



# Still advocating for change: reflections of a consumer advocate

Darlene Cox  
Health Care Consumers' Association  
@darlenecox



"Never doubt that a small  
group of concerned citizens can  
**change the world.**

Indeed it's the only  
thing that ever has."

- Margaret Mead

# About the Health Care Consumers' Association

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
- research into consumer experience of human services.

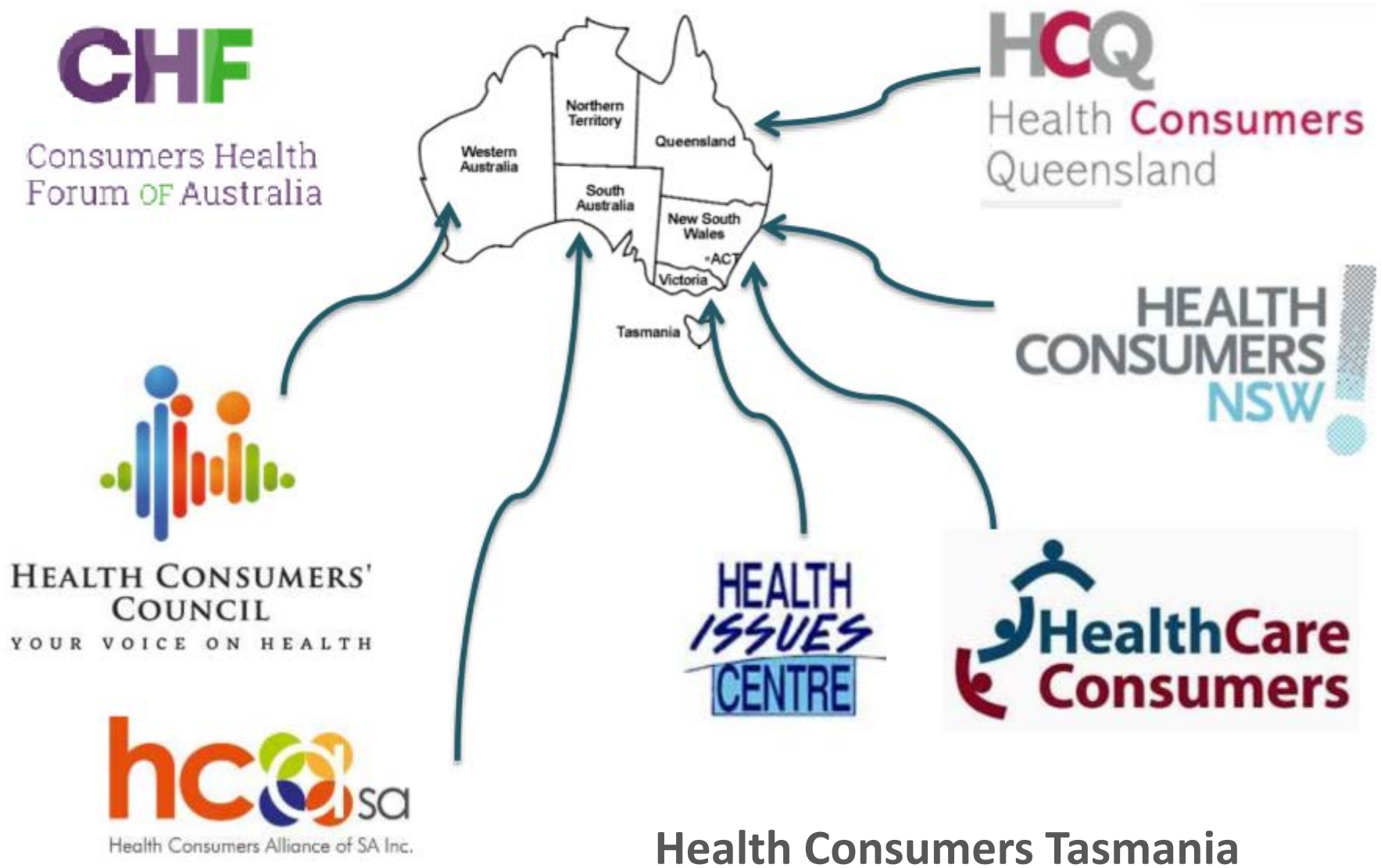
# Making a noise:

