arising from divergent priorities within the context of the shared goal of delivering safe, high quality health services.

7.3. Raising the profile of infrastructure issues of concern to consumersAdvocacy by HCCA and consumer representatives has ensured issues that are important to consumers were consistently heard by ACT Health decision-makers. These issues included:

* The importance of clear signage and wayfinding, including during construction and in new or redesigned buildings;
* The need for careful consideration of consumer access issues, including appropriate transport options;
* The value of early and ongoing consumer involvement in health infrastructure planning, including in site selection and developing models of care;
* The importance of clear communication with the community about health infrastructure programs and projects;
* The importance of patient-centred design of shared spaces and inpatient areas;
* The value of consumer involvement in selection of furniture and fixtures;
* The value of identifying key points for consumer input into complex infrastructure development processes; and
* The value of consumer involvement in POE, including in identifying criteria for evaluation.

7.4. Established and accepted structures for consumer representationNotwithstanding the challenges that accompanied consumer representation to health infrastructure committees, HCCA’s support of consumer representation contributed to wider acceptance by health professionals and policy-makers of the value of consumer representation, including to governance committees.

7.5. Enhanced community capacity to engage with the CADP and **HIP**HCCA’s work and the ACT’s approach to consumer representation between 2009 and 2016 demonstrated the value of a multi-faceted approach to consumer involvement, incorporating consumer representation to committees alongside consumer consultation and engagement through workshops, forums and information sessions.

Dedicated resources to support CALD community engagement enabled HCCA to involve this group of consumers, who are often under-serviced in our health system, in infrastructure decision-making. A key lesson learnt from this engagement is that a focus on health literacy and knowledge of health services is a necessary foundation for engaging consumers in health infrastructure planning.

7.6. Health services that meet consumer expectations and needsConsumer involvement in health infrastructure projects has contributed tangible positive outcomes in the design of new and redesigned health services. To take just the example of UCPH, HCCA’s support of consumer involvement was essential to the delivery of:

* Inpatient areas and shared spaces that feature as much natural light as possible;
* Inpatient areas that offer consumer control, for example a higher ratio of single bed rooms and openable windows; and
* Improved access (for example flat entrance surroundings, accessible car parking, on-site car parking and public transport access).

Consumer involvement has also identified key gaps in services, and consumer representatives have successfully advocated in support of ACT Health proposals such as the provision of a Community Development Officer to be based at the Gungahlin Community Health Centre.

HCCA played an important role in supporting consumers to be involved in ameliorating challenges encountered in infrastructure projects. For example HCCA worked collaboratively with consumers and key consumer organisations to respond to the access issues created by the ACT Government’s unilateral selection of the Village Creek Centre site. HCCA also supported consumer involvement in designing POE criteria for the Village Creek Centre.

# Conclusion

While HCCA has had a longstanding commitment to consumer involvement in health service planning, implementation and evaluation, our work in this area expanded significantly between 2009 and 2016 during the ACT Government’s jurisdiction-wide program of health service expansion and redesign. The recognition of the importance of early consumer input into this ambitious program of work meant a vast increase in the need for consumer representatives and systems to support their effective engagement.

Consumer and community involvement in health infrastructure projects was not a new thing, either in the ACT or other jurisdictions. What set the ACT approach apart in the CAPD and HIP was the partnership approach between HCCA and ACT Health and the level of involvement by consumers in strategic decision-making and governance at both project and program levels. ACT Health’s recognition of the need to provide specific funding and enhanced resources to support HCCA to undertake this work reflects both our effective advocacy for consumer interests, and ACT Health’s understanding that consumer engagement and partnership are essential to the process of infrastructure renewal.

The systematic involvement of healthcare consumers in health infrastructure decision-making contributed to the delivery of safe, high quality health services in the ACT that are better equipped to meet consumer and community expectations.[[128]](#footnote-128)

Consumers brought to the attention of planners, clinicians and policy-makers issues that would likely otherwise have been overlooked: consumer control of inpatient areas, physical barriers to accessing services, poor connections to public transport links, the inappropriate layout of shared spaces such as waiting rooms, and the essential importance of consumer involvement in site selection. We drew attention to gaps in services; and to areas where consumer involvement should be strengthened, for example in POE. And our involvement both highlighted and made practical efforts to respond to persistent challenges for our health system, including by promoting public understanding of health infrastructure renewal and supporting consumers and communities to engage with health services and health service planning. These issues, which emerged as important early in the CAPD, remained fundamental throughout seven years of HCCA’s intensive involvement in health infrastructure projects. This underscores the value of consumer engagement in these areas, and also suggests that these remain areas in which health service planners and consumer organisations should continue to focus their attention, including early in planning for infrastructure development.

# Afterword: Where next for consumer involvement in health infrastructure?

In June 2016, the ACT Government terminated the HIP. It is unclear what framework for future health infrastructure planning will replace it. In the absence of a dedicated health infrastructure program within the ACT Government it is also uncertain what role consumers will play in future decision-making in this important area. The ACT Labor Government was re-elected in October 2016, and has committed to significant investment in health infrastructure. In this context a clear framework for health infrastructure planning and for consumer involvement remain crucial.

One of the strengths of the CADP and HIP were the clear role and accepted place that they established for consumer representation in strategic decision-making, and in program and project governance. It is an accepted element of good practice in consumer representation that consumers be represented at the highest possible level of governance.[[129]](#footnote-129) In the interests of safe, high quality health services it is hoped that this successful aspect of the CAPD and HIP will be replicated in any future framework for health infrastructure planning that is established in the ACT, and the consumer involvement is sought in the design of this framework. This will assist to ensure that the lessons learnt during HCCA’s partnership with ACT Health between 2009 and 2016 are retained and built on to deliver a safe, high quality health system that will continue to meet the needs of residents of the ACT and surrounding areas in the future.

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# Appendices

## Appendix A: Consumer representative appointments

Between 2010 and 2016 HCCA supported consumer representatives on the following committees:

**2015-16**

ACT Health Infrastructure Program Strategic Committee: Darlene Cox\*

HIP Executive Steering Committee: Kerry Snell\*

Health Infrastructure Program Information Communication Technology Reference Group: Russell McGowan

Health Infrastructure Program Staging and Decanting Project Control Group: Russell McGowan

Arts in Health Committee: Geri Badham

Emergency Department Expansion Project Control Group: Kerry Snell\* and Nick Wales\*

Calvary Health Infrastructure and Planning Executive Steering Committee: Alan Thomas

Ophthalmology Service Relocation Project Board: Russell McGowan

UCPH Communication Operational Commissioning Working Group: Kerry Snell\* and Nick Wales\*

UCPH Day Services User Group: Kerry Snell\*, Nick Wales\* and Marion Reilly

UCPH Equipment Loan Service User Group: Joanne Baumgartner

UCPH Facility Wide Operational Working Group: Nick Wales\*

UCPH Hydrotherapy User Group: Kerry Snell\*, Nick Wales\* and Joanne Baumgartner

UCPH Inpatient Units User Group: Kerry Snell\* and Nick Wales\*

UCPH Interior Finishes and Wayfinding User Group: Kerry Snell\* and Nick Wales\*

UCPH Landscape Design User Group, Main Entry, Reception, and Amenities UserGroup: Kate Gorman\* andNick Wales\*

