



# HEALTH CONSUMERS' COUNCIL

## Introduction to consumer partnership and engagement

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HEALTH CONSUMERS' COUNCIL WA  
JUNE 2021



# Acknowledgement of Country



Source: Snapshots by Narelle Henry

We acknowledge that we are meeting on the traditional country of the Whadjuk people of the Noongar Nation and pay respect to Elders past, present and into the future. We acknowledge that they have occupied and cared for this country over countless generations and we celebrate their continuing contribution to the life of this region.



# Questions to consider:

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- What do we mean by partnership and engagement?
- What are the requirements for successful partnership and engagement?
- Who is involved in the partnership?
- In what context are the partnerships happening?

## Key messages

- Partnering with consumers will add value – the earlier the better
- Be prepared to be challenged and make changes – if not, why partner?
- Think diversity – what perspectives are not at the table? How can you hear them?
- Allow time and allocate resources
- Build capacity for partnership
- There are lots of options
  - Try different approaches
  - Reach out for help



# What I'll cover

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- Introduction to Health Consumers' Council
- Why engage or partner with consumers?
- Who do we mean when we say consumers?
- What do we mean when we say engagement and partnership?
- Different types of engagement and partnership
- Engaging with people from groups that experience health inequities
- What consumer engagement and partnership mechanisms exist across the system?
- What are some possible opportunities?
- What support exists to help you partner and engage?

## Key messages

- Involving consumers will add value – the earlier the better
- Be prepared to be challenged – if not, don't ask
- Think diversity – what perspectives are not at the table?
- Allow time
- Allocate resources
- There are lots of options – you can reach out for help



HEALTH CONSUMERS'  
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# About Health Consumers' Council

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## Our Purpose

To increase the capacity of all people to influence the future direction of health care and to make informed choices

## Our Vision

Equitable, person-centred healthcare for all West Australians



Individual Advocacy



Engagement



Systemic Advocacy

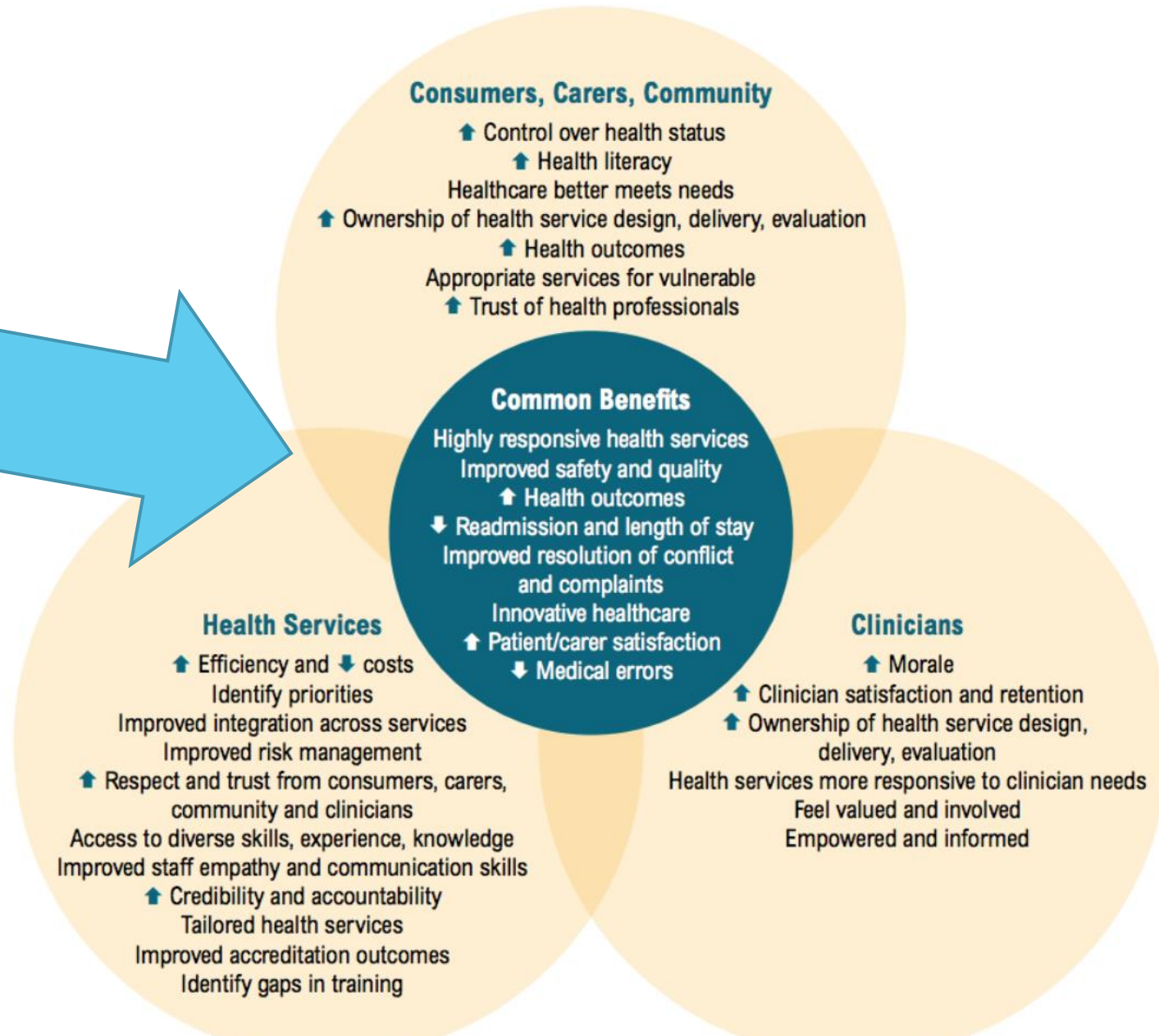
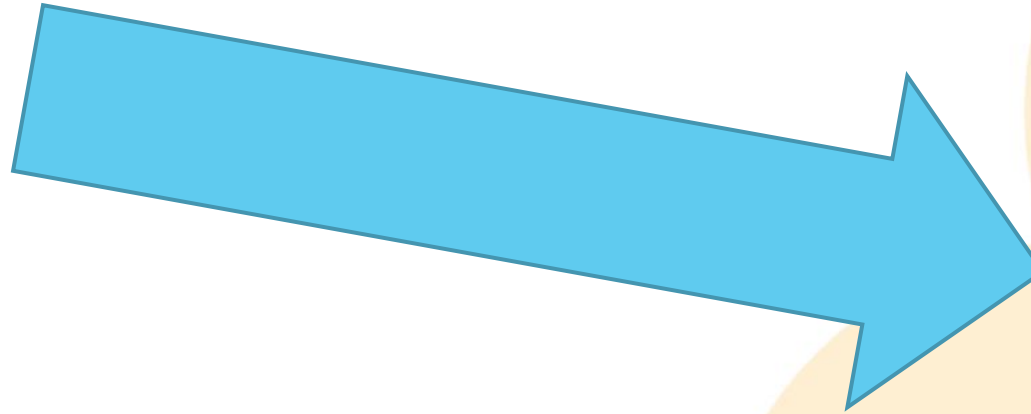