40 years of consumer health  
advocacy in the ACT

Robyn Clough

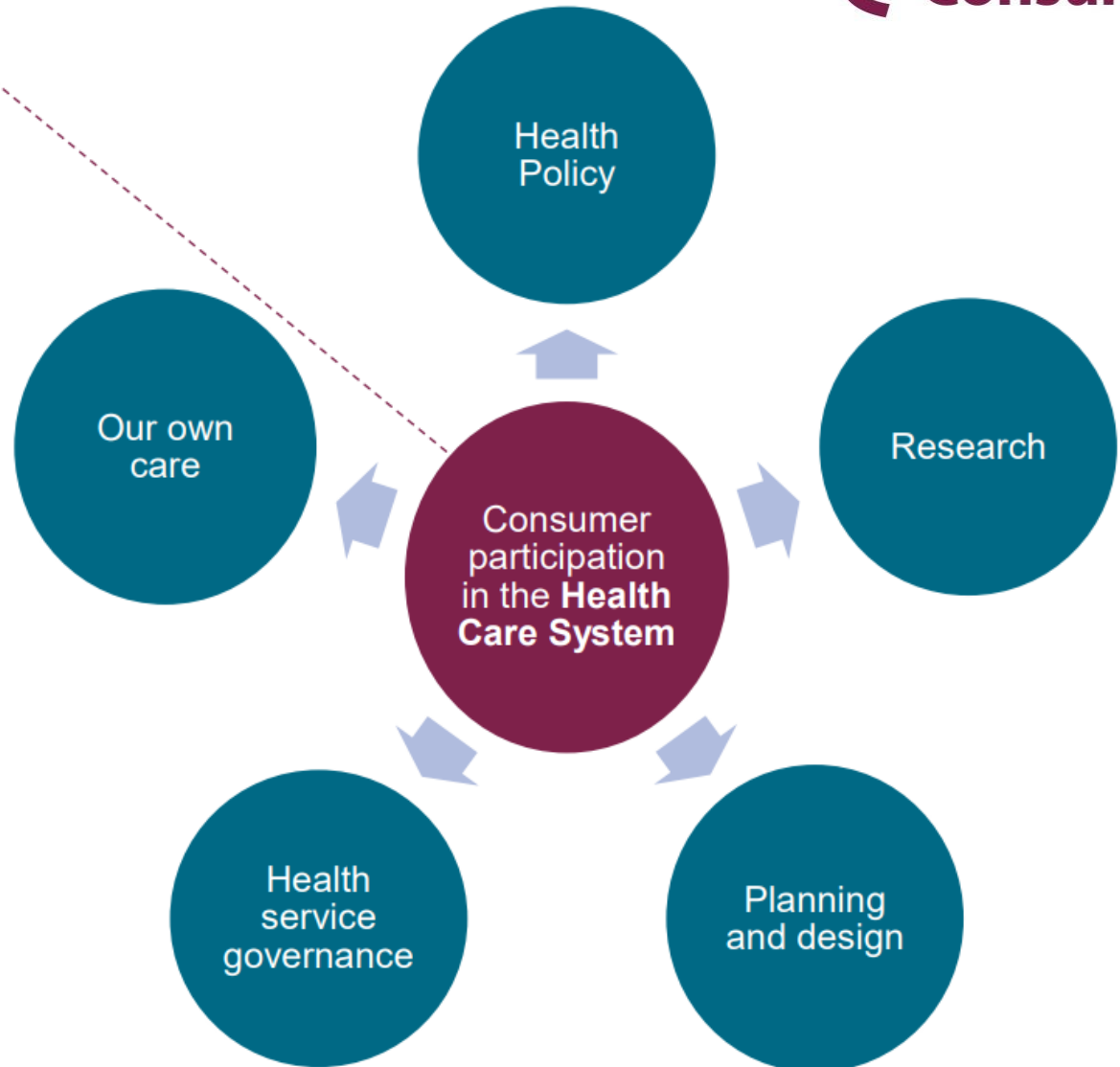
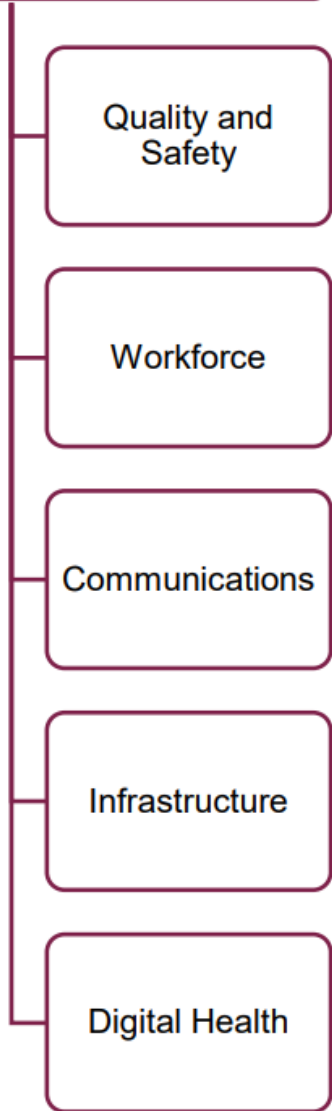


# Health Consumer Organisations in Australia





# Health Care System



# My healthcare rights

This is the second edition of the **Australian Charter of Healthcare Rights**.

These rights apply to all people in all places where health care is provided in Australia.

The Charter describes what you, or someone you care for, can expect when receiving health care.

## I have a right to:

### Access

- Healthcare services and treatment that meets my needs

### Safety

- Receive safe and high quality health care that meets national standards
- Be cared for in an environment that is safe and makes me feel safe

### Respect

- Be treated as an individual, and with dignity and respect
- Have my culture, identity, beliefs and choices recognised and respected

### Partnership

- Ask questions and be involved in open and honest communication
- Make decisions with my healthcare provider, to the extent that I choose and am able to
- Include the people that I want in planning and decision-making

### Information

- Clear information about my condition, the possible benefits and risks of different tests and treatments, so I can give my informed consent
- Receive information about services, waiting times and costs
- Be given assistance, when I need it, to help me to understand and use health information
- Access my health information
- Be told if something has gone wrong during my health care, how it happened, how it may affect me and what is being done to make care safe

### Privacy

- Have my personal privacy respected
- Have information about me and my health kept secure and confidential

### Give feedback

- Provide feedback or make a complaint without it affecting the way that I am treated
- Have my concerns addressed in a transparent and timely way
- Share my experience and participate to improve the quality of care and health services

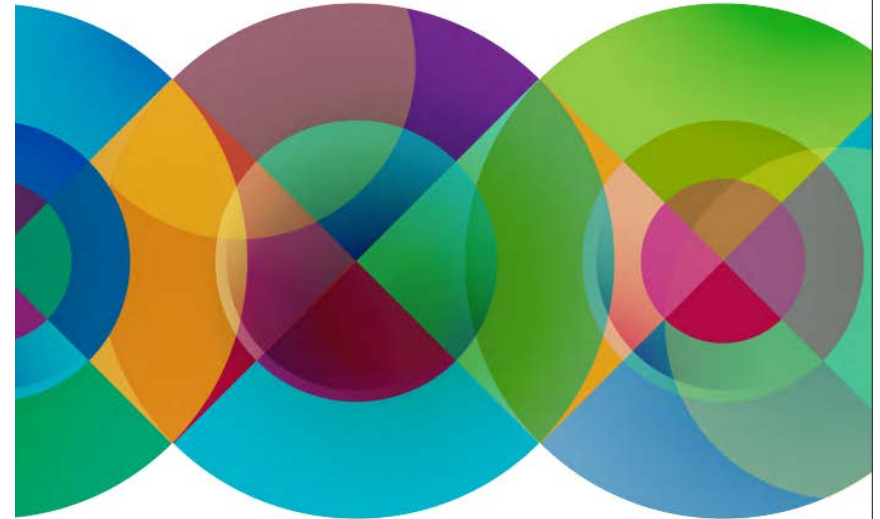


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AUSTRALIAN COMMISSION  
ON SAFETY AND QUALITY IN HEALTH CARE

For more information  
ask a member of staff or visit  
[safetyandquality.gov.au/your-rights](https://www.safetyandquality.gov.au/your-rights)

