

Being a health  
consumer 101:  
*the fundamentals of  
advocacy, the consumer  
journey and knowing  
your rights*

*YHF Masterclass slides*

# Consumer 101

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# Acknowledgement to Country



# Agenda



Acknowledgement  
to Country



Setting the  
scene



Your role



Your  
responsibilities



Your rights



Your toolkit



Knowing the  
system



Panel  
discussion



Takeaways  
Wrapping up

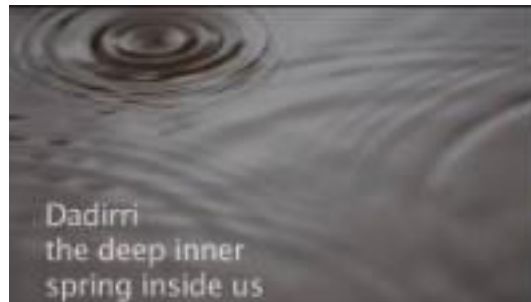


# Safety briefing

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Before we start, we want to make sure you feel safe in this space, recognising differences in views and experiences.

We also want to make sure that you are ready to really learn.



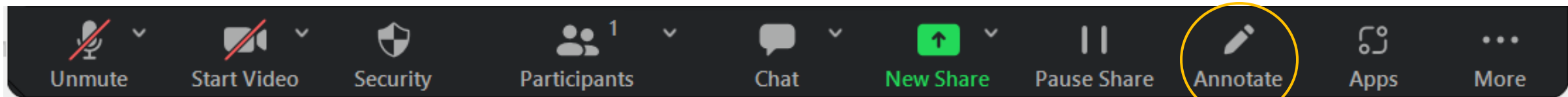
# Introductions

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**Where are you?**

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# Where are you joining from (Annotate tool)





# Where are you joining from?



**How much health  
consumer advocacy  
experience do you  
have?**

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# Who are you, really?

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**In the chat, share three emojis that tell us a little about who you are**

# Who are we?

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Georgia (they/them)



Zinab

Jordan

# Your Role

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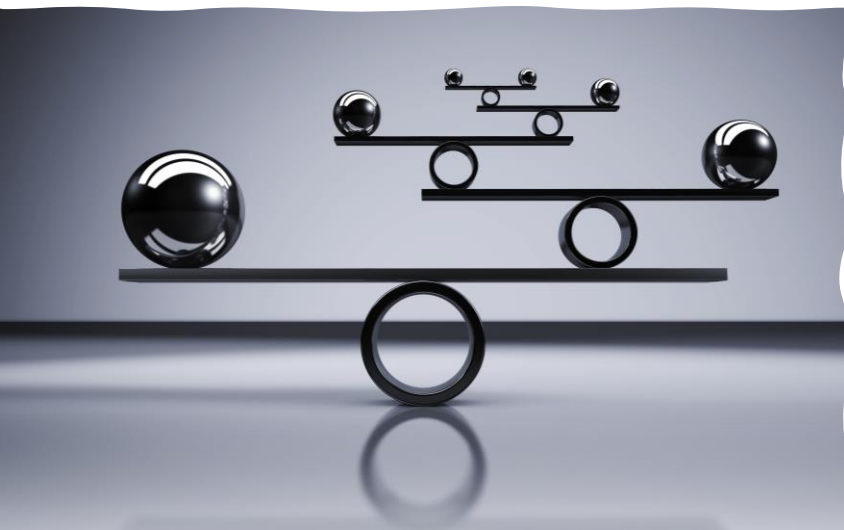
# What are health consumers?

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Patients and potential patients, carers and people who use health care services. Collectively, 'consumers' and 'community members' may be referred to as 'the public'. This includes those with lived experience.

The Australian Commission on Safety and Quality in Health Care definition: members of the public who use or are potential users of health care services – patients, consumers, families, carers and other support people

Australian Commission on Safety and Quality in Healthcare. 2012. [\*Standard 2 Partnering with Consumers\*](#).