Figure 1. Benefits of engagement

# Why engage?

# Why wouldn't you?



“You Matter” Guideline, WA Health



# Why engage?

## Accreditation – Standard 2: Partnering with Consumers

“The Partnering with Consumers Standard aims to create health service organisations in which there are mutually beneficial outcomes by having:

- consumers as partners in
  - planning
  - design
  - delivery
  - measurement and
  - evaluation
  - of systems and services



2. Partnering with Consumers

- patients as partners in their own care, to the extent that they choose.”

<https://nationalstandards.safetyandquality.gov.au/2.-partnering-consumers>

## Sustainable Health Review – Rec 4:

“Commit to new approaches to support citizen and community partnership in the design, delivery and evaluation of sustainable health and social care services and reported outcomes.

Priorities in implementation include:

- Expansion of Care Opinion and real-time consumer feedback mechanisms;
- Transparent public reporting of patient and carer reported experience and outcomes (PREMs and PROMs)
- Consumer and carer voices embedded into health system governance structures and make consumer/carer/clinician partnerships and co-designed projects a normal part of business
- Engagement and support for carers embedded...”

<https://ww2.health.wa.gov.au/Improving-WA-Health/Sustainable-health-review/Final-report>



“Designing or planning health services without involving consumers is like throwing someone a birthday party and not inviting them...”





# What do we mean by partnership and engagement?

<https://www.mhc.wa.gov.au/about-us/consumer-family-and-carer-participation/statewide-engagement-framework-and-toolkit/>

# Consumers, carers, family, community

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- **Consumers:** Consumers can be defined as people who are potential, current or previous user of health services.
- **Carers:** A carer is a person who provides ongoing unpaid care and support to family members and friends who have a disability, a mental illness, chronic condition, terminal illness or are frail.
- **Family:** Members of a family who may, or may not, be in a formal caring role.
- **Community:** A community is a group of people who share something in common, such as a location, interests, culture, language, beliefs, values or traditions.



*Adapted from the You Matter Guideline, WA Dept of Health*

<https://ww2.health.wa.gov.au/~media/Files/Corporate/general%20documents/health%20improvement/PDF/You-Matter-Guideline.pdf>

# What perspective?

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- **Lived experience** – people with personal experience, as a consumer, or as a family member or carer, of a particular condition or situation
- **People with experience of advocating for themselves and others** – with a particular condition or health experience
- **Consumer advocates** – people with experience and knowledge of the health system and its complexities – who advocate for a consumer perspective – may not necessarily have a lived experience of the particular issue or health condition – but bring a consumer lens