AUSTRALIAN COMMISSION  
ON SAFETY AND QUALITY IN HEALTH CARE



## National Safety and Quality Health Service Standards

Second edition



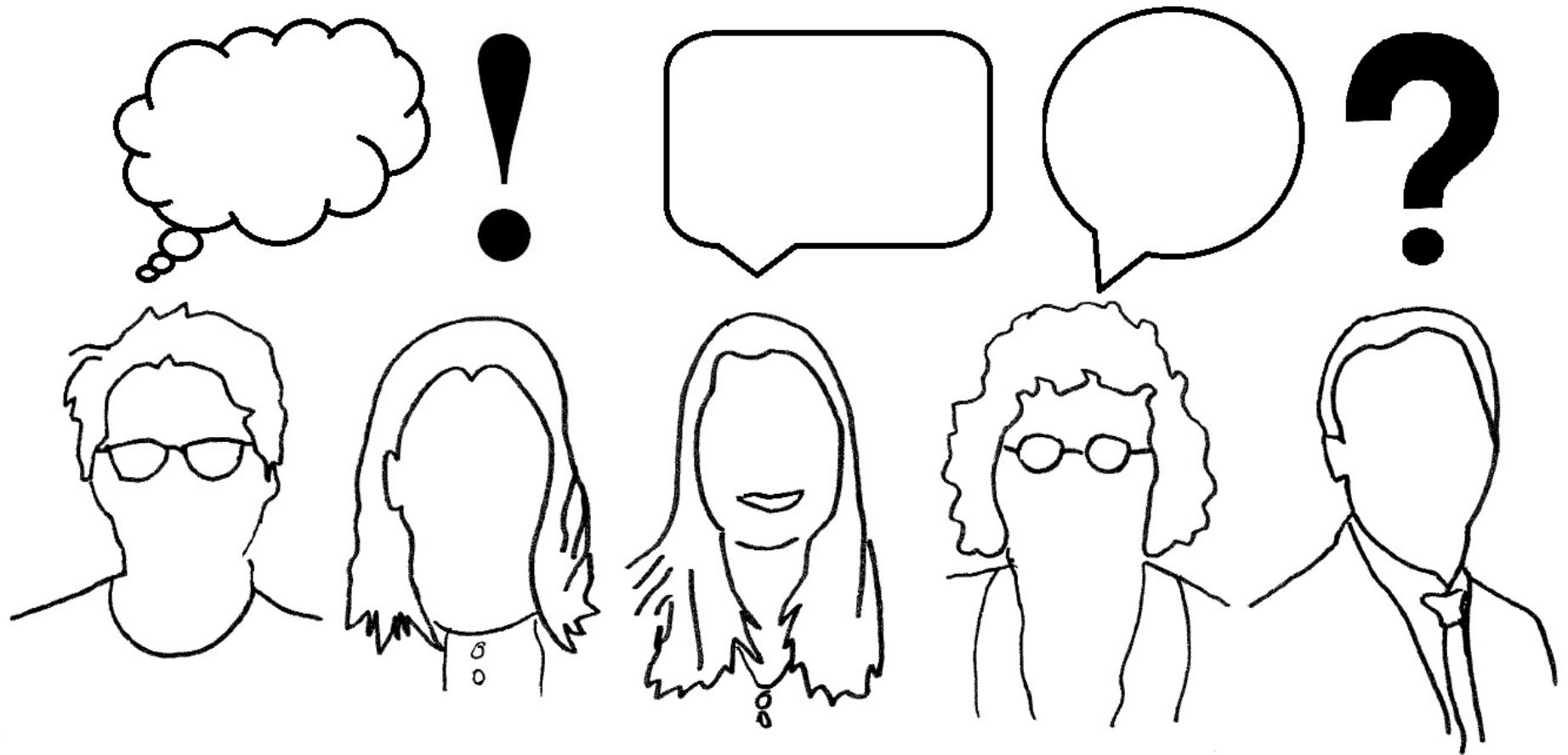
<https://www.safetyandquality.gov.au/>



# Involving Consumers in our own care



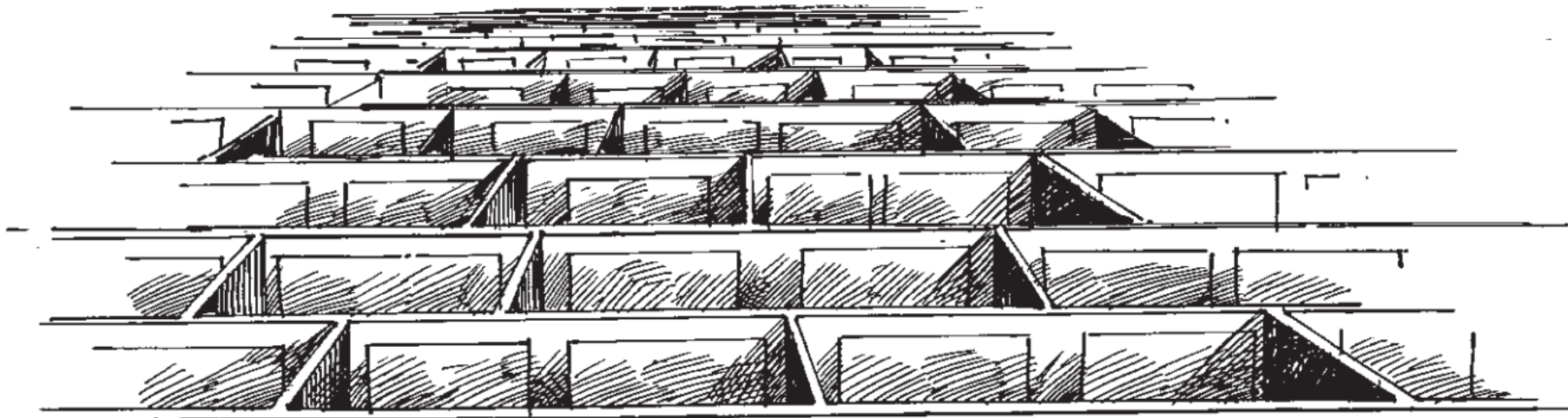
Does consumer feedback drive change in your health service?



Health literacy is the combined knowledge, skills, confidence and motivation used to make sound decisions about your health in the context of everyday life.