# What is consumer advocacy?

Consumer advocacy means different things to different people.

Broadly, it can refer to a movement to regulate goods and services in the interests of the end user.

Consumer advocacy is part of the movements for social justice, fairness, and inclusion.





# What's in a name?

- Consumer advocate
- Lived experience representative
- Youth voice
- Community representative
- Committee member
- Consumer peer



# Nothing about us, without us

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Consumer participation

# Activity: Breakout Rooms

## What brings you to this role?

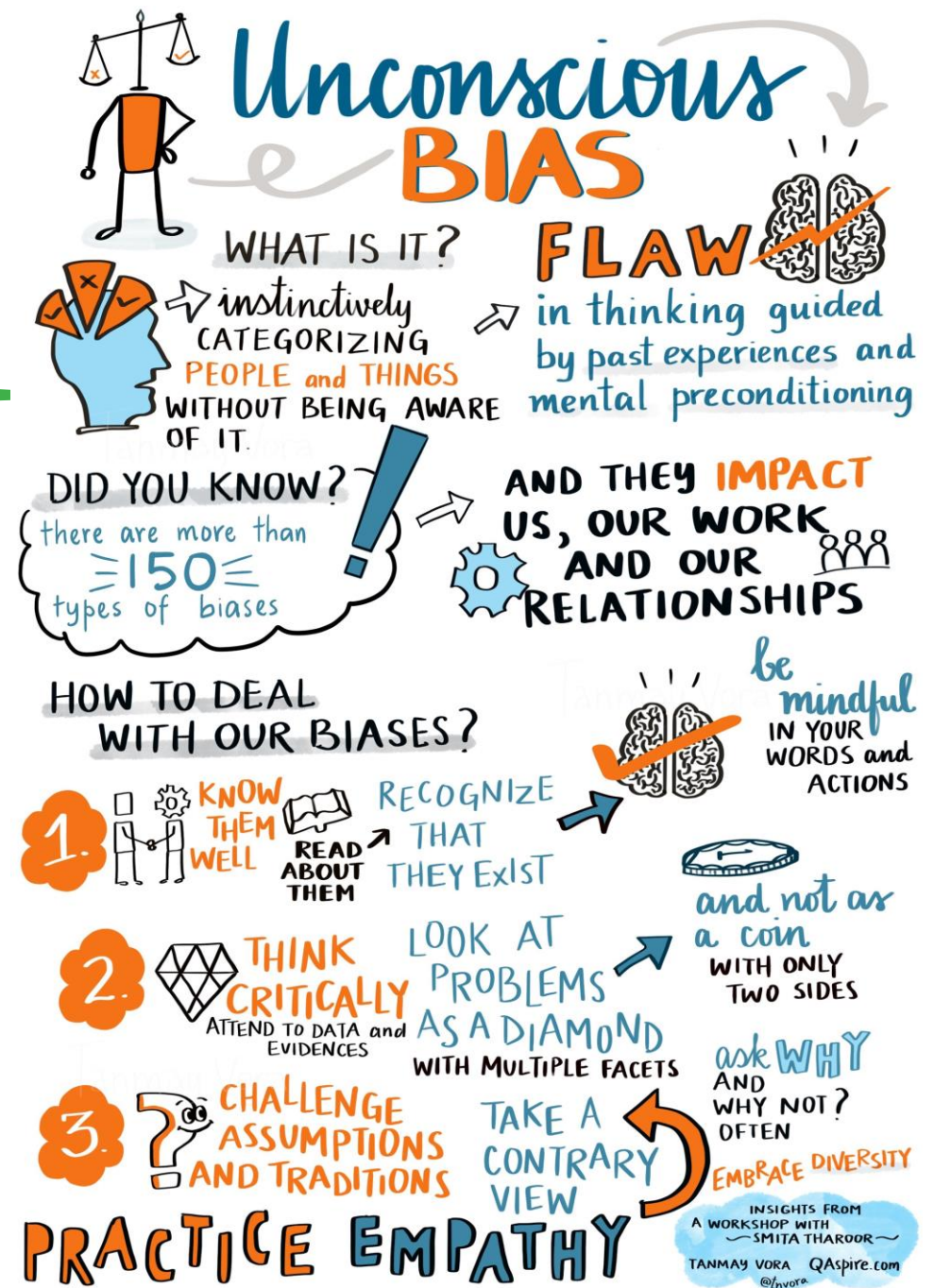
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- What drives us as consumer advisors to offer service, advice and advocacy?
- Why are you here and what impact do you want to have?