# Who is involved?

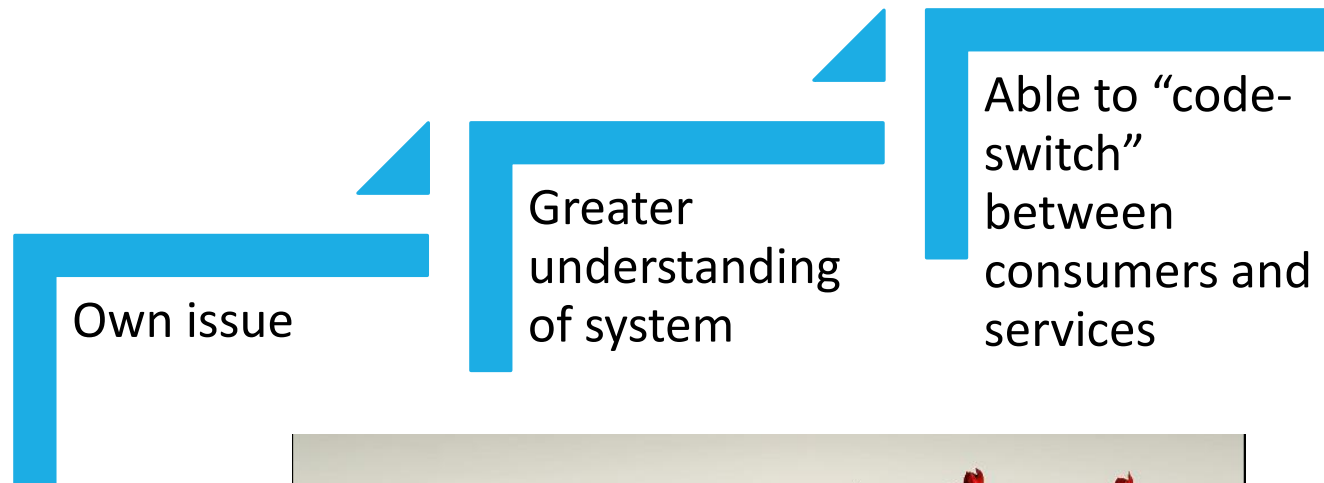
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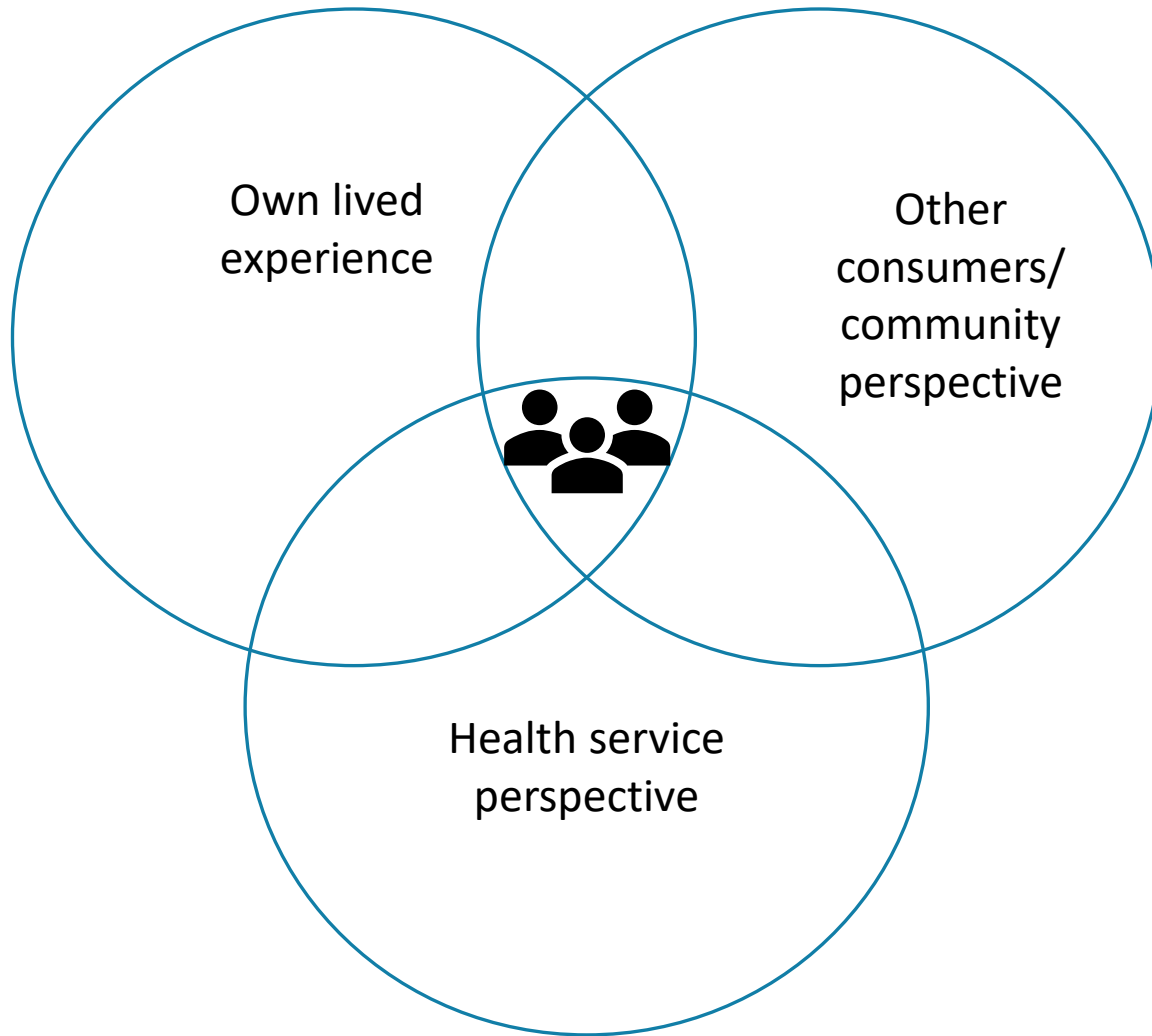


## Evolution of a consumer representative:

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# Code switching

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“Effective consumer representatives advocate on behalf of a range of health consumers” ...