HCCA Health Literacy Position Statement

<https://www.hcca.org.au/wp-content/uploads/2018/09/Health-literacy-position-statement-FINAL.pdf>



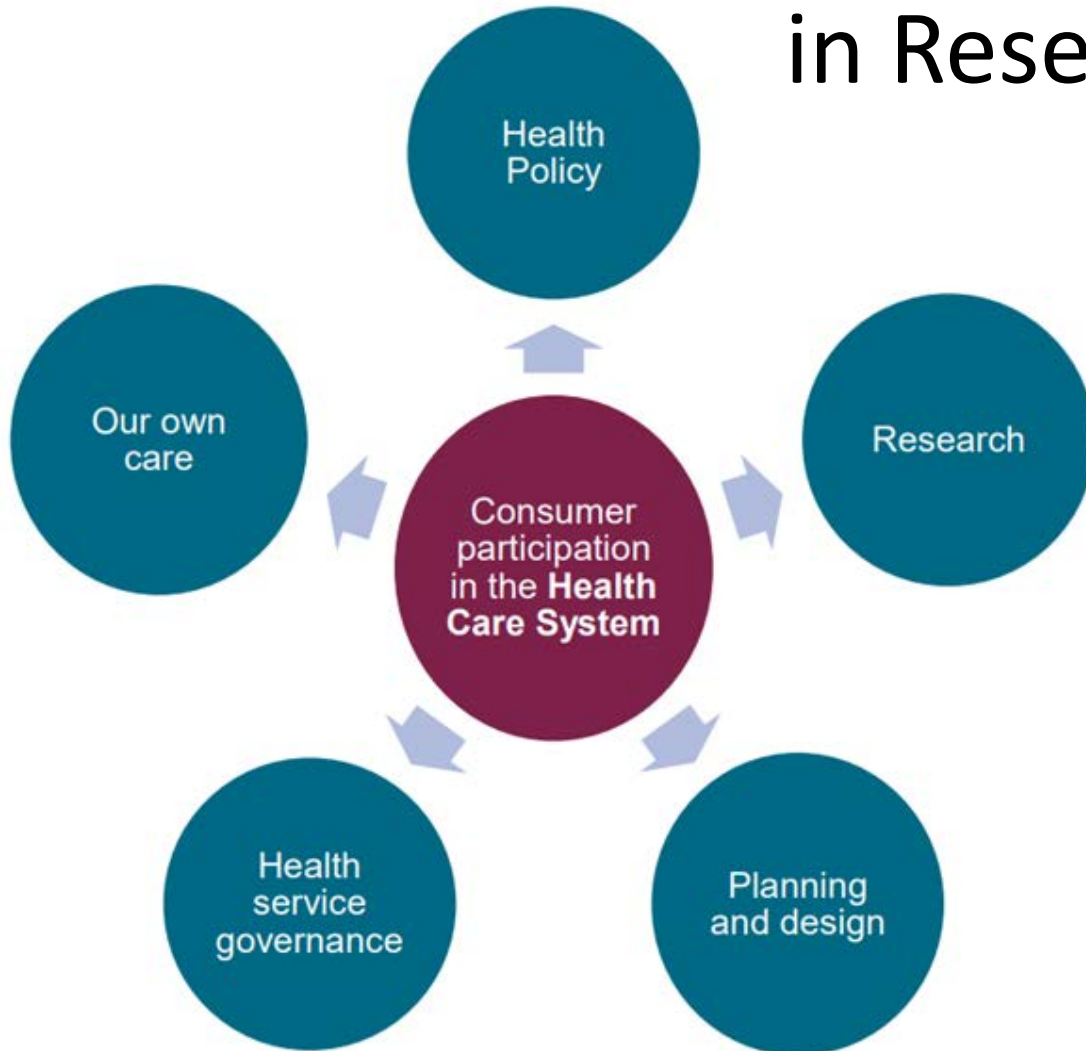
WELCOME  
TO THE  
SYSTEM.

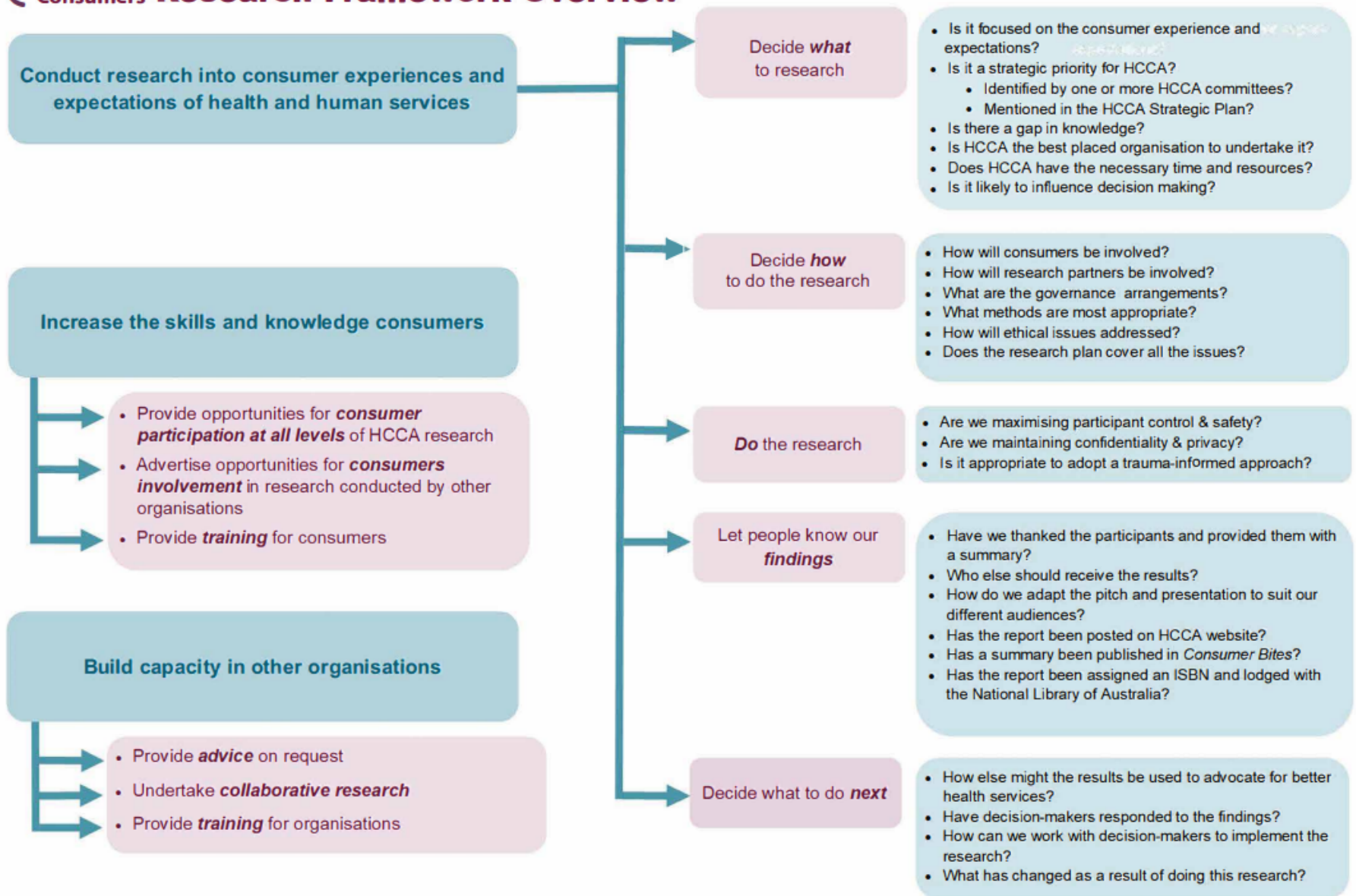
PLEASE ENTER  
THEN KNOCK.