# Our motivations and biases

Understanding our motivations is really important. It helps us know what kind of roles we might be interested in, but can also help us identify biases.

- Understand your own personal motivations and expectations.
- Manage these within the boundaries of your role.
- Be part of the decision making on behalf of a “collective”.



We need to dispel the myth that empathy is 'walking in someone else's shoes.' rather than walking in your shoes, I need to learn how to listen to the story you tell about what it's like in your shoes and *believe you even when it doesn't match my experience.*

Brene Brown

# What do consumer advocates actually do?

- Writing Submissions
- Storytelling
- Creative projects
- Providing feedback
- Researching
- Attending meetings
- Seeking and providing feedback
- Attending facilitated workshops
- Public speaking
- Completing surveys
- Designing surveys
- Testing products
- Chairing boards
- Designing products
- Evaluating services
- Writing letters
- Giving speeches
- Saying “You’re on mute”
- Organising events
- Meet politicians
- Decide on priorities
- Participate in budgets
- Deliver training
- Network with other consumers



# Activity: Breakout Room

- What do you want to do?
- What kinds of activities are interesting to you?
- How would you like to spend time as a consumer advocate?

# Your responsibilities

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# Limitations

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Understanding what consumer advisors are or are not (advocacy versus representative)

Being clear about the limitations of your lived experience

- Are your experiences universal?
- Are your experiences contemporary? Have things changed?
- Are you connected to other consumers to learn from their experiences about this topic?



# Who do I represent?

- Consumer advisors are accountable to consumers
- Consumer advisors are not technical advisors
- Consumer advisors represent consumers **NOT their endorsing organisations**

# Who is in the room?

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Diversity, equity, inclusion and intersectionality

# Being respectful

- Of other consumers
- Of staff and facilitators
- Of your self

Healthy boundaries are about knowing what's okay and what's not okay. It's okay to be frustrated, upset, or disappointed in a consumer role. It's not okay to be disrespectful or aggressive.

# Being effective

- Positive first impression
- Introducing issues and ideas
- Speak with potential allies (internal and external)
- Consult – remaining current (webinars, forums)
- Review – resources, training (recognise the importance of maintaining lived experiences)
- Network – understanding other perspectives in the same/similar sphere
- Get a briefing – know who to contact, know the lead
- Report regularly – keep everyone informed

# Your rights

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# Australian charter of healthcare rights

Australian Commission on Safety and Quality in Health Care - ACSQHC

## 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://safetyandquality.gov.au/your-rights)

# Partnering with consumers standard

ACSQHC National  
Standards



## Better patient and community experience

- ✓ Improved patient satisfaction
- ✓ Improved patient engagement
- ✓ Improved community perceptions of healthcare organisations



## Better workforce experience and improved wellbeing

- ✓ Improved workforce satisfaction
- ✓ Improved workforce attitudes
- ✓ Less workforce turnover
- ✓ Reduced emotional stress for the healthcare workforce
- ✓ Improved workforce wellbeing



## Better clinical outcomes, safety and quality

- ✓ Lower mortality
- ✓ Reduced readmissions
- ✓ Reduced length of stay
- ✓ Reduced healthcare acquired infections
- ✓ Improved treatment adherence



## Better value care through lower costs of care

- ✓ Shorter length of stay
- ✓ Lower costs per case
- ✓ Better utilisation of low versus high cost workforce members
- ✓ Less workforce turnover

# Patient (Person) Centred Care

ACSQHC

- Foundation to safe, high-quality healthcare.
- It is care that is respectful of, and responsive to, the preferences, needs and values of the individual patient.
- It involves seeking out, and understanding what is important to the patient, fostering trust, establishing mutual respect and working together to share decisions and plan care.