...(not just themselves)

Code-switching between:

- Lived experience perspective
  - own
  - others
- Health system perspective



# Evolution of consumer partnership:

Where do you see yourself?

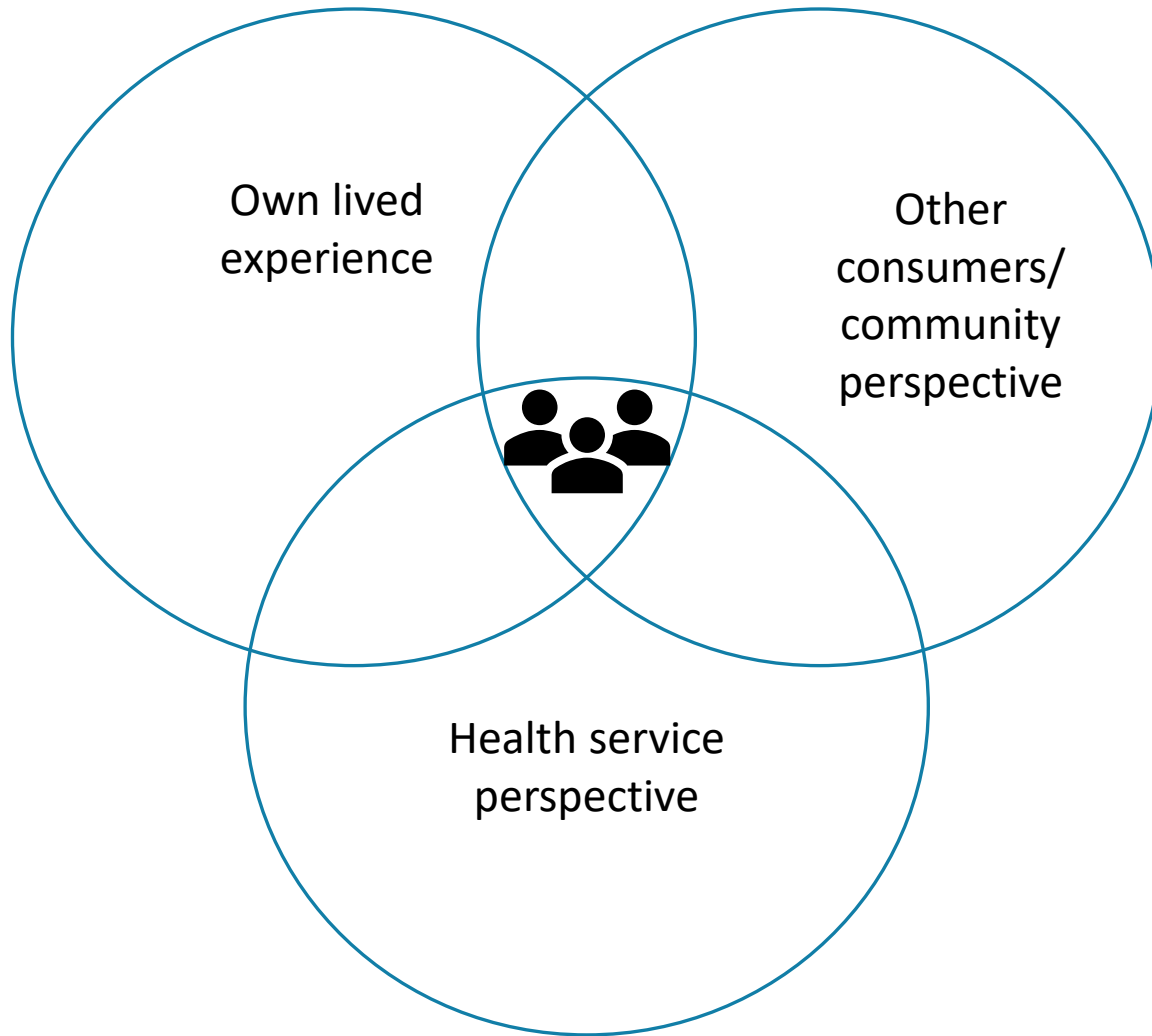
Know we need to –  
not sure who to  
approach or how

Inviting feedback  
on services –  
surveys etc

Seeking input to  
inform service  
development –  
earlier, wider and  
deliberative

Active involvement  
in strategy  
development - with  
ways to hear from  
diverse groups





# Code switching

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“Effective consumer representatives advocate on behalf of a range of health consumers” ...