UCPH Management of a Deteriorating Patient Working Group: Adele Stevens and Nick Wales\*

UCPH Medical Imaging User Group: Bill Heins

UCPH Operational Commissioning Steering Committee: Kerry Snell\* and Nick Wales\*

UCPH Overall Design User Group: Kerry Snell\* and Nick Wales\*

UCPH Pathology User Group: Denise Mott

UCPH Pharmacy User Group: Trish Lord

UPCH Project Control Group: Kerry Snell\*

RACC Inpatient Unit User Group: Pam Graudenz

RACC Model of Care Commissioning Working Group: Kerry Snell\* and Nick Wales\*

Queue Flow Project Steering Committee: Kerry Snell\* and Nick Wales\*

Queue Flow Management Solution Project Working Group: Joanne Baumgartner

Queue Flow Management Solution Client Interface Working Group: Joanne Baumgartner

Queue Flow Management Solution Implementation Planning and Design Workshops: Bill Heins

**2014-15**

ACT Health Infrastructure Program Strategic Committee: Darlene Cox\*

HIP Executive Steering Committee: Kerry Snell\*

HIP Project Control Group: Alan Thomas

Building 3/2, Clinical Services (TCH), Ambulatory Care User Group: Eleanor Kerdo\*

Building 3/2, Clinical Services (TCH), Food Services User Group: Yelin Hung\* and Sandra Avila\*

Building 3/2, Clinical Services (TCH), Family Resource Areas User Group: Caitlin Stamford\*

Building 3/2, Clinical Services (TCH), Chaplaincy Services: Terry Swarner

Building 3/2, Clinical Services (TCH), ICU User Group: Russell McGowan

Building 3/2, Clinical Services (TCH), Inpatient Units User Group: Alan Thomas and Kerry Snell\*

Building 3/2, Clinical Services (TCH), Main Entry User Group: Lisa Harris

Building 3/2, Clinical Services (TCH), Medical Imaging User Group: Roger Killeen

Building 3/2, Clinical Services (TCH), Patient Admissions User Group: Fran Parker

Building 3/2, Clinical Services (TCH), Pharmacy User Group: Trish Lord

Building 3/2, Clinical Services (TCH), Project Control Group: Nick Wales\*

Staging and Decanting, Clinical Services (TCH), Project Control Group: Russell McGowan

Administration, Allied Health Education, Renal, Neurology, Neurosurgery, Rheumatology, Surgical, Clinical Trials, Discharge Nurse, Stomal Therapy, RACC Executive User Group: Bill Heins

Acute Aged Care Inpatient Units and Rehabilitation User Group: Kerry Snell\*

General Beds User Group: Marion Dean

Oncology Haematology User Group: Marion Dean

Pastoral Care and Multifaith User Group: Terry Swarner

Physio, Exercise Physio, Cardiac Rehab, Speech, OT, Renal, Neurology User Group: Christine Bowman\*, Nick Wales\*

Psychology, Nutrition, Social Work , ALO User Group: Nick Wales\*

Psychology/RAC/Nutrition User Group: Christine Bowman\*

Shared Reception / Waiting User Group: Christine Bowman\*, Nick Wales\*

Speech Pathology, Occupational Therapy, Renal User Group: Denise Mott

UCPH Project Management Group: Kerry Snell\*

Clinical Support Medical Imaging: Nick Wales\*

Clinical Support Pathology/Body Holding User Group: Alan Thomas\*

Clinical Technology & Equipment Services User Group: Bill Heins and Denise Mott

Concept Design Committee: Kerry Snell\*

Day Services User Group: Ian Trewhella

Hydrotherapy User Group: Joanne Baumgartner

Main Entry & Hospital Operations, Front of House Staff Amenities: Marion Dean

Medical Imaging User Group: Bill Heins

Operational Commissioning Communication Working Group: Kerry Snell\*

Pathology and Body Holding User Group: Alan Thomas\*

Pharmacy User Group: Trish Lord

Rehabilitation & Aged Care Inpatient Unit Shared Space User Group: Denise Mott

Rehabilitation and Aged Care Inpatient Units User Group: Adele Stevens

Safe Design Committee: Kerry Snell\*

Security, Fire Safety, Parking and Fleet Management: Nick Wales\*

Shared Education & Research User Group: Darlene Cox\*

Staging and Decanting Operational Commissioning Working Group” Kerry Snell\*

Support Services User Group: Bill Heins

Workforce Planning Forum: Darlene Cox\*, Joanne Baumgartner, Kerry Snell\*

UCPH Rehabilitation, Aged and Community Care Model of Care/Service Delivery Reference Group: Kerry Snell\*

Aged Care Inpatient Services User Group: Adele Stevens

Aged Care Outpatient Services User Group: Sue Schreiner

Community Based Services User Group: Pam Graudenz

Village Creek Centre Services User Group: Nick Wales\*

Round One User Groups: Alan Thomas\*, Christine Bowman\*, Joanne Baumgartner

Round Two User Groups: Bill Heins, Joanne Baumgartner

Round Three User Groups: Bill Heins, Joanne Baumgartner

Round Four User Groups: Adele Stevens, Bill Heins, Joanne Baumgartner, Kerry Snell\*

Emergency Department Expansion (TCH), Project Control Group: Kerry Snell\*

Emergency Department Expansion (TCH), Adult Acute and Stream B User Group: Marion Dean

Emergency Department Expansion (TCH), Emergency Medical Unit User Group: Joanne Baumgartner

Emergency Department Expansion (TCH), Forecourt User Group: Nick Wales\*

Emergency Department Expansion (TCH), Paediatrics Streaming User Group: Kerry Snell\*, Nick Wales\*

Emergency Department Expansion (TCH), Resuscitation and Triage User Group: Denise Mott

Queue Flow Project Steering Committee: Kerry Snell\*

Queue Flow Implementation Planning and Design Workshops: Bill Heins, Joanne Baumgartner, Yelin Hung\*

Queue Flow Working Group: Joanne Baumgartner

Queue Flow Client Interface Working Group: Joanne Baumgartner, Yelin Hung\*

Arts in Health Committee: Geri Badham

Capital Region Cancer Centre Executive Reference Group: Victoria Toulkidis, Denis Strangman

**2013-14**

ACT Health Redevelopment Committee: Darlene Cox\*

Project Control Group: Alan Thomas, Kerry Snell\*

Capital Region Cancer Centre Executive Reference Group: Denis Strangman, Victoria Toulkidis

Cancer Centre Art Project Working Group: Sally Saunders

Cancer Outreach Treatment Team Redesign Working Group: Fran Parker

MediHotel User Group (TCH): Heather McGowan\*

Outpatients Refurbishment User Group (TCH): Kerry Snell\*

Women’s and Children’s Hospital Executive Reference Group: Jenny Berrill, Kerry Snell\*

Signage and Wayfinding Stakeholder Group (TCH): Kerry Snell\*, Marion Reilly, Sharon Eacott, Yelin Hung\*

Walk-in Centre Development User Group: Kerry Snell\*

Stand-Alone Birth Centre Feasibility Study Executive Reference Group: Darlene Cox\*