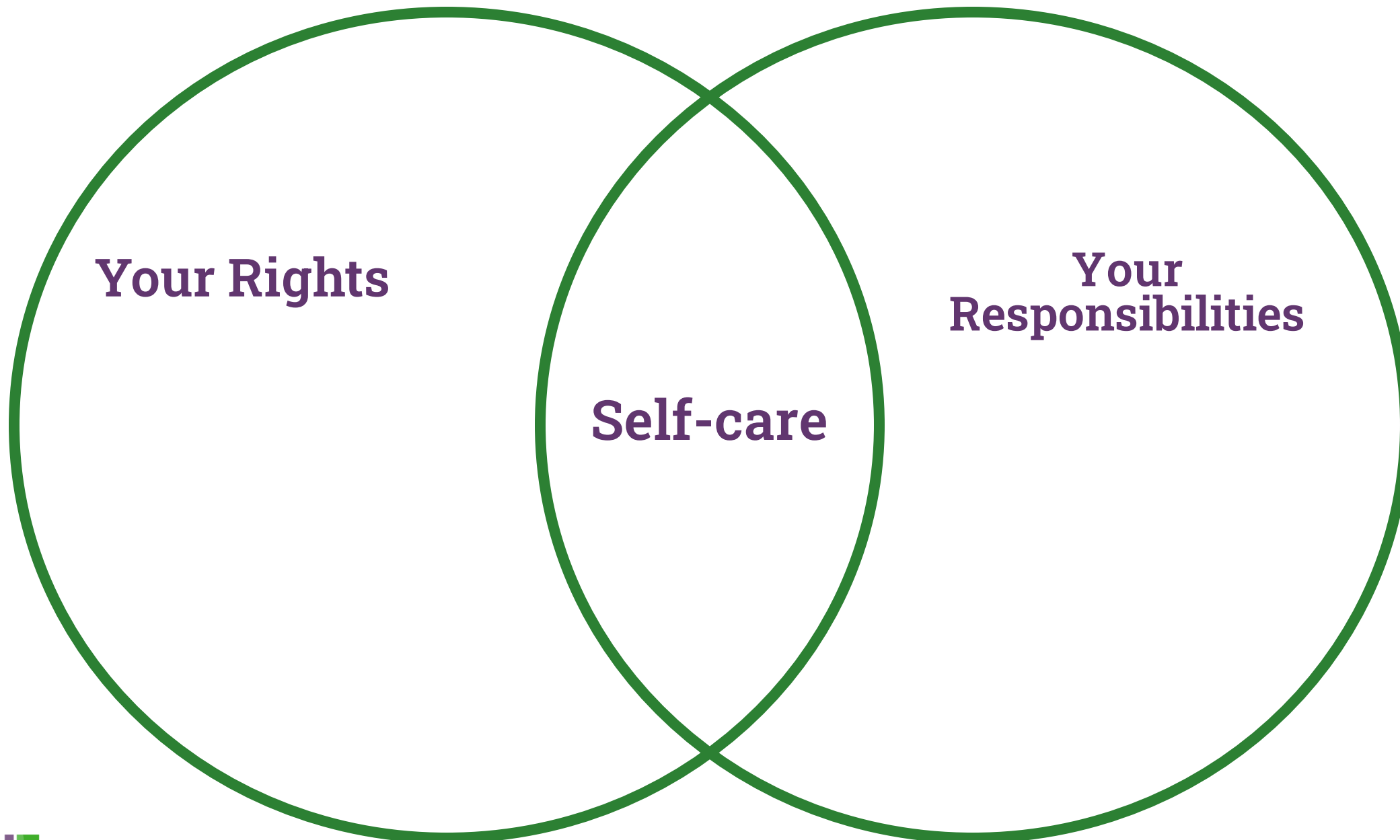
# Providing feedback – compliments & complaints

Do you know you have the right to make a compliment and complaint?