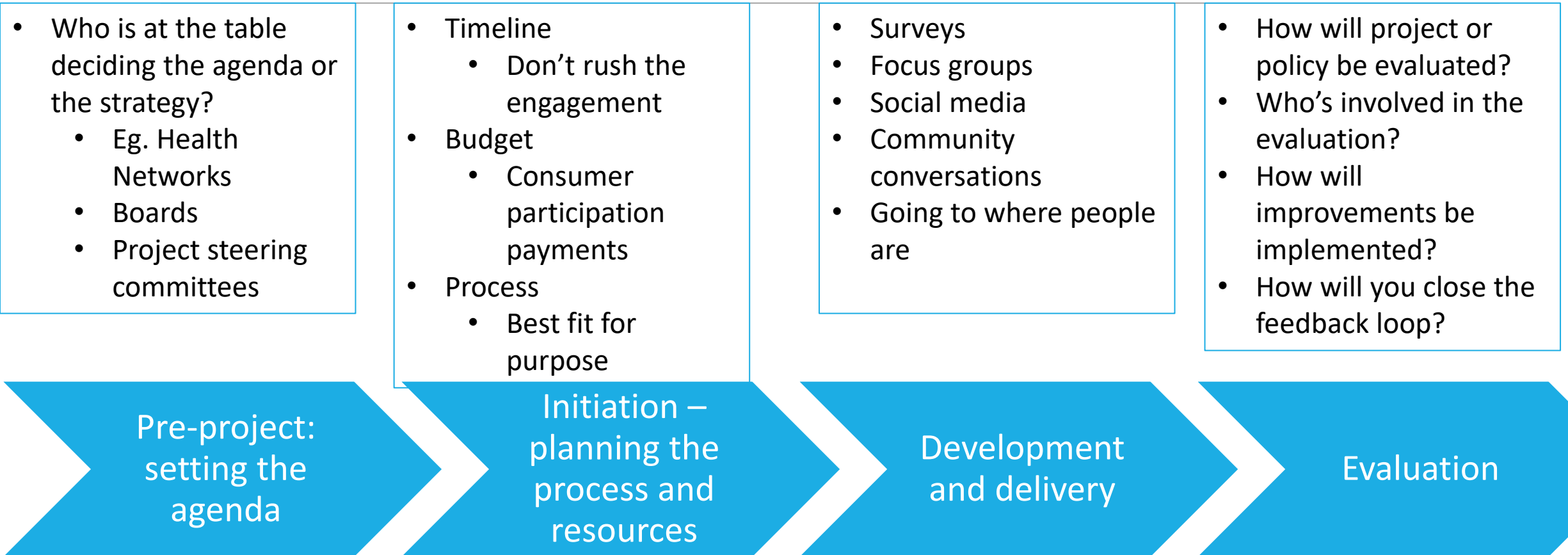
...(not just themselves)

Code-switching between:

- Lived experience perspective
  - own
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- Health system perspective



# When to engage?



# Where is the partnership happening?

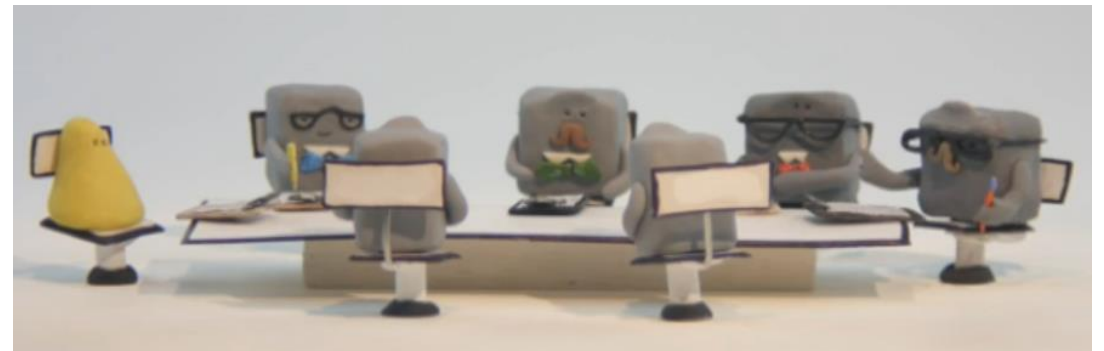
	Individual	Service	Site	System
It could look like:	<ul style="list-style-type: none"> <li>• Choosing Wisely</li> <li>• Question Builder</li> <li>• Time for a real discussion</li> <li>• Teach-back</li> <li>• Calm, compassionate, comfortable</li> <li>• <a href="#">Care that fits</a></li> <li>• <a href="#">MyLife MyHealthcare</a></li> </ul>	<ul style="list-style-type: none"> <li>• Value-based outcome data on public display – quadruple aim</li> <li>• Consumers involved in training</li> <li>• Consumers in the QI team</li> </ul>	<ul style="list-style-type: none"> <li>• Consumer Advisory Councils reviewing S&amp;Q data</li> <li>• Care Opinion acted on</li> <li>• “Data” includes consumer stories as well as numbers</li> </ul>	<ul style="list-style-type: none"> <li>• Health Networks</li> <li>• Boards</li> <li>• Input to pricing, performance and improvement mechanisms</li> </ul>
Considerations:	<ul style="list-style-type: none"> <li>• Trust, whole person approach, humanity</li> <li>• Balancing access, cost, acuity, speed</li> </ul>	<ul style="list-style-type: none"> <li>• Quality, performance – how do consumers know?</li> <li>• Equity</li> </ul>	<ul style="list-style-type: none"> <li>• Organisational culture</li> <li>• “Critical friend”</li> </ul>	<ul style="list-style-type: none"> <li>• Diverse perspectives sought</li> </ul>