*George*

# Involving Consumers in Research





# ACT Health and Wellbeing Partnership Board

**CHARM 2019**



**Trauma and  
Orthopaedic  
Research**



**Opportunities**



**Pre-Clinical Research  
Services**

**Research Ethics and  
Governance**



**IP and Contracts**

The ACT Health and Wellbeing Partnership Board is responsible for identifying shared priorities and setting the overall framework that will improve the health and wellbeing of the Canberra community and surrounding regions of NSW. This will be achieved by integrating and driving more collaborative relationships across education, research and health service sectors.

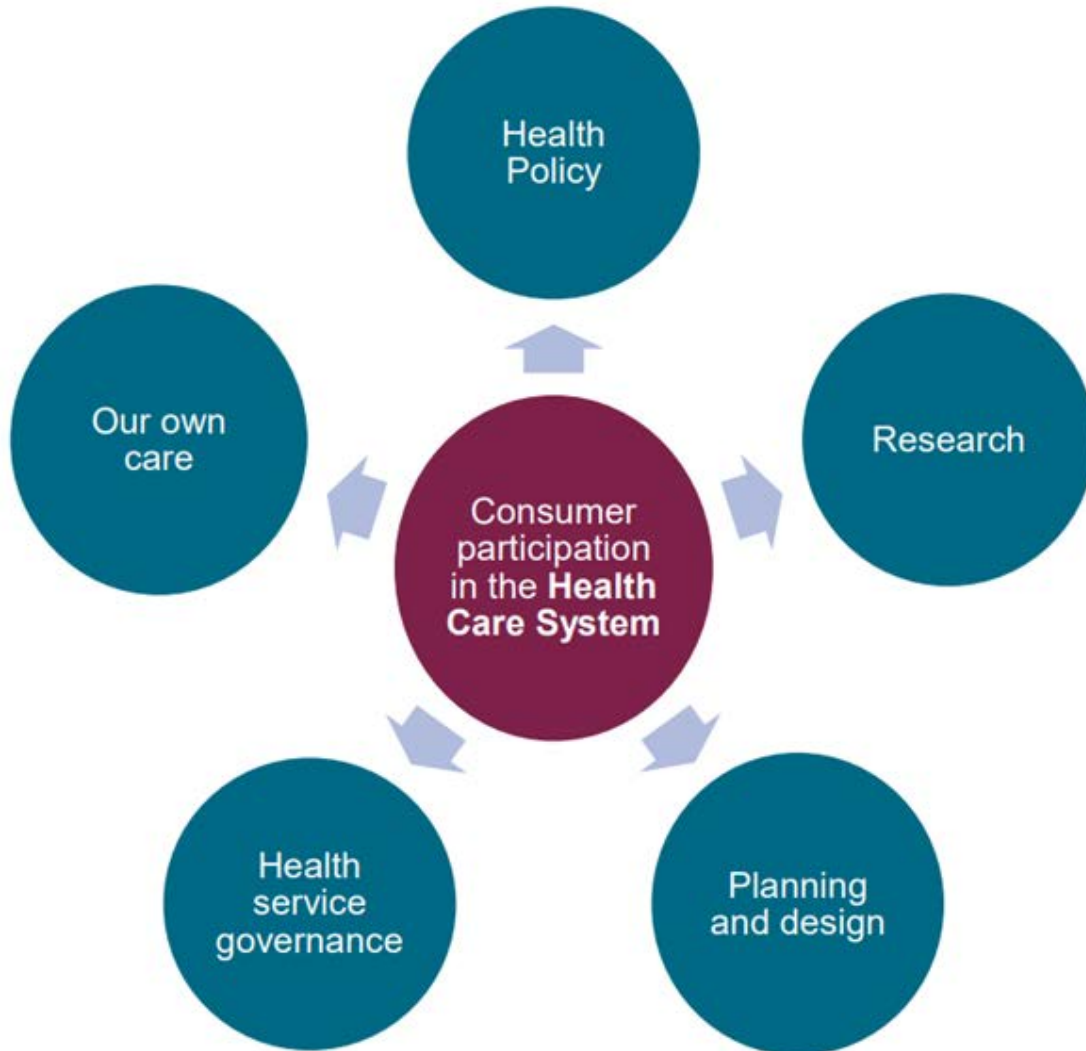
The ACT Health and Wellbeing Partnership Board was established as a key outcome from the [ACT Health Summit: Teaching Training and Research](#) held in November 2018. The Summit brought together local leaders and decision makers—in health, tertiary education and research—to agree on shared priorities that will improve the health of Canberra and drive a new vision for our health system.

The Partnership Board meets quarterly and reports to the Minister for Health and Wellbeing, Minister for Medical and Health Research, Vice-Chancellor, Australian National University and Vice-Chancellor, University of Canberra.

Membership includes:



# Planning and Design







*"Of course it's better if we're there":*

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

December 2016





University of Canberra Hospital

# The dark art of infrastructure projects

- Probity standards and commercial in confidence
- Procurement models
- Contract management
- Government budget cycles
- Design processes
- How to read floor plans