Emergency Department Paediatrics Streaming User Group (TCH): Kerry Snell\*

Building 3/2, Clinical Services (TCH) Ambulatory Care User Group: Eleanor Kerdo

Emergency Department User Group (TCH): Indra Gajanayake

Building 3/2, Clinical Services (TCH) Family Resource Area User Group, Caitlin Stamford\*, Elizabeth Proctor

Building 3/2, Clinical Services (TCH), Food Services User Group: Sandra Avila\*, Yelin Hung\*

Building 3/2, Clinical Services (TCH), Inpatient Units User Group: Alan Thomas

Building 3/2, Clinical Services (TCH), Intensive Care Unit/High Dependency Services User Group: Russell McGowan

Building 3/2, Clinical Services (TCH), Main Entry User Group: Lisa Harris

Building 3/2, Clinical Services (TCH), Medical Imaging User Group: Roger Killeen

Building 3/2, Clinical Services (TCH), Pastoral Care User Group: Terry Swarner

Building 3/2, Clinical Services (TCH), Patient Admissions User Group: Fran Parker

Community Health Centres Executive Reference Group: Bill Heins, Yelin Hung\*

Tuggeranong Community Health Centre Patient Pathway Workshops: Bill Heins

Community Health Centres Art Project Working Group: Sally Saunders

UCPH Executive Reference Group: Kerry Snell\*

UCPH Clinical Support User Group: Bill Heins, Trish Lord

UCPH Clinical Technology and Equipment Services User Group: Bill Heins, Denise Mott

UCPH Hydrotherapy User Group: Joanne Baumgartner

UCPH Main Entry, Reception, Amenities, Multi- Faith area, Hospital Administration, Clinical Records, Ward Services User Group: Marion Dean

UCPH Medical Imaging User Group: Bill Heins

UCPH Pathology and Body Holding User Group: Alan Thomas

UCPH Pharmacy User Group: Trish Lord

UCPH Rehabilitation and Aged Care Day/Community/Ambulatory Services User Pharmacy User Group: Trish Lord

UCPH Rehabilitation and Aged Care Day/ Community/Ambulatory Services User Group: Ian Trewhella, Rick Lord

UCPH Rehabilitation and Aged Care Inpatient Units User Group: Adele Stevens

UCPH Workforce Workshop: Darlene Cox\*, Joanne Baumgartner, Kerry Snell\*

**2012-13**

ACT Health Redevelopment Committee: Marion Reilly, Russell McGowan, Darlene Cox\*

Capital Region Cancer Centre Art Project Working Committee: Sally Saunders

Capital Region Cancer Centre Executive Reference Group: Denis Strangman, Sally Saunders, Victoria Toulkidis

Community Health Centres Art Project Working Committee: Sally Saunders

Community Health Centre Executive: Reference Group: Adele Stevens, Bill Heins, Jacinta Dugbaza, Yelin Hung

Health Infrastructure Project (HIP) Project Control Group: Kerry Snell\*, Louise Bannister

MediHotel User Group: Heather McGowan\*

UCPH Aged Care Day /Community/ Ambulatory Services User Group: Rick Lord

UCPH Clinical Support User Group: Trish Lord

UCPH Main Entry, Reception, Amenities, Multi-Faith area, Hospital Administration, Clinical Records, Ward Services Group: Marion Dean

UCPH Support Services User Group: Bill Heins

UCPH Rehabilitation Day/Community/ Ambulatory Services User Group: Joanne Baumgartner

UCPH Rehabilitation and Aged Care Inpatient Units User Group: Adele Stevens

UCPH Executive Reference Group/Super User Group: Kerry Snell\*

Women’s and Children’s Centenary Hospital Executive Reference Group: Jenny Berrill, Kerry Snell\*

ACT Cancer Services Plan Steering Committee: Rick Lord, Russell McGowan, Kerry Snell\*

Nursing Model of Care/Service Workshop: Bill Heins

Radiation Oncology Major Equipment Replacement Program: Bill Heins

ICT Cancer Services Consumer Reference Group: Alan Thomas

ACT Health Redevelopment Committee: Marion Reilly, Russel McGowan, Darlene Cox\*

Cancer Services Building Executive Reference Group: Sally Saunders, Denis Strangman

Capital Region Cancer Services Nursing Models of Care Working Group: Bill Heins, Russel McGowan

Capital Region Cancer Services Commissioning Working Group: Bill Heins, Terry Swarner

Community Based Services Models of Care Executive Reference Group: Adele Stevens

Community Based Services Project Control Group: Jenny Berrill

Community Health Business Operations User Group: Adele Stevens

Community Health Centres Executive Reference Group: Yelin Hung, Adele Stevens

Community Health ICT User Group: Karen Jameson

Community Health Program & Community Partnership User Group: Yelin Hung

Health Infrastructure Project Control Group: Louise Bannister

Integrated Cancer Centre Committee: Denis Strangman

Integrated Food Services Management System Project Steering Committee: Terry Swarner

Village Creek Services Steering Committee: Darlene Cox\*

**2011**

ACT Health Redevelopment Committee: Marion Reilly, Russel McGowan

Project Control Group: Olivia Macdonald\*

Cancer Information Management System Project Steering Committee: Terry Swarner

Community Based Services Models of Care Executive Reference Group: Adele Stevens

Community Based Services Project Control Group: Jenny Berrill and Olivia Macdonald\*

Community Based Health Services Steering Committee: Jenny Berrill

Community Health Centres Executive Reference Group: Jenny Berrill, Olivia Macdonald\*

Community Health Centres User Group: Adele Stevens

Enhanced Community Health Centre Models of Care: Colin Hales

Integrated Cancer Centre Committee: Denis Strangman, Sally Saunders

Integrated Food Services Management System Project Steering Committee: Terry Swarner, Olivia Macdonald\*

Intensive Care Unit Clinical Information System: Caroline Polak Scowcroft

TCH Emergency Department Models of Care: Anna Saxon-Taylor, Colin Hales

TCH Design Options Group: Olivia Macdonald\*

Village Creek Relocation Steering Committee: Darlene Cox\*

**2010**

ACT Health Redevelopment Committee: Marion Reilly, Russel McGowan

Community Based Services Project Control Group: Jenny Berrill, Olivia Macdonald\*

Community Based Health Services Steering Committee: Jenny Berrill

Community Health Centre DOS Management Group: Alan Thomas

Integrated Cancer Centre Committee: Val Lee

Integrated Food Services Management System Project Steering Committee: Terry Swarner

Intensive Care Unit Clinical Information System: Caroline Polak Scowcroft

Project Control Group, CADP: Angela Wallace, Olivia Macdonald, Tamás de Takach-Tolvay

Project Control Group Intensive Care Unit: Alan Thomas

The Canberra Hospital Design Options Group: Olivia Macdonald

Village Creek ILC Working Group: Kerry Snell\*

Village Creek Relocation Steering Committee: Darlene Cox\*

The Canberra Hospital Emergency Department Models of Care: Colin Hayes, Anna Saxon-Taylor