- Health services – Aboriginal Health Liaison Officers (AHLOs), Protective Service Officers (PSOs) or equivalent
- State Commissioners – Health, Mental Health, Information, Equal Opportunity and Human Rights, Disability Services
- Australian Health Practitioner Regulation Agency (AHPRA)
- Ombudsman Schemes

# Quiz – Your Rights





# Activity: What happens when..?

You don't understand the context or the content being discussed?

You feel you're not up on the issues or the communities/ individuals affected by the decisions, policy being made?

You feel that you cannot "blend" your lived experience and system knowledge?

You don't understand the systems or processes?

You feel alone – you're the lone consumer voice at the table?

You feel that it's taking forever for change to occur?

Or, you just feel out of your depth?

# Break - Ten Minutes



# Your toolkit

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# Resources

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Your toolkit to build capacity in your role as a consumer advisor.

- Consumer Advisor toolkit
- CHF Consumer Fact Sheets
- CHF Guidelines
- People – your colleagues, CHF staff, other consumers advisors



# Training

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There are training opportunities available through State consumer health peaks, research organisations, some are available free of charge.

We also recommend looking at State government opportunities for consumers, peak organisation (National and State) webinars and newsletters.

Think broadly, think locally and organisations that support community and advocacy in health and wellbeing.





# Consumer advisor training

- Health Consumers NSW – online training (free)
- Telethon Kids Research Institute – online training (free)
- Fee-for-service opportunities including, Health Issues Centre (HIC), Health Consumers NSW, Health Consumers Qld

# Important things to note

Reference the CHF Guidelines

Key parts of the guidelines are:

- Obligations
- Expectations - know the basic content, read the strategic plan, familiarise yourself with the agenda
- Entitlements – check to make sure that the entitlements will be met i.e. reimbursement
- Before, during and after the meeting
- Being effective – communication, resources

# Reimbursement

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CHF believes consumer advocates should receive reimbursement for their time and should not be financially disadvantaged by their roles and involvement.

Reimbursement policies varies from organisation to organization. You should always feel able to about payment and reimbursement before you take on a role.

Speak to the committee lead or secretariat before commencing in the role to understand payment requirements timeframes, rates, and any tax requirements.



# Reimbursement – things to know

It is important for you to consider all the ways being reimbursed for your participation may impact you.

Many consumer advocacy roles are remunerated (which means paid) as an honorarium – which means payment for services given voluntarily.

Payment received in this way can be considered as reportable income for people receiving income supports through Centrelink. Payment for consumer advocacy roles can also affect what you need to report when you do your taxes.

Consider seeking independent financial advice if you are concerned that reimbursement for consumer advocacy could impact you.

# Networks

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**If you want to go fast, go alone. If you  
want to go far, go together**

African Proverb, source unknown

# Partnerships & networks

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Forming partnerships should be a key part of your role.

This can include:

- signing up for updates,
- networking opportunities,
- webinars and forums,
- information sessions.