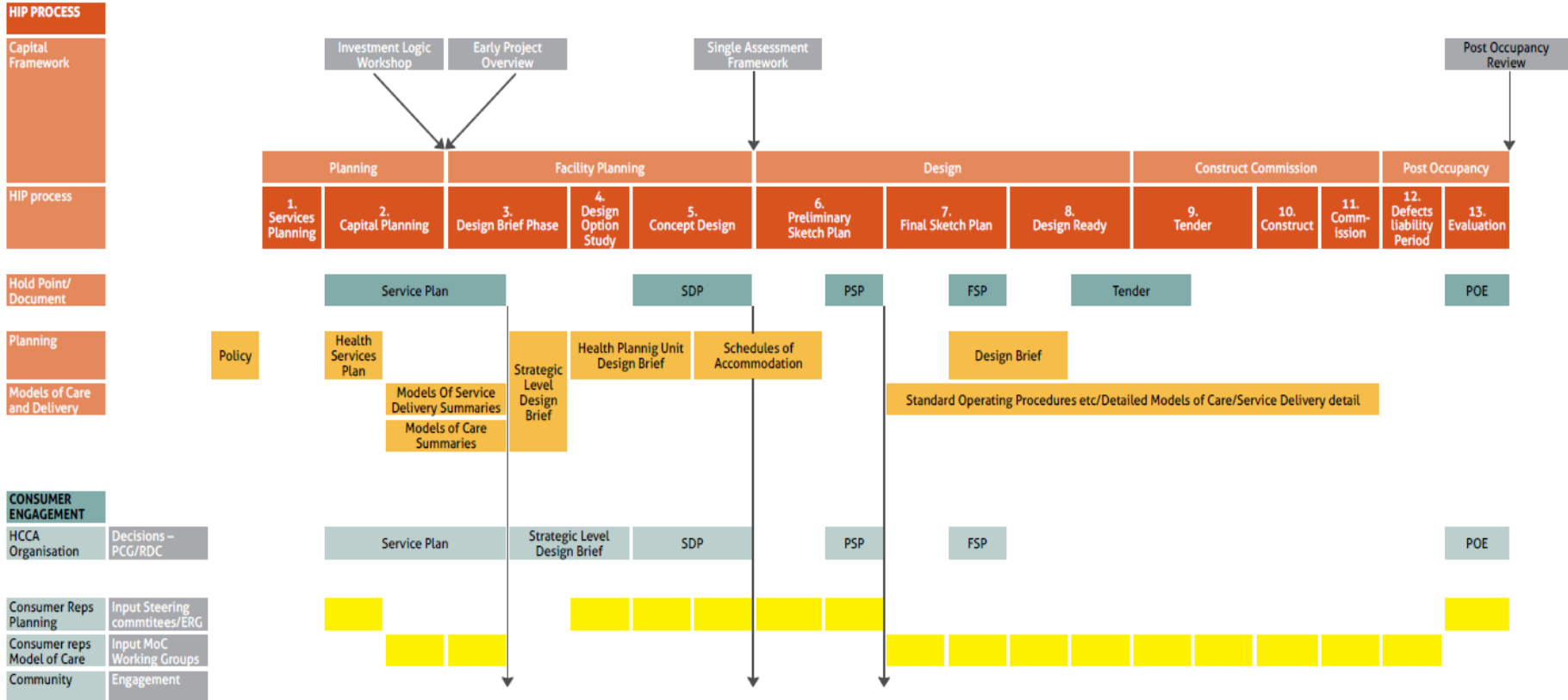
# Tips to Support Consumers to Participate

- Reimbursement us for our costs and recognise the time we contribute
- Provide adequate time to allow us to work through the papers
- Let us have a contact person we can contact to talk through issues
- Be mindful of your enthusiastic use of jargon
- Support us to network with other consumers involved



**HEALTH INFRASTRUCTURE PROGRAM**  
Investing in Canberra's health

Indicative Process Diagram



# Service Design

Hospitals and Health Centres

Services and Programs

Health Professionals

Businesses

Careers

Research

A

[Home](#) > [Services and Programs](#) > [Women, Youth and Children](#) > [Women's Health](#) > [Transvaginal Mesh](#)

## Transvaginal Mesh

On 30 November 2017, the Therapeutic Goods Administration removed a number of mesh products whose sole use is the treatment of pelvic organ prolapse via transvaginal implantation from the Australian Register of Therapeutic Goods. The TGA has established a Transvaginal (urogynaecological) surgical mesh hub webpage for consumers.

Women, Youth and  
Children



Newborn Care

There has been a great deal of interest and comment recently about the use of mesh as part of the surgical treatment of vaginal prolapse and urinary incontinence. A Senate Inquiry into the Number of women in Australia who have had transvaginal mesh implants and related matters was held and the report on its findings was released on 28 March 2018. ACT Health has incorporated the findings and recommendations of this report into our response.

TOP

# Service Evaluation – Obesity Management Service

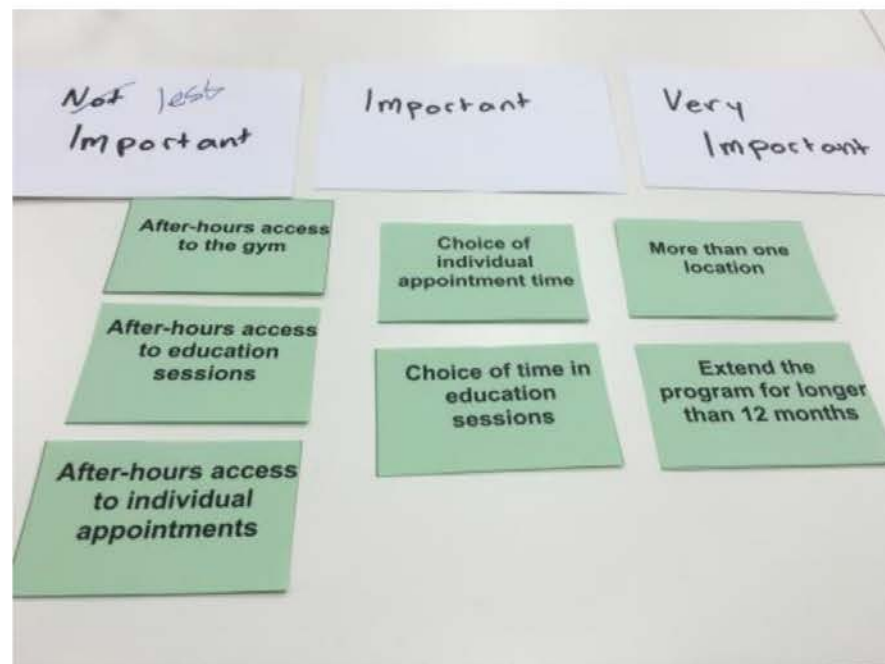
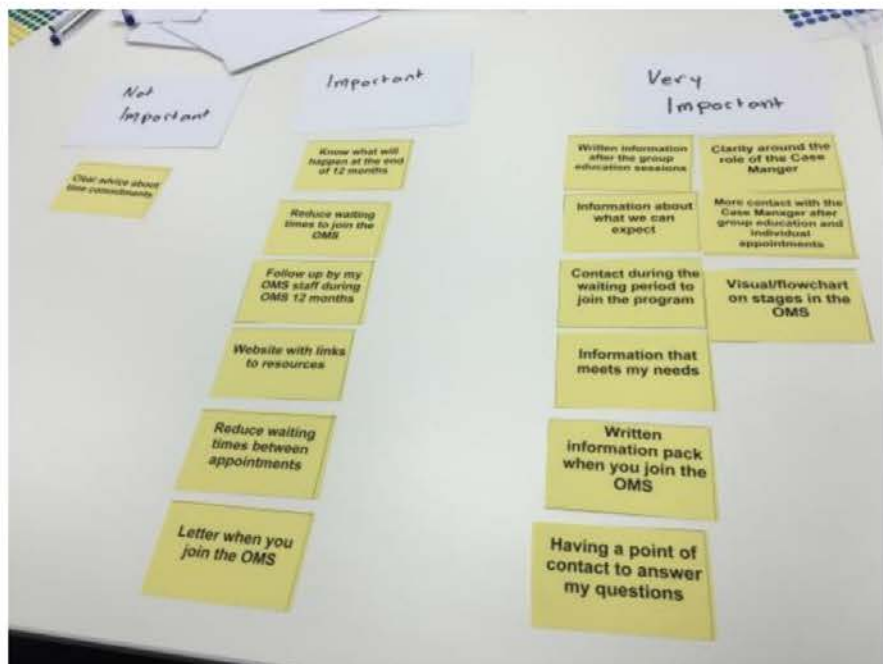