**2009**

ACT Health Redevelopment Committee: Marion Reilly, Russel McGowan

Community Health Project Control Group: Olivia Macdonald\*

Intensive Care Unit Project Control Group: Alan Thomas

Project Control Group: Olivia Macdonald\*

*\* Organisational representatives*

## Appendix B: HCCA staff who worked on the CADP and HIP

Alan Thomas 28/10/2013 to 1/08/2014

Darlene Cox 01/01/2008 to 31/06/2016

Heather McGowan 28/11/2008 to 16/01/2014

Kerry Snell 19/06/2008 to 31/06/2016

Nick Wales 20/08/2014 to 24/06/2016

Olivia Macdonald 12/06/2009 to 17/02/2012

Yelin Hung 08/08/2011 to 31/06/2016

## Appendix C: Roles of CADP and HIP committees

**Key CADP Committees[[130]](#footnote-130)***The CADP Redevelopment Committee (RC)*This committee is the executive overarching Inter-governmental Project Committee for the CADP. It provides a whole of government view on the conduct of, and progress on, the CADP; delivers overall guidance on matters of policy, process and approvals and monitors progress of and risks associated with the CADP. This Committee is chaired by the Director General of ACT Health.

*The Strategic Implementation Group (SIG)*This committee is the executive working group for the Redevelopment Committee, and ensures a co-ordinated and integrated application of the major “pillars” that are the foundations of the reform agenda as it impacts on the CADP; namely models of care, workforce (including workforce planning and change management), technologies and infrastructure/facilities. This committee also deals with issues arising from any of the projects, trouble shoots as necessary and provides a decision making capacity to allow fast tracking where required and budget decisions regarding expenditure within delegation.

The committee provides advice and reviews the entire CADP project progression and any information, risks or issues brought to the Group by the executive or members of a project team for resolution prior to submission to the Redevelopment Committee. It is responsible for overseeing the day to day implementation issues of the ACT Health CADP and monitoring the Risk Matrix for CADP.

*Project Control Groups (PCGs)*The PCGs are responsible to the Redevelopment Committee for leading the specific project activities that will result in the redevelopment of health facilities at the various healthcare sites across the ACT. The Project Director is responsible for delivering a monthly progress report to the ACT Health PCG (excluding Calvary Hospital PCG at this time) for review and discussion.

The PCGs report to the Redevelopment Committee through a monthly report developed and delivered by THINC Health PD. The PCGs are responsible for resolving all project related matters within their control and are to escalate any issues requiring higher/broader/timely decision making to the SIG for guidance and resolution.

*Executive Reference Groups (ERGs)*Each project will establish an ERG to guide and monitor the planning, design and operational commissioning inputs and outputs for the main deliverables on the project. The main function of the group is to facilitate the input of expert clinical and consumer advice on service delivery and functional requirements for a given project initiative. Membership may vary during different stages of the project. (i.e. health planning brief development, design option studies/value management studies, concept design and design and construction phases). The ERG membership, terms of reference and scope evolves in line with the project evolution. The ERGs will report to the PCGs through the Deputy Project Director/Assistant Project Director and the Executive Director/ Clinical Lead. The ERGs are responsible for endorsing each project deliverable, understanding their responsibility to remain within scope and budget and for the submission of reports and escalation of issues via the Project Director to the PCGs for higher endorsement.

The ERG’s focus will shift from design inputs mid way through the design phase (after final sketch plans as discussed below) and into commissioning and change management, etc.

*User Groups (UGs)*[User groups] should include anyone who has a stake in the project such as doctors, nurses, allied health, pharmacy, pathology etc. and consumers where appropriate…

These groups have responsibility to provide expert and detailed service specific inputs and advice to the PC and /or the PM during the planning and design phases of the project. The UG will need to inform and review project outputs and provide advice and recommendations regarding service user issues and functional requirements. Any issues that cannot be resolved at this level will be escalated to the relevant ERG for resolution. It is important that the membership of these groups is stable, engaged and aware of the scope and budget limitations of the project.

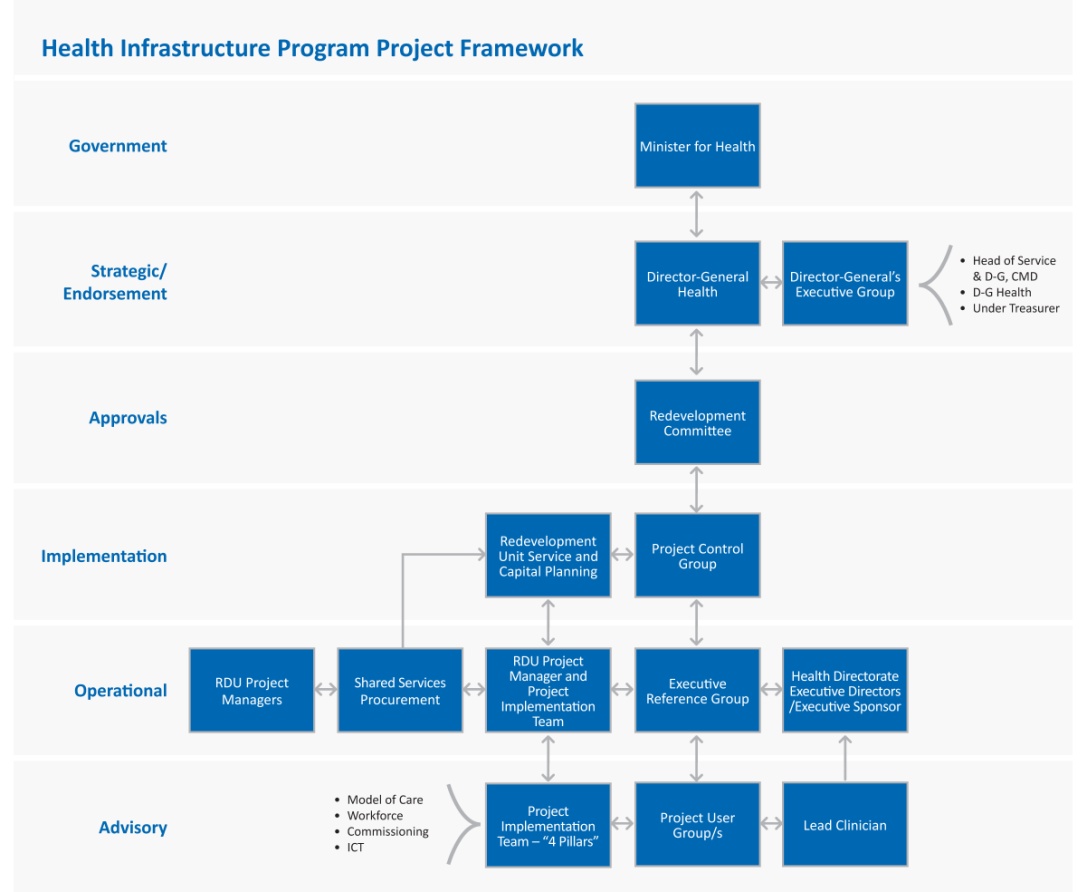
## Key HIP committees[[131]](#footnote-131)

