

# Being a health consumer 101:

the fundamentals of advocacy, the consumer journey and knowing your rights

Workbook



CHF Youth Health Forum
Masterclass
Consumer 101

Workbook

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### About this workbook

This workbook has been co-designed with young leaders and to be followed alongside the Masterclass presentation and after the session to add any questions and reflections you might have.

This workbook includes:

- Masterclass worksheets
- Support contacts
- References and resources
- Your checklist things to remember

We have also included a section for your ongoing reflections and notes following the Masterclass and to raise any issues with the Youth Health Forum Coordinator or the Young Leaders group.

This workbook is also a useful resource to support you in your consumer and community roles outside the Consumers Health Forum (CHF).

# Masterclass worksheets

# Getting to know you

- 1. Using the table, draw a picture, use simple words and tell us who you are.
- 2. Be witty, be inciteful.

# What are your experiences?

# Lived experiences What parts of the health system have you had direct, personal experiences of due to your own health needs? Loved experiences What parts of the health system have you seen up close due to the health needs of close people in your life? Network/community experiences What parts of the health system do you know about through storytelling and sharing of people and communities that you are connected to?

# Your Interests and Motivations Reflecting on your goals

What brings you to youth health consumer advocacy? What do you want to achieve?
What kinds of work interests you in this field? Use the list below for ideas if you're not sure where to start

#### What do Consumer Advocates 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
- Organising events
- Meet politicians
- Decide on priorities
- Participate in budgets
- Deliver training
- Network with other consumers
- Review marketing material
- Protesting

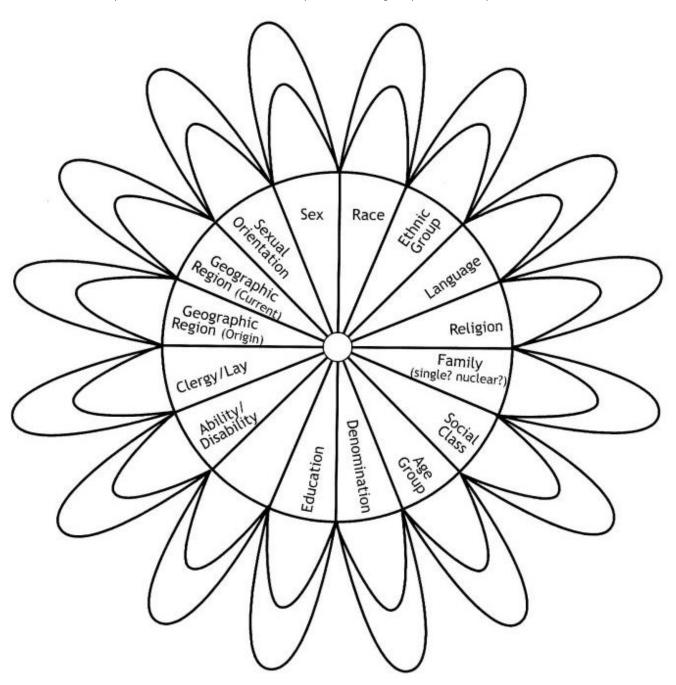
# Knowing your limits Who do I represent?

Reflect on who you are representing when you share your lived experiences. Are you a member of an organization or group that you are speaking on behalf of? Are you sharing someone else's story? Do you have permission to speak on behalf of these groups or people? Who could you speak with to obtain permission?
Limits of my experiences What are the limits of my lived experiences? Are/were my experiences universal? Are my experiences contemporary? Have things changed? Am I connected to other consumers to learn from their experiences about this topic? These are good questions to reflect on to understand how your experience might differ from another consumers' experience.
What do I not want to share?
Consumer Advocates have a right to privacy about their health experiences as well. You do not need to share any part of your experience that you don't want to. Use this section to reflect on whether there are any parts of your experiences that you do not wish to share.

# Diversity, equity, inclusion and intersectionality Who is in the room?

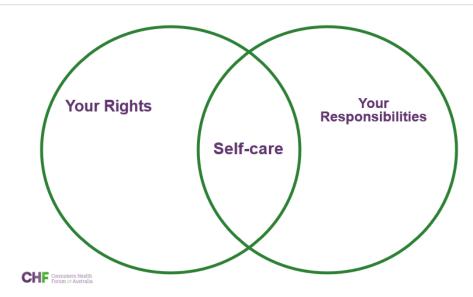
As consumer advocates, we have a responsibility and commitment to elevating voice. This is especially important when it comes to diversity, equity and inclusion. Reflecting on our own identities can help us see where our experiences challenge the mainstream norm, and also identify where other voices may need to be elevated.

The Power Flower (below, from *Education for a Change*) the innermost petal shows different dimensions of identity. In the middle petal, write your personal identity in the named dimension. In the outer most petal, you can write which identities are assumed to be the norm or generally hold the most power or privilege. For example, in age, you might write 'teenager' in the middle petal, and 'adults' in the outer petal as the group who hold power.