# Planning for successful partnerships

- Prepare for change – individually and organisationally
- Be honest about what's on the table – but don't dampen aspirations
- Consider the perspectives of the people you want to hear from: other commitments, their health, make it easy
- Go to where people are – in person and online
- Ensure participants are well supported
  - Context and jargon
  - Fed and watered
  - Consumer payments – and covering costs
- Make extra effort to reach those groups who may not engage with traditional approaches – **this will take time** so plan it in from outset
  - Work with existing groups with existing relationships
- Use a range of ways – face to face, online, deliberative, kitchen table discussions – not just the lone consumer on a committee
- Wherever possible, build relationships and capacity



# What are the ingredients of successful consumer partnerships?

- Partners are able and willing to **invest time** in the relationship
- There are **shared expectations** and a clear purpose
- Partners **respect** each other's perspectives, contributions and situations
  - Consumer participation payments
  - Go to where consumers are – not just inviting people in
  - How can it be made **easy for consumers to be involved?**
- **Differences of opinion** are expected and even encouraged
- There's an **exchange** between partners
- There's an openness to, and an **expectation of change**
  - For the individual
  - For the organisation



# What contributes to effective consumer partnership?

## Consumer

- Willingness and ability to build positive relationships
- Being clear about expectations
- Resilience and self awareness
- A support network
- Willingness and confidence to speak up
- Ability to commit time
- Ability to use own and others' experience to provide insights – big and small pictures
- Ability to balance emotion and “professional” responses
- An understanding of the constraints of the system – and an ability to rock the boat while staying in it

## Health service

- Willingness and ability to build positive relationships
- Being clear about expectations and purpose
- An openness to hearing and acting on consumer input
- A plan for how feedback will be used – and to close the loop
- Awareness of the needs of the consumer rep
- Understanding that consumer reps don't represent all consumers
- Time and willingness to brief and train the consumer rep if required
- An understanding of the different types of consumer input that may be required
- Time and support
- Financial resources - consumer participation payments





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*“The success of an intervention depends on the interior condition of the intervenor”*

*Bill O'Brien, former CEO of Hanover Insurance*

[https://www.ottoscharmer.com/sites/default/files/2003\\_TheBlindSpot.pdf](https://www.ottoscharmer.com/sites/default/files/2003_TheBlindSpot.pdf)



# How to engage?

- Use a range of ways – face to face, online, deliberative
- Consider the people you want to hear from perspectives – other commitments, their health, make it easy
- Go to where people are – in person and online
- Ensure participants are well supported
  - Context
  - Jargon
  - Fed and watered
- Make extra effort to reach those groups who may not engage with traditional approaches – this will take time so plan it in from outset
  - Work with existing groups
- Be honest about what's on the table for discussion
- Wherever possible, build relationships

## A note of caution about co-design...

*“Co-design is what happens behind the curtain”  
(Kelly Ann McKercher)*

It's a specific process, and it's a mindset.

Many things will benefit from co-design but the internal conditions need to be ready:

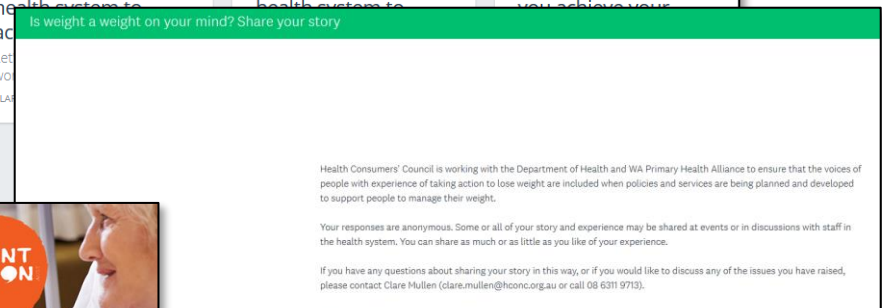
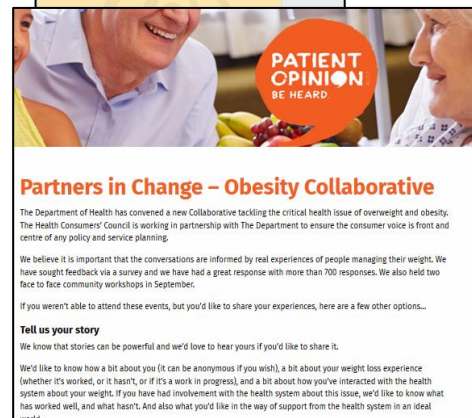
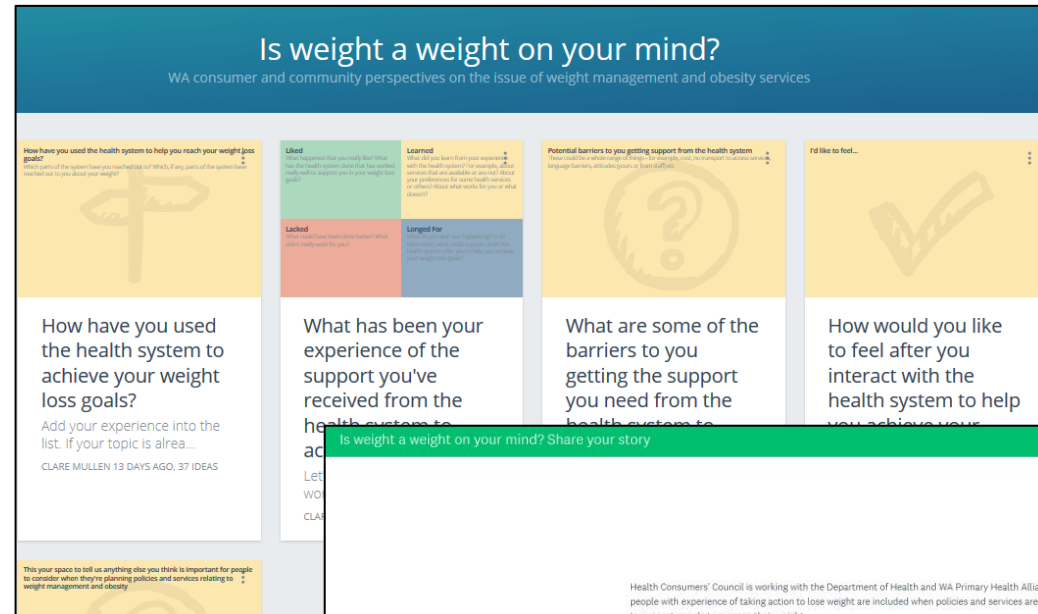
- Share power
- Prioritise relationships
- Use participatory means
- Build capability to participate