|  |  |  |
| --- | --- | --- |
| **Committee/meeting across projects** | **Purpose** | **Key governance relationship** |
| **Redevelopment Committee** | The Health Directorate Redevelopment Committee (RDC) is the chief decision making body for the Health Directorate Health Infrastructure Program. It is responsible for providing advice, monitoring progress and monitoring risk of the HIP. | Final approval process of individual elements of a project  Final approval of program status to report and make recommendations to the Executive Group |
| **Project Control Group** | A project control group leads the work of the Health Infrastructure Program, as it relates to the facilities of the organisation (eg: Canberra Hospital and Health Services Group/Calvary Health Care – Bruce Campus). It is responsible for ensuring the effective delivery of all elements of the HIP and providing information and recommendations relating to this as required. | Makes recommendations and reports to Redevelopment Committee |
| **Committee/meeting specific to a project** | **Purpose** |  |
| **Executive Reference Group** | An Executive Reference Group provides expert advice on the service delivery functional requirements, project wide. It guides and monitors the planning, design and operational commissioning of a project and provides endorsed recommendations to the Project Control Group. | Makes recommendations and reports to relevant Project Control Group |
| **Project User Groups** | User Groups facilitate consultation about specific user requirements. They provide input to and consideration of the clinical, technical, and operational issues driving the development of a project. | Provides input and advice to relevant Executive Reference Group |
| **Working Groups** | Working groups are time-limited, task specific groups established to achieve specific goals to assist a project. They will have varied membership and participants depending on the task to be achieved. | Provide input and advice to relevant committee meeting as required. |

## Appendix D: CADP and HIP governance arrangements

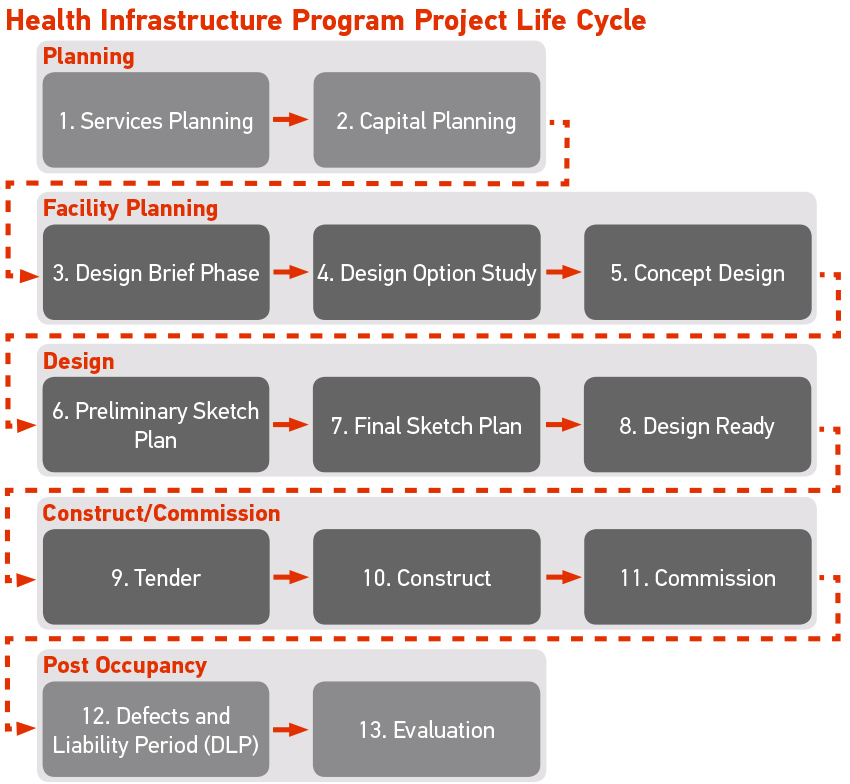
## 

ACT Health, date unknown, *Summary Guide to CADP Governance Roles and Responsibilities, Capital Asset Development Program*



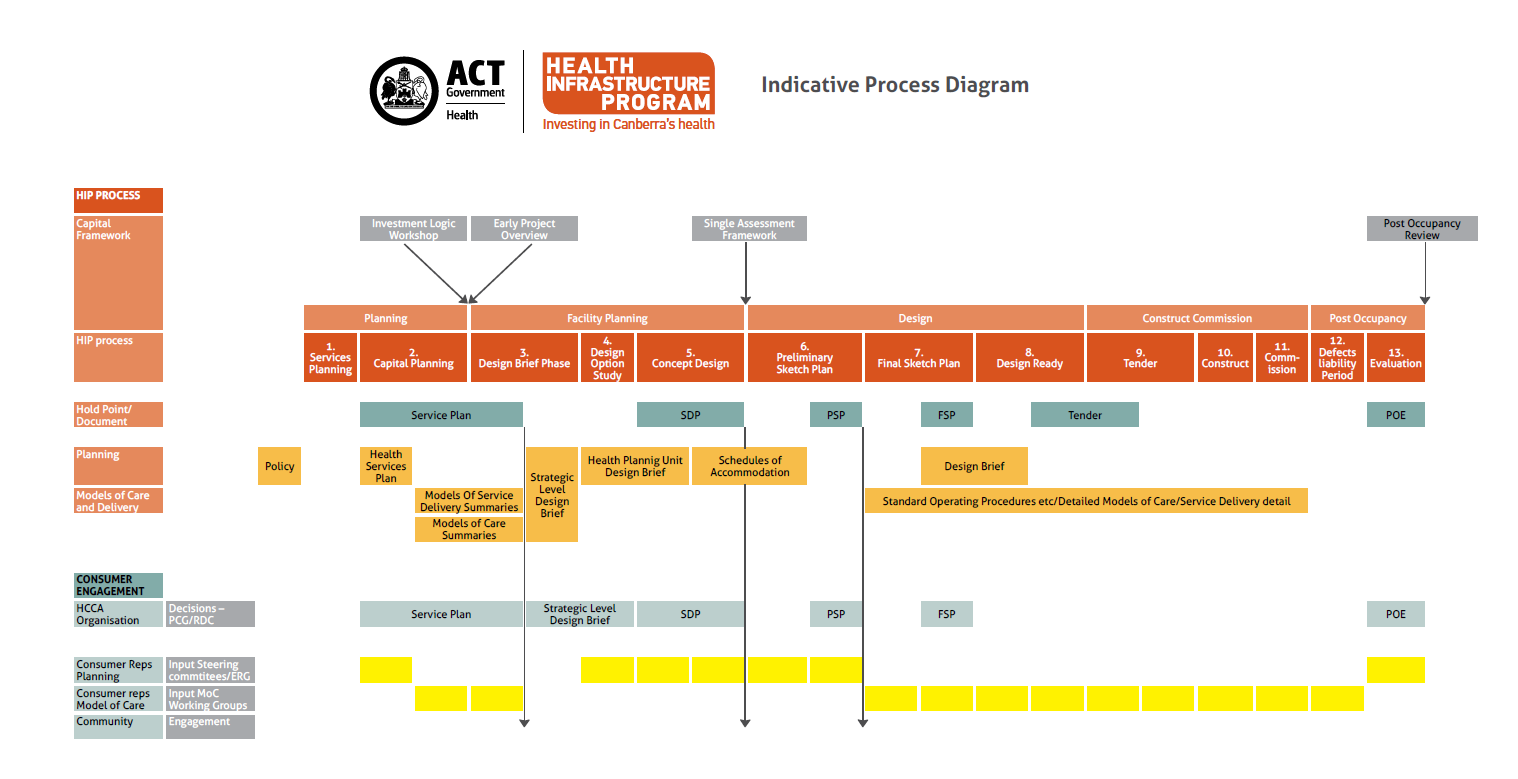
ACT Health, 2012, *Health Infrastructure Program Governance, Roles and Responsibilities, Health Infrastructure Program Foundation Document.*