# Understanding your community/ network

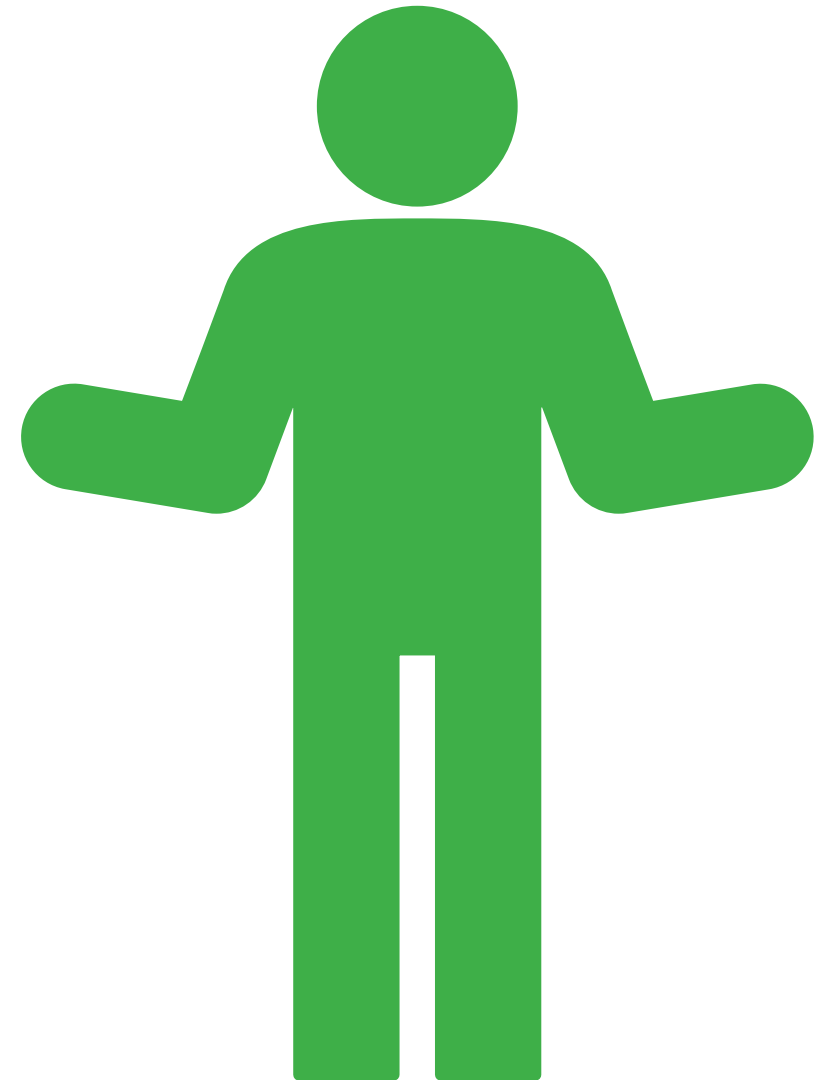
- **Locally** – health and community services, social services
- **Peaks** – remember Aboriginal and Torres Strait Islander peoples, diversity and inclusion (Federal and State)
- **Data and research** – Australian Bureau of Statistics (ABS), Australian Institute of Family Studies (AIFS), Australian Council of Social Services (ACOSS)
- **Policy**



# Sometimes, its not what you know, its who you know...

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- Who do you know that you can call – remember confidentiality
- What networks or groups do you belong to or can reach out to?
- Consider reaching out to CHF or a State Health Consumer peak organisation to gain an understanding of the issues and current conversations in health policy
- Recognise the potential conflicts of interest in your involvement



# Activity

Who are your networks?