Figure 4 Card Sort Prioritisation Exercise Examples

# A MODEL for PATIENT NAVIGATION in the ACT



## objective

REMOVE BARRIERS THAT PREVENT a SMOOTH TRANSITION BETWEEN HOSPITAL and the COMMUNITY for PEOPLE with CHRONIC CONDITIONS



## key principles



ADVOCACY



LINKAGE



EDUCATION



HEALTH SYSTEM IMPROVEMENT

## criteria



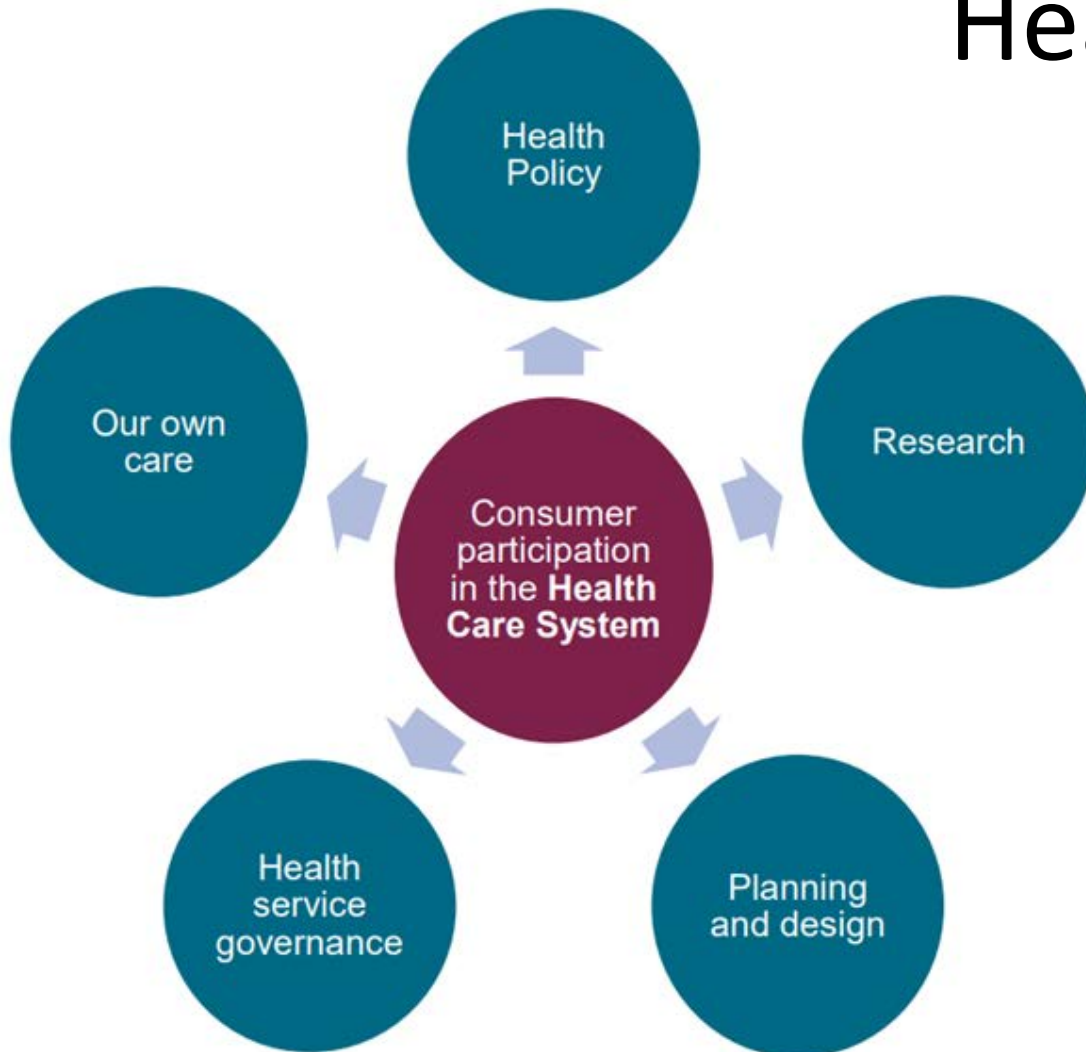
## outcome

IMPROVE QUALITY of LIFE for CONSUMERS and PARTNER with THEM to ACHIEVE the BEST HEALTH & WELLBEING POSSIBLE





# Health Policy



## Policy Response Development Process

### Consulting consumers

- ◆ Approach consumers and members with relevant knowledge and experience individually for in depth comment ASAP by phone or email, providing due dates for responses.
- ◆ Send out a general request for consumer input (e.g. Consumer Bites, e-mail). Include consultation document as an attachment if not too large, otherwise include link.
- ◆ Contact relevant stakeholder organisations for comment. Consider how HCCA can support their key points if they are also making a policy response.
- ◆ For *strategically significant and major policy responses*
  - ◇ contact the Health Policy Advisory Committee for early input and guidance
  - ◇ attend consultation forums to collect perspectives and raise issues early, where offered.
- ◆ Develop, test and analyse survey, if appropriate.

### Researching the topic

- ◆ If clarification is needed, contact the organisation taking submissions ASAP and ask for additional information or supporting documents.
- ◆ Compare with interstate or overseas equivalent policies/ programs
- ◆ Review relevant qualitative, patient experience research.
- ◆ See past work by HCCA on relevant issues on the shared drive.
- ◆ Review analysis of previous surveys as appropriate.

\* HCCA Position Statements follow the same process but are endorsed by the Executive Committee.