# Appendix E: HIP project phases



ACT Health, 2015, *Health Infrastructure Program, Phases and Stages of a Project Lifecycle, Health Infrastructure Program Foundation Document.*

## Appendix F: Indicative Process Diagram



# Appendix G: Key HCCA community consultations, 2012-2016

|  |  |  |
| --- | --- | --- |
| Date | Participants | Consultation |
| 2012 | Canberra Combined Community Council Executives | Overview of completed, planned, and future health infrastructure projects being undertaken by ACT Health,  Q and A with follow up |
| 2012 | ACT Carer’s Greek community Group | Overview of completed, planned, and future health infrastructure projects being undertaken by ACT Health,  Q and A with follow up |
| 2012 | ACT Carer’s Indian Community Group | Overview of completed, planned, and future health infrastructure projects being undertaken by ACT Health,  Q and A with follow up |
| 2012 | ACT Carer’s Chinese Community Group | Overview of completed, planned, and future health infrastructure projects being undertaken by ACT Health,  Q and A with follow up |
| 2012 | Gungahlin Community Council Meeting | Overview of completed, planned, and future health infrastructure projects being undertaken by ACT Health,  Q and A with follow up |
| 2012 | Woden Community Council | Overview of completed, planned, and future health infrastructure projects being undertaken by ACT Health,  Q and A with follow up |
| 2013 | Weston Creek Community Council Meeting | Overview of completed, planned, and future health infrastructure projects being undertaken by ACT Health,  Q and A with follow up |
| 2013 | Belconnen Community Council Meeting | Overview of completed, planned, and future health infrastructure projects being undertaken by ACT Health,  Q and A with follow up |
| 2013 | Brindabella Women’s Group | Overview of completed, planned, and future health infrastructure projects being undertaken by ACT Health,  Q and A with follow up |
| 2013 | Majura Women’s Group | Overview of completed, planned, and future health infrastructure projects being undertaken by ACT Health,  Q and A with follow up |
| 2013 | Canberra Soroptimist meeting | Overview of completed, planned, and future health infrastructure projects being undertaken by ACT Health,  Q and A with follow up |
| 2013 | Inner South Community Council | Overview of completed, planned, and future health infrastructure projects being undertaken by ACT Health,  Q and A with follow up |
| 2013 | Queanbeyan Community Council | Overview of completed, planned, and future health infrastructure projects being undertaken by ACT Health,  Q and A with follow up |
| 2014 | Community members and Peak Community Organisations | UCPH draft Model of care consolation |
| 2014 | Peak Community Organisations | UCPH Peaks Consultation to discuss issues around the planning and design of UCPH |
| 2015 | Community members and Peak Community Organisations | UCPH Reference Design consolation |
| 2015 | Community members and Peak community Organisations | UCPH final Model of care consultation |

# Appendix H: HCCA presentations to ACT Health, 2012-2016

|  |  |  |  |
| --- | --- | --- | --- |
| **Date** | **Research /Presentation** | **Presented to** | **Rationale** |
| 2012 | submission on North side Hospital proposal | Senior Health Planners | Provide consumer input into the proposal for the North side Hospital ( which would become UCPH) |
| 2012 | Report on Melton Health Centre and Queue Flow Implementation | Senior Health Planners | To share the lessons learnt from the implementation of the Queue Flow electronic management system and the model of care of one of Australian’s first publicly funded GP super clinics which provided specialist, dental, and GP services to Victoria’s fastest growing area |
| 2013 | Feedback on Secure Mental Health Model of care | Health Planning Unit | Provide broad consumer feedback |
| 2013 | HCCA Report on visits to Victorian sub-acute facilities | For inclusion in presentation to HIP Governance committees by Health Planning unit | To inform planning for UCPH |
| 2013 | Report on Single Bed ratio in hospital design | Tabled and discussed at HIP Executive Steering Committee | Informed debate and decision regarding final decision on the single bed ratio at UCPH |
| 2014 | Report on tour of Gold coast university Hospital and interview with Sunshine coast University Hospital senior planner | Provided to ACT Health, Health Planning Unit senior staff | To share the contemporary planning and evidence based design elements from these projects |
| 2014 | Submission on UCPH Service delivery Plan and Planning Briefs | Provided to ACT Health Infrastructure Planning Unit n | To provide the consumer perspective on the planning for UCPH |
| 2015 | Consumer Engagement in Health Infrastructure in ACT Health | HCCA presentation to Australian and New Zealand Health Alliance Conference hosted by ACT Health | Showcase ACT Health’s embedded model of consumer participation in health infrastructure |
| 2015 | Community Consultation on UCPH Reference Design | HIP Health Planning Unit | Feedback community feedback on the Reference Design of UCPH |
| 2015 | Submission on Community Consultation on the UCPH Model of Service Delivery and RCC Model of Care | HIP Health Services Planning Unit | Feedback form community consultation and Issues Register for UCOH Model of Care / Service Delivery |
| 2015 | Emergency Department drop off traffic study | Provided to HIP Deputy Director General | Informed consumer concerns around safety issues at TCH Emergency Department |
| 2016 | Snapshot survey of patient experience of Inpatient Room type | Tabled and discussed at HIP Executive Steering Committee and Strategic Committee | Informed the debate around the variation to design proposal for UCPH to include 4 bed room model |
| 2016 | Consumer participation in health infrastructure in the ACT | Australian Consumer Participation conference, Melbourne. | Showcase HCCA and ACT Health’s embedded model of consumer participation in health infrastructure |
| 2016 | Efficiency through healthcare technology | ACT Health Senior ICT staff | Share conference highlights of significance to ACT Health’s current HIP projects |

# Appendix I: HCCA interstate health infrastructure tours

|  |  |  |  |
| --- | --- | --- | --- |
| Year | Name | Jurisdiction | Rationale |
| 2009 | Melton Health Community Health Centre | Melton, Victoria | Early adopter of Queue Flow – electronic Patient queuing management solution |
| 2013 | McKellar Centre | North Geelong, Victoria | Sub-acute Rehabilitation Centre |
| 2013 | Belmont Centre | Belmont, Victoria | Sub-acute Rehabilitation Centre |
| 2013 | Kingston Centre | Cheltenham, Victoria | Sub-acute Rehabilitation Centre |
| 2014 | Lady Cilento Hospital | Brisbane, Queensland | Pre –opening tour focusing on design elements |
| 2014 | Gold Coast University Hospital | Southport, Queensland | New era Tertiary hospital Infrastructure Project - Greenfield |
| 2015 | Royal north Shore | Sydney, NSW | NSW Tertiary Hospital Infrastructure Re-Development - Brownfield |
| 2015 | Royal Melbourne Hospital | Melbourne, Victoria | Land locked Redeveloped |
| 2015 | Lady Cilento Hospital | Brisbane, Queensland | Lessons learnt |
| 2016 | Blacktown Hospital | Blacktown, NSW | Winner of award for patient centred approach to health infrastructure design |
| 2016 | Fiona Stanley Hospital | Perth, western Australia | Major Australian health infrastructure project with both sub-acute and acute facilities and private /public partnership implications |
| 2016 | St John of God Midlands | Perth, Western Australia | New development with rehabilitation, acute, and mental health units |
| 2016 | National Capital Private Hospital | Canberra, ACT | Expansion of services |