# Knowing the system

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How Change Happens



# Youth Health

Who's who in the zoo

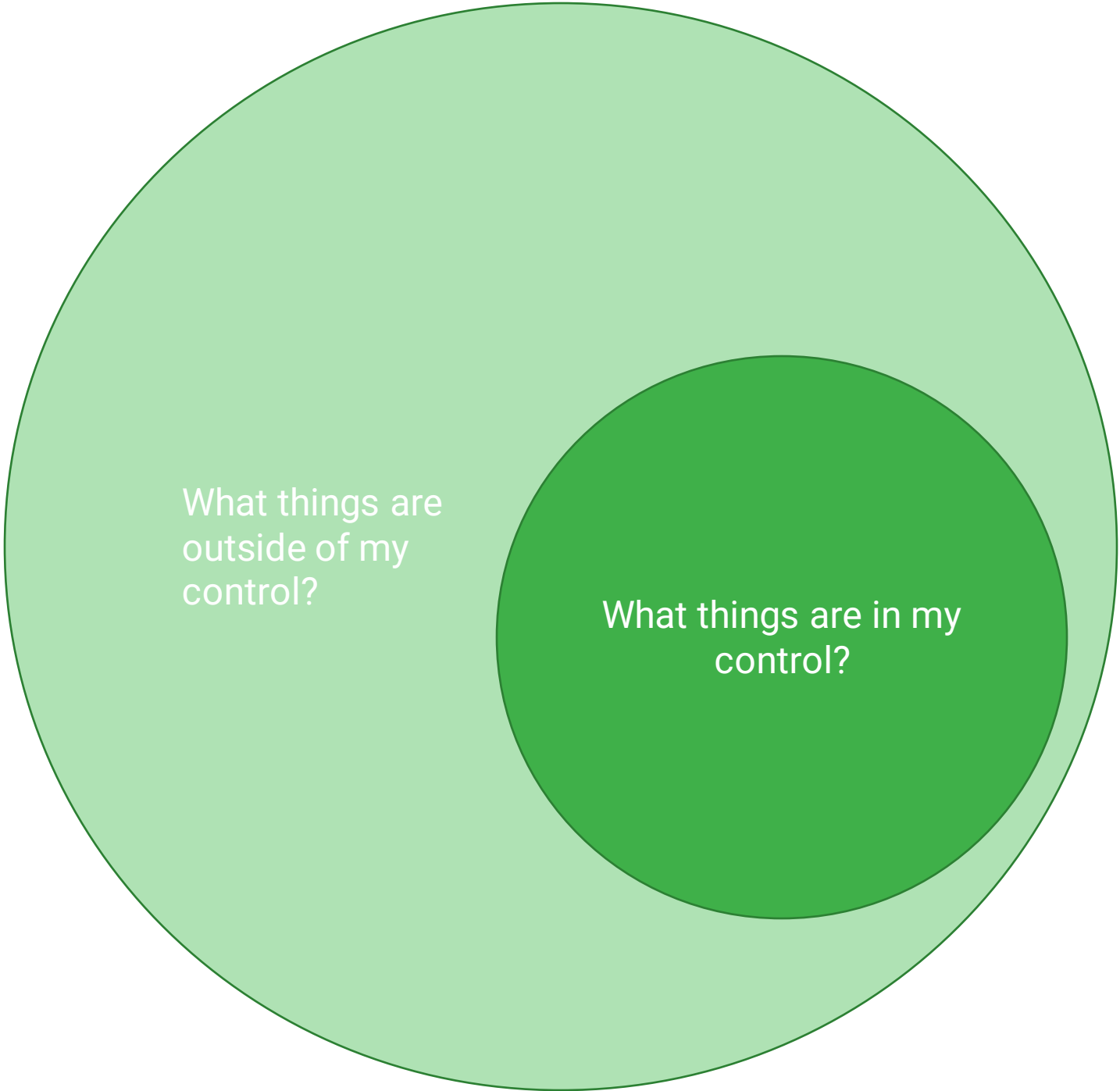


# The decision- makers

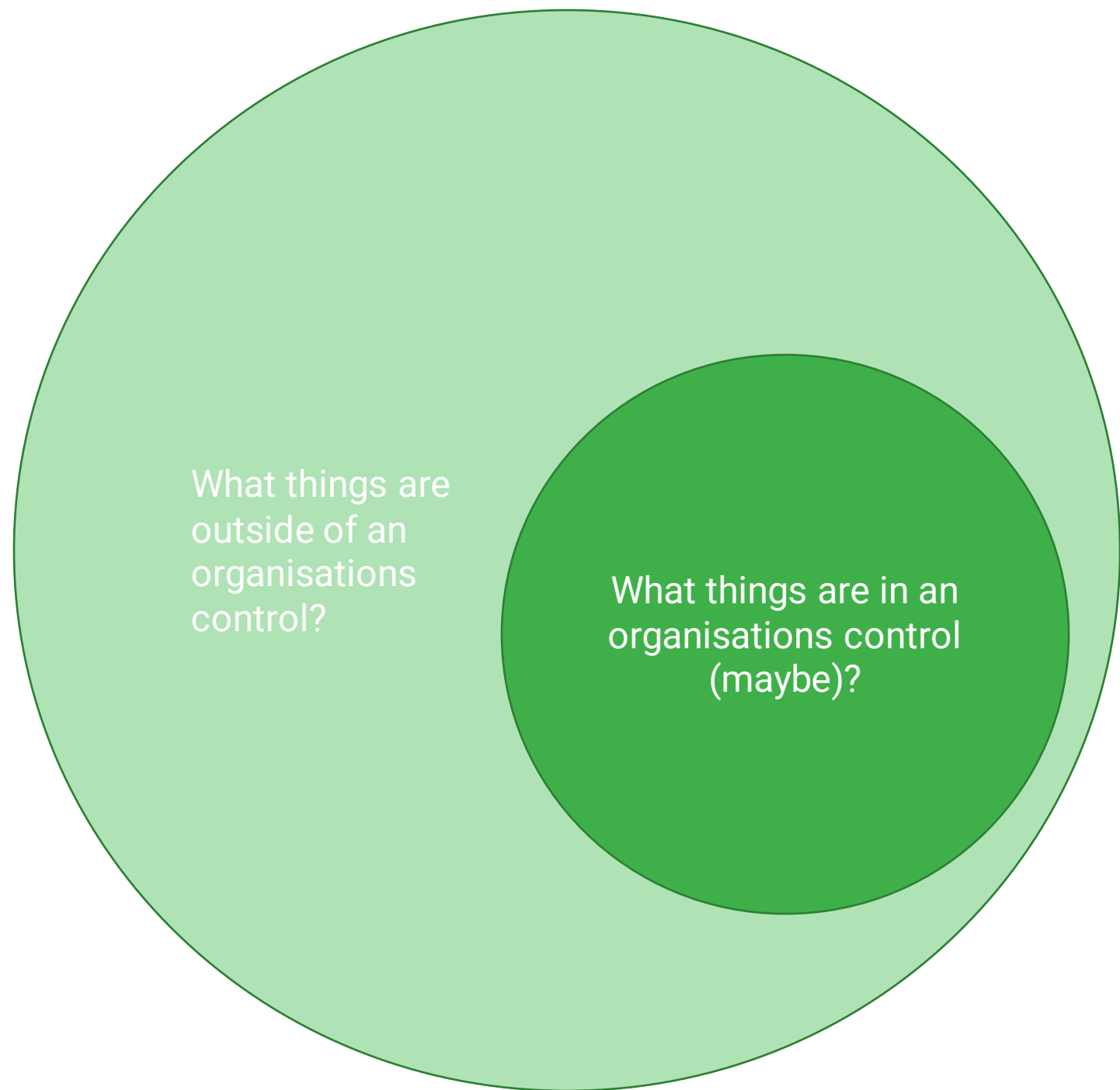
- Local, State and Federal peaks – government, non-government (ngo) and not for profit (nfp), social and community services
- Think broadly across sectors – recognising the social determinants of health and what affects our day-to-day lives.

# Activity

Scope of practice



# Organisations and scope of practice



# Thinking about the future

Planning for the future is one of the ways youth health advocacy is unique.

Are you studying or working in the healthcare industry?

As you go through your consumer advocate journey, how can you support younger youth voices?



# Activity: How will you get involved

- Sign up for email newsletters
- Follow on social media
- Subscribe to updates from
- Start an online training module
- Book in for live training
- Apply for a formal role

**Connection is the energy that exists  
between people when they feel seen,  
heard and valued...**

Brene Brown

# The panel

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# Wrapping up & take-aways

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# Evaluation

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After our final session today, please make sure you complete the evaluation form.

We welcome your feedback and the suggestions for change or improvement, or you might have loved it!



# Thank you!

## Questions?



Consumers Health  
Forum of Australia



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[www.chf.org.au](http://www.chf.org.au)