Just involving people early is not co-design.



# Partners in change – Healthy Weight Action Plan

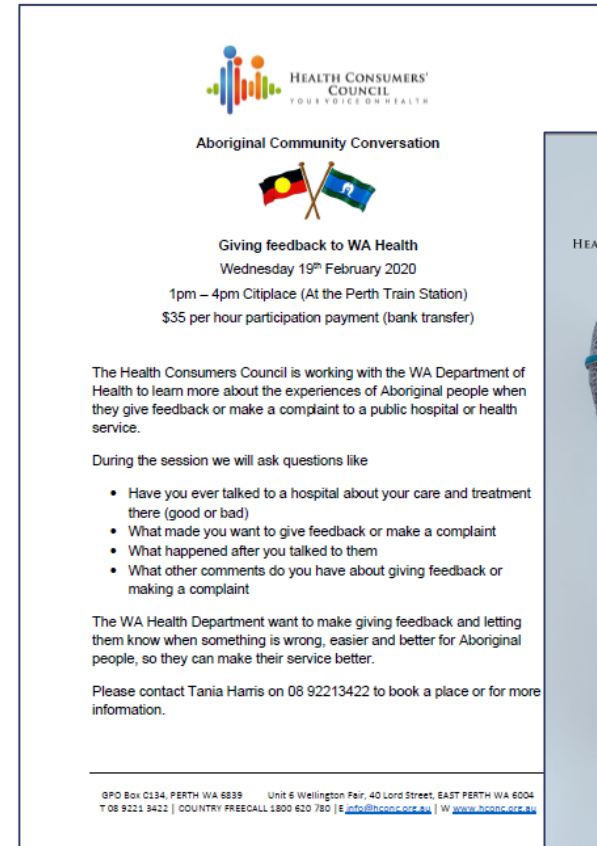
- An online survey – 750 responses
- Mailing list with approx. 270 members
- Consumer focus groups – open invitation and with community groups
- People invited to share their stories
- Online group brainstorm process
- Community Advisory Group
- Facebook group (about 110 members)
- In first wave, had approximately 800 responses across all methods
- Re-engaging at various points – feeding back to people
- Funded – staff time allocated
- HCC involved in governance structures to provide consumer perspective






# Datix consumer feedback - DoH

- Approached by Patient Safety Surveillance Unit to run 2 workshops
- Requested advice on how to reach particular groups
- HCC advised on targeting Aboriginal people and consumers of mental health services
- Connected the team with Consumers of Mental Health WA
- Ran 4 workshops in total, and did telephone interviews with some Aboriginal people in the regions
- Feedback available on DoH intranet at <https://doh-healthpoint.hdwa.health.wa.gov.au/directory/Clinical%20Services%20and%20Research/Patient%20Safety%20Clinical%20Quality/PSSU/Documents/Consumer/Datix-CFM-Review-HCC-Consumer-feedback-consultation-sessions-summary.pdf>



HEALTH CONSUMERS' COUNCIL  
YOUR VOICE ON HEALTH

Aboriginal Community Conversation



Giving feedback to WA Health  
Wednesday 19<sup>th</sup> February 2020  
1pm – 4pm Citiplace (At the Perth Train Station)  
\$35 per hour participation payment (bank transfer)

The Health Consumers Council is working with the WA Department of Health to learn more about the experiences of Aboriginal people when they give feedback or make a complaint to a public hospital or health service.