# Appendix J: HCCA attendance at health design and infrastructure conferences

|  |  |  |
| --- | --- | --- |
| **Date** | **Conference** | **Rationale** |
| 2013 | Australian Health Facility Design Conference, Sidney | 2 day s Australia wide showcase of current and future health infrastructure projects with emphasis on lessons learnt |
| 2014 | Australian Health Facility Design Conference, Sidney | 2 day s Australia wide showcase of current and future health infrastructure projects with emphasis on lessons learnt |
| 2014 | World Health Design Congress, Brisbane | 3 day Global showcase on evidence based healthcare design with an emphasis on Salutogenics |
| 2015 | Planning and Delivering Health infrastructure, Sydney | 2 day Australian conference with a focus on Government planning processes and procurement |
| 2016 | Delivering and Planning Health Infrastructure | 2 day s Australia wide showcase of current and future health infrastructure projects with emphasis on lessons learnt |
| 2016 | Efficiency through technology conference | 2 day showcase of Australian hospital’s use of technology to improve patient safety and quality and workflow efficiencies. Global and future technologies also featured. |
| 2016 | Victorian Healthcare Design Conference | 2 day s Australia wide showcase of current and future health infrastructure projects with emphasis on lessons learnt. Included healthcare technology stream. |

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3. Doggett, Jennifer, 2015, *‘Unique and essential’: a review of the role of consumer representatives in health decision-making*, Consumers Health Forum of Australia, Canberra. [↑](#footnote-ref-3)
4. Health Care Consumers’ Association *Report to ACT Health for the period 1 January 2016 to 30 June 2016* [↑](#footnote-ref-4)
5. Email from Ms Megan Cahill to HCCA Executive Director, 24/10/2016 [↑](#footnote-ref-5)
6. Health Directorate, undated, *Summary Guide to CADP Governance Roles and Responsibilities, Capital Asset Development Program,* Service and Capital Planning Branch. [↑](#footnote-ref-6)
7. Letter from HCCA Executive Director Darlene Cox *Re: Position Consumer Coordinator CADP,* to Ms Olivia Macdonald, June 2009; Letter from HCCA Executive Director Darlene Cox, *Re: Resourcing to sustain consumer input to the Capital Asset Development Program,* to Ms Megan Cahill, Executive Director Government Relations and Planning ACT Health, 23 March 2009 [↑](#footnote-ref-7)
8. Health Care Consumers’ Association of the ACT *Report to ACT Health, For the period 1 July 2010 to 31 December 2010*  [↑](#footnote-ref-8)
9. ACT Health April 2015, *Health Infrastructure Program Introduction and Overview Foundation Document Draft* 0.2 p5 [↑](#footnote-ref-9)
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11. ACT Government Service Funding Agreement with Health Care Consumers Association, 2013, Schedule 2B, *Resources to Support the Health Infrastructure Program* [↑](#footnote-ref-11)
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20. ACT Health, undated, *Summary Guide to CADP Governance Roles and Responsibilities, Capital Asset Development Program*. [↑](#footnote-ref-20)
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22. Health Care Consumers Association of the ACT , 4 March 2011, *Capital Asset Development Plan (CADP), Training Session for Consumer Representatives* [↑](#footnote-ref-22)
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24. Consumer representative to the CADP Redevelopment Committee, September 2016. [↑](#footnote-ref-24)
25. HIP Consumer Coordinator, October 2016 [↑](#footnote-ref-25)
26. Doggett, Jennifer, 2015, *‘Unique and essential’: A review of the role of consumer representatives in health decision-making,* Consumers Health Forum of Australia, Canberra. [↑](#footnote-ref-26)
27. Health Care Consumers Association, 2008, *Service Funding Agreement C07322 Contract Report for 1 July – 31 December 2008* [↑](#footnote-ref-27)
28. Health Care Consumers’ Association *Report to ACT Health for the period 1 July 2009 to 31 December 2009* [↑](#footnote-ref-28)
29. Health Care Consumers Association, 2013, *Agenda for Maternity Services Meeting 8 March 2013* [↑](#footnote-ref-29)
30. HCCA HIP Consumer Coordinator, October 2016 [↑](#footnote-ref-30)
31. ACT Health, undated, *Summary Guide to CADP Governance Roles and Responsibilities, Capital Asset Development Program*. [↑](#footnote-ref-31)
32. Consumer representative to the CADP Redevelopment Committee, September 2016 [↑](#footnote-ref-32)
33. Consumer Representative to a Project Control Group, September 2016 [↑](#footnote-ref-33)
34. HCCA HIP Consumer Coordinator, October 2016 [↑](#footnote-ref-34)
35. Consumer Representative to CADP Redevelopment Committee, September 2016 [↑](#footnote-ref-35)
36. Consumer representative to Canberra Hospital Project Control Group, September 2016 [↑](#footnote-ref-36)
37. Consumer Representative to a User Group, Capital Region Cancer Centre, September 2016 [↑](#footnote-ref-37)
38. Health Care Consumers Association HIP Coordinator, September 2016 [↑](#footnote-ref-38)
39. Consumer Representative to CADP Redevelopment Committee, September 2016 [↑](#footnote-ref-39)
40. HCCA Executive Director Darlene Cox, 2012, drawn from transcript of interview with Dr Anni Dugdale, University of Canberra, recorded as part of data collection for a study of HCCA’s impact on health policy in the ACT. [↑](#footnote-ref-40)
41. Consumer Representative to the Capital Region Cancer Centre, September 2016 [↑](#footnote-ref-41)
42. Consumer representative to a User Group, September 2016 [↑](#footnote-ref-42)
43. Consumer representative to a User Group, September 2016 [↑](#footnote-ref-43)
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49. Health Care Consumers’ Association of the ACT *Report to ACT Health for the period 1 July 2009 to 31 December 2009;*  [↑](#footnote-ref-49)
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53. Health Care Consumers Association, March 2012, *HCCA Proposal - Resourcing for Health Care Consumers Association (HCCA) to sustain consumer input in to the Health Infrastructure Program* [↑](#footnote-ref-53)
54. Health Care Consumers Association, *Report to ACT Health for the period 1 July to 31 December 2010* [↑](#footnote-ref-54)
55. Health Care Consumers Association, *Report to ACT Health for the period 1 July to 31 December 2010* [↑](#footnote-ref-55)
56. Health Care Consumers Association, *Report to ACT Health for the period 1 July to 31 December 2010* [↑](#footnote-ref-56)
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58. Disability and Community Services Commissioner, ACT Human Rights Commission *Report by the Disability and Community Services Commissioner under the Human Rights Commission ACT 2005: Relocation of Equipment and other services, and the Independent Living Centre (ILC) to the Village Creek Precinct,* 2 October 2009 [↑](#footnote-ref-58)