#### Self-Care

Self-care is often pictured as relaxation or pampering. While this may be a piece of it, the largest, and most difficult, part of self-care is understanding your needs and taking actions to make sure your needs are being met. While you do have a right to self-care, you also have a responsibility to yourself and others to take care of yourself.



#### What happens When...

An important part of Self Care can be planning how you will take care of yourself if something doesn't go to plan. Consider the following scenarios, and write one or two actions you could take to take care of yourself in that situation.

- 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?

# Your Toolkit

### Resources

List three resources (thinl	k factsheets, gu	uidelines, wo	orkbooks or	r knowledgeabl	<u></u>
people) who can be a rese	ource in your to	olkit.			

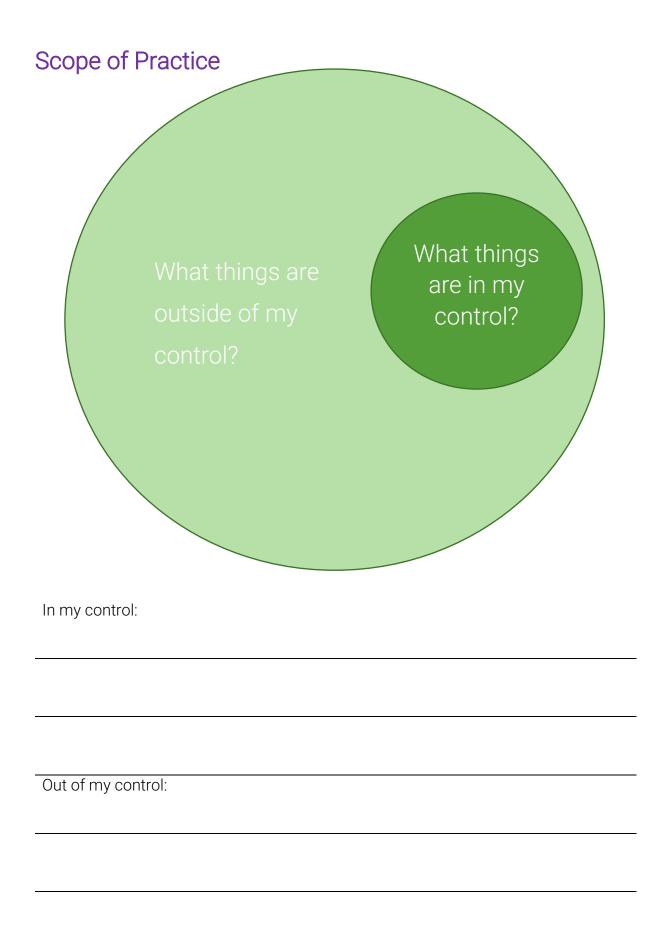
people) who can be a resource in your toolkit.
1.
2.
3.
Training List three places you can seek training, or types of training you would like to seek, that can be a resource in your toolkit.  1.
2.
3.
Networks List three networks you are already connected with who can be a resource in your toolkit.  1.
2.
3.

# Who do you know?

Consumer advocacy is a group activity. We can't go it alone.

On this page, brainstorm all the people you know, personally or professionally, who you could reach out to for information, advice, connections or support. This is an important activity for two reasons. It helps you identify your support and knowledge network. It also identifies where you might have conflicts of interest. Conflicts of interest are something you will often need to declare, so it's good to think about in advance.





# Your takeaways

# What do you want to know more about?

Here is a space to think of topics you'd like to research further in your own time, or questions you'd like to ask our panel.

1.
2.
3.
4.
5.
What actions are you going to take? Use this space to set yourself three to five actions or goals you'd like to set for yourself to take this work forward. At least one should be something you can accomplish this weekend.
1.
2.
3.
4.
5.

# Support contacts

If anything in today's content was distressing for you, please feel very welcome to contact us to provide feedback.

CHF can be contacted at <a href="https://chf.org.au/contact-us">https://chf.org.au/contact-us</a> or (02) 6273 5444.

Here are some additional resources for seeking support.

•<u>Lifeline</u>: 13 11 14

•<u>Headspace</u>: 1800 650 890

•<u>13YARN</u>: 13 92 76

•<u>Qlife</u>: 1800 184 527

•<u>1800RESPECT</u>: 1800 737 732

# References and resources

There are many opportunities for you to improve your knowledge and capacity as a consumer advisor through free and fee-based training options. There are also many supporting resources that you can access through support organisations, consumer and health and policy sectors. We encourage you to have a look at these over the coming months, add to these with your own research and to also revisit to update your skills or as a simple refresher. You can also refer to the fact sheets on specific roles, guides and the CHF Consumers on Committees' guidelines.