### Developing the policy

- ◆ Use policy response templates in *Policy Submissions* folder.
- ◆ Ensure the policy response is aligned with HCCA's overarching policies and positions.
- ◆ Most policy responses can be framed around the Australian Charter of Healthcare Rights.
- ◆ Ensure consumer confidentiality is protected.
- ◆ Reference supporting evidence consistently using agreed HCCA style.
- ◆ Reference all quotes consistently using agreed HCCA style.
- ◆ Do not identify individual service providers in responses.
- ◆ Resolve any conflicting consumer feedback with ED.
- ◆ Verify any specific accusations or claims made by consumers before including in policy response.
- ◆ List key issues in an Executive Summary.

**Note:** The focus of HCCA policy responses is always to present experiential knowledge and a consumer perspective. For this reason, we rely primarily on case studies and consumer stories. While quantitative research can be useful to strengthen our argument, this is not our focus.

### Reviewing and clearing the policy \*

- ◆ Send to the ED for initial comments
- ◆ Provide drafts of strategically significant and major policy responses to the Health Policy Advisory Committee, where possible.
- ◆ Clear response with contributing members of HCCA.
- ◆ Make necessary amendments and clear final version with ED

### Sending the policy

- ◆ Submit as a PDF attachment in an email addressed to the head of the agency seeking input, unless otherwise indicated.
- ◆ Upload PDF to HCCA's website under Submissions, unless confidential.
- ◆ Archive submission card on Trello.
- ◆ Circulate final copy to those who contributed via e-mail, social media and Consumer Bites.
- ◆ Create advocacy brief, if needed.



JOIN NOW

# CONSUMER REFERENCE GROUPS

## IN THIS SECTION

- Policy Work
- Policy Submissions
- Research
- Research Reports
- Consumer Reference Groups**
  - Health of Older People Consumer Reference Group
  - Quality and Safety Consumer Reference Group
  - Accessibility and Design

### Consumer Reference Groups

- inform HCCA's position on health policy and
- identify issues of importance to consumers.

The goal is for the consumer voice to shape the health services we use. These groups also help ensure that future health strategies and policies are, in fact, consumer driven.

Currently there are five active Consumer Reference Groups in the areas of

- [eHealth](#)
- [Health of Older People](#)
- [Quality and Safety](#)
- [Access & Design](#)
- [Maternity Services](#)

The Consumer Reference Groups bring together

- members,

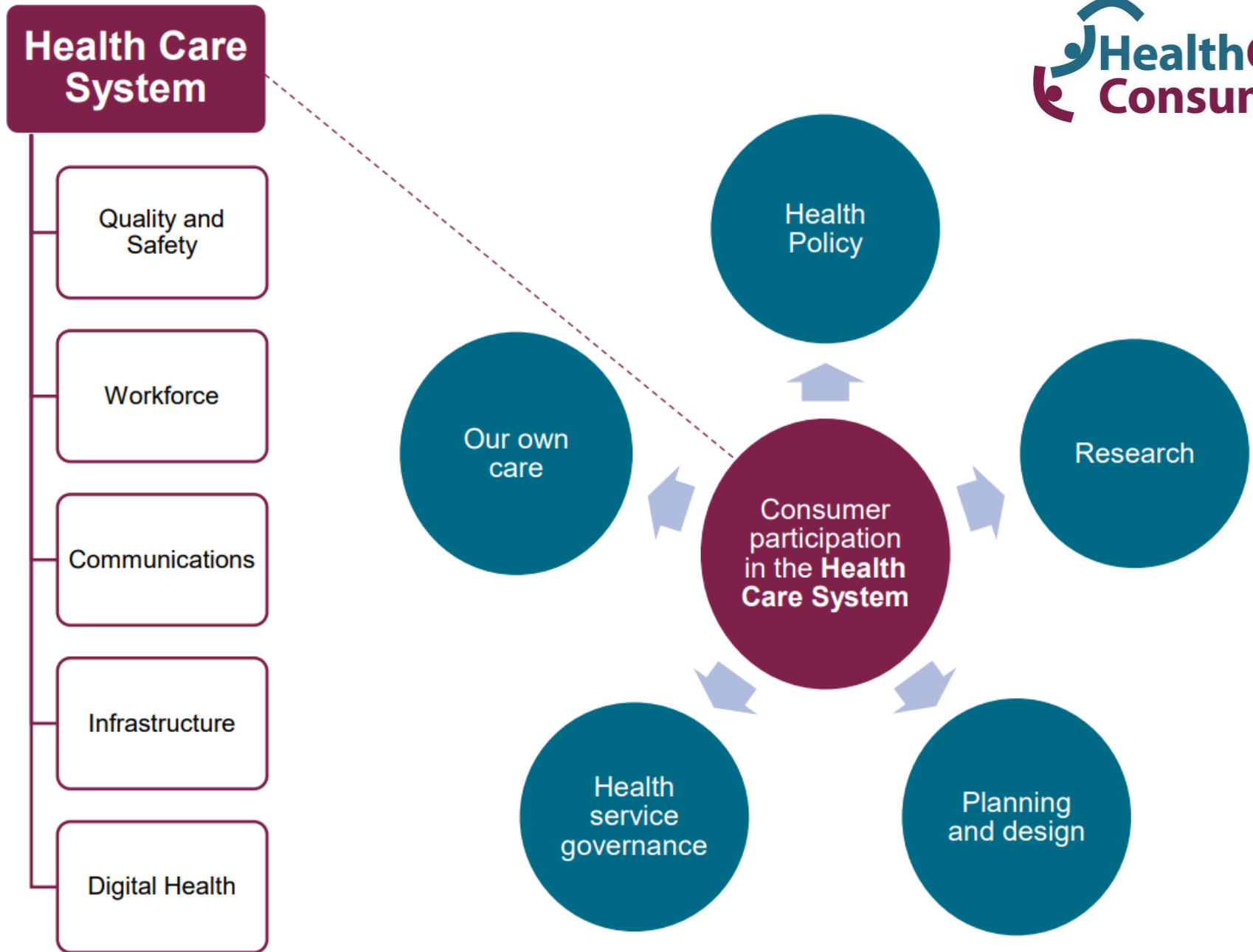
# Health Service Governance



“Health Care Consumers’ Association here 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”

Katy Gallagher, Health Minister 2012

- Canberra Health Services Executive Committee
- Culture Review Oversight Group
- Clinical Leadership Forum
- Quality and Safety Committees
- Clinical Council
- Clinical Governance Committee
- Health and Wellbeing Partnership Board
- Primary Health Network Board
- Technology Strategy Group
- Digital Health Program Board
- Medical School Review Task Force
- NGO Leadership Forum



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