59. Canberra Times 9/11/09, p7. [↑](#footnote-ref-59)
60. ACT Health officer to consumer representative, *Re: TRANSPORT STRATEGY VILLAGE CREEK*, 24/08/2010 [↑](#footnote-ref-60)
61. Health Care Consumers Association, *Village Creek Models of Care Report Card, Report from a Consumer Workshop held on 14th September 2009* [↑](#footnote-ref-61)
62. ACT Health ACRS Executive Director Grant Carey-Ide, letter to HCCA Executive Director Darlene Cox, 27/7/2009. [↑](#footnote-ref-62)
63. Review of Village Creek Evaluation Indicators, Draft 3. [↑](#footnote-ref-63)
64. ACRS Village Creek Steering Committee Meeting Minutes 21st July 2009, Agenda Item 1. [↑](#footnote-ref-64)
65. Email from ACT Health officer to HCCA Consumer Coordinator *Re: Village Creek Working Groups* [↑](#footnote-ref-65)
66. *Questions for the architect,* undated, PWD ACT Consumer Representative. [↑](#footnote-ref-66)
67. Consumer representative to the Belconnen and Gungahlin Community Health Centres, September 2016 [↑](#footnote-ref-67)
68. Consumer Representative to the Belconnen and Gungahlin Community Health Centre, September 2016 [↑](#footnote-ref-68)
69. HCCA Multicultural Liaison Officer, September 2016 [↑](#footnote-ref-69)
70. ACT Health April 2015, Health Infrastructure Program Introduction and Overview Foundation Document Draft 0.2 p5 [↑](#footnote-ref-70)
71. ACT Health, 6/11/12, *An introduction to the Health Infrastructure Program (HIP), Roles and Responsibilities,* Version 3.0 [↑](#footnote-ref-71)
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74. Health Care Consumers’ Association *Report to ACT Health for the period 1 January 2012 to 30 June 2012* [↑](#footnote-ref-74)
75. Health Care Consumers’ Association *Report to ACT Health for the period 1 January 2012 to 30 June 2012;* Email from Health Care Consumers Association Executive Director, Darlene Cox *Re: CADP Advisory Board and CADP resourcing,* to Executive Director Service and Capital Planning ACT Health, 20 January 2012; Letter from Health Care Consumers Association Executive Director Darlene Cox, 26 March 2012, *Re: Resourcing for Health Care Consumers Association (HCCA) to sustain consumer in put to the Health Infrastructure Program,* to Executive Director Service and Capital Planning ACT Health [↑](#footnote-ref-75)
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77. Health Care Consumers’ Association *Report to ACT Health for the period 1 July 2012 to 31 December 2012* [↑](#footnote-ref-77)
78. Health Care Consumers Association Multicultural Liaison Officer, September 2016 [↑](#footnote-ref-78)
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80. HCCA Health Infrastructure Program Multicultural Liaison Officer Report December 2012 [↑](#footnote-ref-80)
81. Health Care Consumers’ Association *Report to ACT Health for the period 1 July 2012 to 31 December 2012* [↑](#footnote-ref-81)
82. Health Care Consumers Association Executive Director, September 2013 [↑](#footnote-ref-82)
83. Health Care Consumers’ Association *Report to ACT Health for the period 1 July 2014 to 31 December 2014* [↑](#footnote-ref-83)
84. ACT Government Service Funding Agreement with HCCA, 2013-2016 [↑](#footnote-ref-84)
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86. Health Care Consumers’ Association *Report to ACT Health for the period 1 January 2016 to 30 June 2016* [↑](#footnote-ref-86)
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88. Health Care Consumers’ Association *Report to ACT Health for the period 1 January 2016 to 30 June 2016* [↑](#footnote-ref-88)
89. Health Care Consumers Association Executive Director, September 2016. [↑](#footnote-ref-89)
90. Consumer Representative to a UCPH User Group, September 2016 [↑](#footnote-ref-90)
91. Health Care Consumers’ Association *Report to ACT Health for the period 1 January 2013 to 30 June 2013* [↑](#footnote-ref-91)
92. Health Care Consumers’ Association *Report to ACT Health for the period 1 January 2013 to 30 June 2013* [↑](#footnote-ref-92)
93. HCCA HIP Consumer Coordinator, October 2016 [↑](#footnote-ref-93)
94. HCCA Executive Director, September 2016 [↑](#footnote-ref-94)
95. HCCA Executive Director, September 2016 [↑](#footnote-ref-95)
96. HCCA HIP Consumer Coordinator, October 2016 [↑](#footnote-ref-96)
97. HCCA President, October 2016 [↑](#footnote-ref-97)
98. Consumer Representative to Project Control Group, September 2016 [↑](#footnote-ref-98)
99. HCCA Executive Director, 2012, drawn from transcript of interview with Dr Anni Dugdale, University of Canberra, recorded as part of data collection for a study of HCCA’s impact on health policy in the ACT. [↑](#footnote-ref-99)
100. ACT Health, undated, *Summary Guide to CADP Governance Roles and Responsibilities, Capital Asset Development Program*; ACT Health April 2015, *Health Infrastructure Program Introduction and Overview Foundation Document Draft 0.2* [↑](#footnote-ref-100)
101. Consumer Representative to Redevelopment Committee, September 2016 [↑](#footnote-ref-101)
102. HCCA HIP Consumer Coordinator, October 2016 [↑](#footnote-ref-102)
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112. HCCA HIP Consumer Coordinator, October 2016 [↑](#footnote-ref-112)
113. Consumer representative involved in planning for UCPH [↑](#footnote-ref-113)
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119. Health Care Consumers Association, HIP Consumer Coordinator, September 2016 [↑](#footnote-ref-119)
120. Consumer representative involved in planning for UCPH, September 2016 [↑](#footnote-ref-120)
121. HCCA Executive Director Darlene Cox, 29/10/2014, letter to University of Canberra Vice Chancellor Professor Stephen Parker [↑](#footnote-ref-121)
122. Health Care Consumers Association Executive Director, September 2016 [↑](#footnote-ref-122)
123. Health Care Consumers Association, HIP Consumer Coordinator, September 2016 [↑](#footnote-ref-123)
124. Health Care Consumers Association Executive Director, September 2016. [↑](#footnote-ref-124)
125. Health Care Consumers Association HIP Consumer Coordinator, September 2016 [↑](#footnote-ref-125)
126. HCCA HIP Consumer Coordinator, October 2016 [↑](#footnote-ref-126)
127. HIP Consumer Coordinator, October 2016 [↑](#footnote-ref-127)
128. Australian Commission on Safety and Quality in Health Care 2011, *Patient-Centred Care: improving Quality and Safety Through Partnerships with Patients and Consumers,* p9 [↑](#footnote-ref-128)
129. Doggett, Jennifer, 2015, ‘*Unique and essential’: A review of the role of consumer representatives in health decision-making,* Consumers Health Forum of Australia, Canberra. [↑](#footnote-ref-129)
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