Consumer Advisors	Consumer roles
Training & Resources Consumers Health Forum of Australia (CHF) Health Consumers NSW Health Consumers Queensland Health Consumers Council (WA) Health Consumers ACT Health Consumers Tasmania (South Australian Consumers legacy website)	Training Telethon Kids Research Institute – research Resources National Health & Medical Research Council (NHMRC) – Statement on consumer and community involvement in health and medical research Australian Institute of Clinical Governance (AICG) Australian Commission on Safety and Quality in Healthcare (ACSQHC) – National Safety and Quality Health Service Standards Department of Health and Ageing – Preventive Health Strategy
Health Literacy	Youth support
ACSQHC - Health Literacy AIHW - Health Literacy (Australia's youth) Agency for Clinical Innovation (NSW) - Health Literacy Canberra Health Literacy https://cbrhl.org.au Department of Health (Vic) - Health Literacy	Youth Health Forum – Youth Health Forum   Consumers Health Forum of Australia (chf.org.au) AYAC Australian Youth Affairs Coalition (ayac.org.au) Youth Coalition of the ACT - A World For, By And With Young People - The Youth Coalition of the ACT Youth Affairs Council Victoria - Youth Affairs Council Victoria   We advocate for young people and represent the youth sector to uphold the rights of all young Victorians (yacvic.org.au) Youth Network of Tasmania - Homepage   Youth Network of Tasmania (ynot.org.au) Youth Affairs Council of South Australia - YACSA Youth Action (NSW) - Youth Action The Youth Affairs Network of Queensland Inc (YANQ) - Youth Affairs Network Queensland - home (yanq.org.au) Youth Voice NT - Youth Voice NT - NTCOSS - Northern Territory Council of Social Service

Aboriginal & Tarros Strait Jalandar populas	Mental Health
Aboriginal & Torres Strait Islander peoples	
National Aboriginal Community Controlled Health Organisation (NACCHO) Australian Indigenous HealthInfoNet Human Rights Australia	Orygen - Orygen, Revolution in Mind - Youth Mental Health Australia - Orygen, Revolution in Mind  Mental Health First Aid - Homepage   Mental Health First Aid (mhfa.com.au)  Black Dog - Black Dog Institute   Science.  Compassion. Action.  Beyond Blue - Anxiety, depression and suicide prevention support - Beyond Blue
Diversity & Inclusion	Other topics of interest
The Power Flower  Educating for a Change  Training  SBS Inclusion Courses  Resources  Diversity Council Australia  Federation of Ethnic Communities Councils of  Australia (FECCA)	Unconscious Bias - ANU Unconscious Bias - Australian Red Cross Co-design - Department of Health (Victoria) Co-design resources - Design Council UK Co-design toolkit - Agency for Clinical Innovation (NSW) IAP2 - Spectrum of Public Participation The Engagement Cycle (UK) Some light reading Dare to Lead - Brene Brown Beyond Sticky Notes - Kelly Ann McKercher
LGBTIQA+	
QLife - QLife Minus 18 - https://www.minus18.org.au/ LGBTIQ+ Health Australia - LGBTIQ+ Health Australia ACON - ACON - We are a New South Wales based health promotion organisation specialising in HIV prevention, HIV support and lesbian, gay, bisexual, transgender and intersex (LGBTI) healthACON   We are a New South Wales based health promotion organisation specialising in HIV prevention, HIV support and lesbian, gay, bisexual, transgender and intersex (LGBTI) health Meridian - meridianact Intersex Human Rights Australia - Intersex Human Rights Australia - Intersex Australia - formerly OII Australia (ihra.org.au)	

# Your checklist – things to remember

You have	just agreed to be a consumer advisor
	Clarify your position early.
	Understand the requirements of the role; timeframes, reporting, meetings,
	confidentiality etc.
	What do you want to achieve in your role?
	Recognise and understand your entitlements related to your role
Before yo	u start
	Ask for information on the role and committee early, review and ask questions.
	Make some early goals, make a plan and be flexible.
Before, du	ring and after meetings
	Review the before, during and after meeting information.
	Gather information, talk to consumers and committee members.
	Be prepared and seek clarification if you don't understand anything.
Dealing w	ith difficulties
	Recognise the warning signs if difficulties occur.
	Recognise if the difficulty is with other consumer advisors, committee members or something else.
	Be respectful, ask questions and clarify anything if there seems to be a problem.
Being effe	ective
	Recognise your strengths, abilities and knowledge – if you need support ask for it.
	Respect and listen to the views and experience of other committee members.
	If you identify a problem, bring this to the attention of the Chair and the secretary
	and bring a potential solution.
	Look for professional development opportunities to increase your skills and
	knowledge to support your consumer advisory role.

#### A final word

It is worth reiterating that committee work is rewarding but challenging. You will win some issues but not all. If consumer advisors can change the culture of committees, which are often technical, into seeing that consumers are legitimate stakeholders and offer value to the decision-making process, then this is a good achievement.

Each change you make as a consumer advisor is valuable and will benefit all consumers in the long-term.

Sometimes, your gains may not be obvious until many years later. Acknowledge that you have had a valuable and important role in the big picture of consumer and community participation and engagement.

Your notes			