During the session we will ask questions like

- Have you ever talked to a hospital about your care and treatment there (good or bad)
- What made you want to give feedback or make a complaint
- What happened after you talked to them
- What other comments do you have about giving feedback or making a complaint

The WA Health Department want to make giving feedback and letting them know when something is wrong, easier and better for Aboriginal people, so they can make their service better.

Please contact Tania Harris on 08 92213422 to book a place or for more information.

GPO Box 0134, PERTH WA 6839 Unit 6 Wellington Fair, 40 Lord Street, EAST PERTH WA 6004  
T 08 9221 3422 | COUNTRY FREECALL 1800 620 780 | E [info@hccnc.org.au](mailto:info@hccnc.org.au) | W [www.hccnc.org.au](http://www.hccnc.org.au)



HEALTH CONSUMERS' COUNCIL

HEALTH SERVICE COMPLAINTS AND FEEDBACK

**Tell us your experience**

*Have you made a complaint or given feedback to public health services?*

**FEEDBACK SESSIONS**

**Open invitation - Perth**

- Wednesday 12 February
  - 1pm – 4pm
  - Citiplace, Perth

**Open invitation - regional/rural**

- Thursday 13 February
  - 9.30am – 12.30pm
  - Online – via Zoom

**Targeted invitation - Aboriginal people regional/rural**

- Tuesday 18 February
  - 9.30am – 12.30pm
  - Online – via Zoom

**Targeted invitation - Aboriginal people Perth**

- Wednesday 12 February
  - 1pm – 4pm
  - Citiplace, Perth

Click here to find out more and register at the Health Consumers' Council website



# What help is available?

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- Engagement team at Health Consumers' Council
  - General advice – please just email or call!
  - Cultural Diversity Engagement Coordinator
  - Aboriginal Engagement Coordinator
  - Circulate engagement opportunities
  - Training for consumer reps
  - Carry out specific projects – may require some funding
    - Zoom meetings and workshops
    - Face to face workshops
    - Surveys
    - Kitchen Table Discussions
    - Engagement/Partnership planning
- Health Networks Unit at DoH
- Consumer Liaison Teams at HSPs
- Lots of frameworks and guides
- Reach out to consumer organisations to discuss your ideas
  - Health Consumers' Council – all areas of health and all community members
  - Carers WA
  - Consumers of Mental Health WA
  - Consumer and Community Involvement Program at the WA Health Translation Network – health and medical research
    - Ben Horgan in DoH 2 days/week
  - People With disability WA
  - Multicultural Futures Australia
  - ... and many others

# Connecting with consumers and with HCC

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- Monthly e-news
- Advertising consumer rep opportunities
- Culturally and linguistically diverse consumer panel
- Community advisory councils and groups (CACs and CAGs)
- Aboriginal Cultural Advisory Groups
- District Health Advisory Groups (via WACHS)
- Health Networks (via DoH)
- HCC on social media
  - HCC Facebook page (~2300 followers)  
<https://www.facebook.com/hconcwa/>
  - HCC Facebook groups for specific groups of people
    - Source – Connect, Learn, Share – for consumer, carer, community, family reps  
<https://www.facebook.com/groups/hccsource/>
    - Partners in Change – Healthy Life for Longer – people interested in overweight, obesity and healthy living  
<https://www.facebook.com/groups/248123835784261>
  - Twitter <https://twitter.com/hconcwa>
  - LinkedIn  
<https://www.linkedin.com/company/health-consumers'-council/>



# Other sources of guidance

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- Join the Health Engagement Network (it's free)
  - <https://www.healthengagement.org.au/>
  - Includes a link to the many frameworks that provide more guidance (including these below...)
- You Matter Guideline – DoH  
[https://ww2.health.wa.gov.au/Articles/A\\_E/Consumer-carer-and-community-engagement](https://ww2.health.wa.gov.au/Articles/A_E/Consumer-carer-and-community-engagement)
- Health Networks Engagement Suite – DoH intranet  
[https://ww2.health.wa.gov.au/Articles/A\\_E/Consumer-carer-and-community-engagement](https://ww2.health.wa.gov.au/Articles/A_E/Consumer-carer-and-community-engagement)
- Mental Health Commission Framework and Toolkit <https://www.mhc.wa.gov.au/about-us/consumer-family-and-carer-participation/working-together-mental-health-and-alcohol-and-other-drug-engagement-framework-2018-2025-and-toolkit/>
- WA Council of Social Services Lived Experience Framework <https://wacoss.org.au/library/lived-experience-framework-principles-practices-lived-experience-partnerships/>
- Department of Communities Partnership Framework  
<https://www.wa.gov.au/government/document-collections/partnerships-the-department-of-communities#communities-partnership-framework>
- Suite of resources from the CCI program on engaging consumers in research  
<https://cciprogram.org/resources/>
- Participation guidelines for involving children and young people WA Commissioner for Children and Young People  
<https://www.cryp.wa.gov.au/media/1479/report-participation-guidelines-october-2009.pdf>

## Key messages

- Involving consumers will add value – the earlier the better
- Be prepared to be challenged – if not, don't partner
- Think diversity – what perspectives are not at the table? How can you hear them?
- Allow time – remember relationships
- Allocate resources
- There are lots of options – reach out for help
- Don't be afraid to try