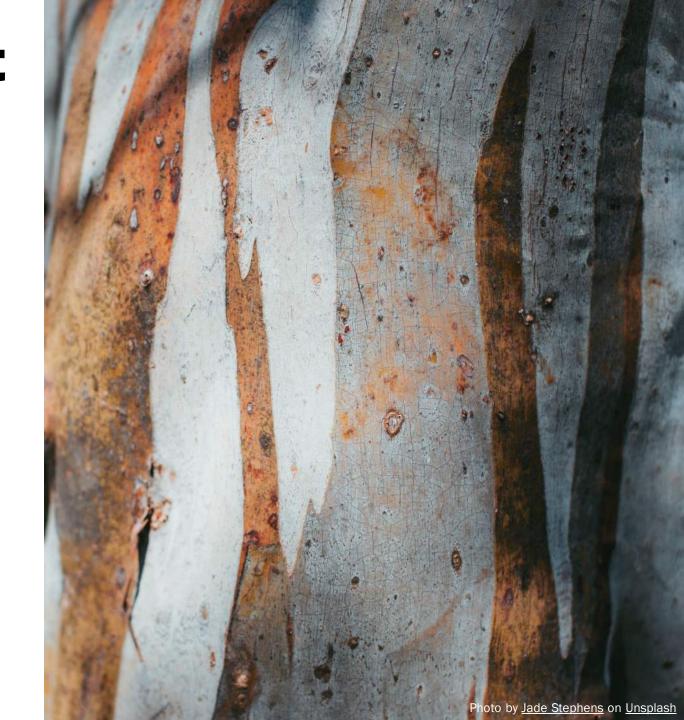


# Acknowledgement of Country





#### **Session aims**

01 Increase understanding of co-design principles and mindsets

02 Learn about a co-design methodology – Experience based Co-design

03 Gain some practical tips for co-design planning and budgeting

04 Consider the ethical issues for human research ethics submissions

We will pause a couple of times for Q&A



#### MISCH Hub

Methods and Implementation Support for Clinical and Health research



## Co-design Implementation Evaluation



Professor Cathy Vaughan

Director, Nossal Institute for Global Health



Erin Davis, Research Fellow

Gender and Women's Health Unit (Nossal)

# A spectrum... of sorts

What types of engagement are most familiar to you?

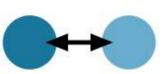
In the chat

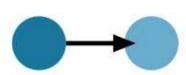












#### **Empower**

Consumers lead the development of activities, products and services with appropriate advice and support

#### Co-design

Consumers co-lead the development, design, implementation and evaluation of activities, products and services

#### Collaborate

Consumers are represented and can make recommendations and influence decisions

#### Consult

Consumers are invited to provide feedback about products and services developed

#### Inform

Consumers receive information about the group's activities (e.g. by being subscribed to the mailing list)

Source: NSW ACI, adapted from IAP2.

#### Some relevant guidelines

#### Research Funding Guidelines

- National Health and Medical Research Council self assessment checklist
- Medical Research Futures Fund
- Both have consumer advisory groups, guiding statements, and strategies

#### Health Policy Guidelines

- National Consumer Engagement Strategy for Health and Wellbeing (draft for consultation)
- National Safety and Quality Health Service Standards Partnering with Consumers Standard

#### Key organisations with guidelines, resources

- Consumers Health Forum (National)
- Health Issues Centre (Victoria)
- Safer Care Victoria Partnering in Healthcare Framework

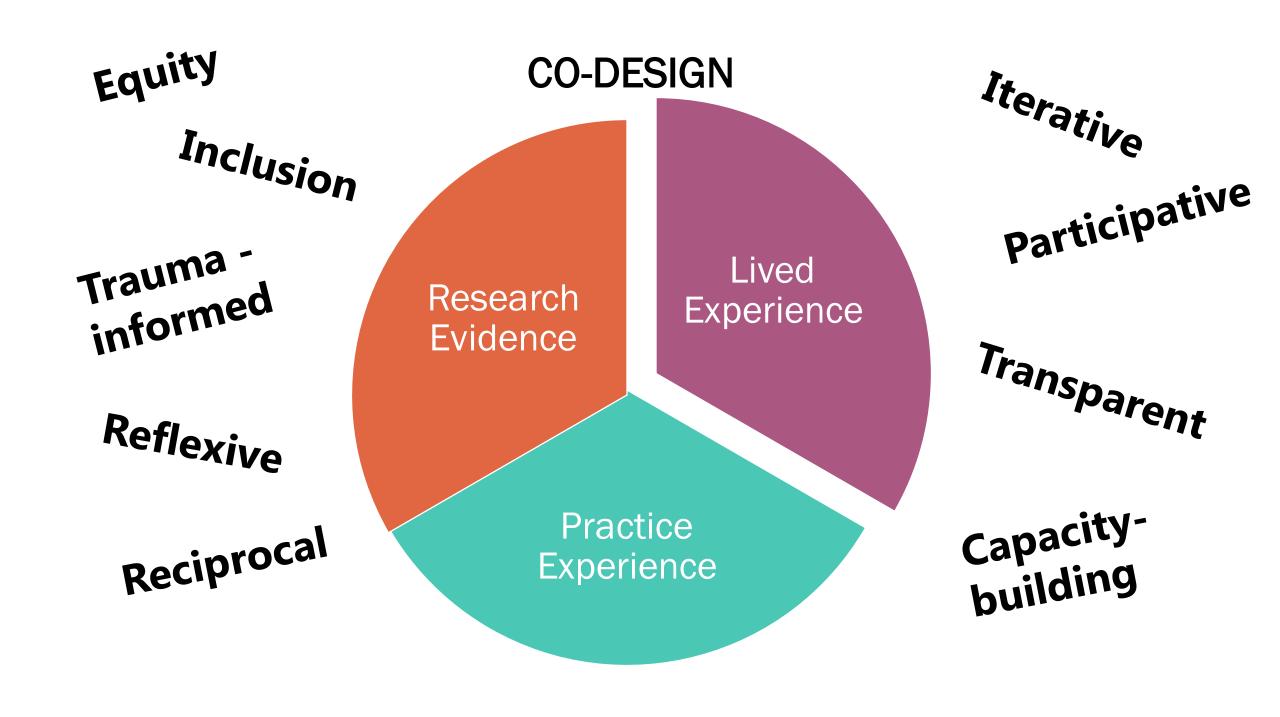
## What IS co-design?

Co-design is an *iterative and* participatory process that brings people together to design solutions with the aim of improving outcomes for those who need it most.



## What co-design IS NOT

- A consultation or one-off event
- A quick fix to meet 'consumer engagement' requirements
- Low-cost qualitative research
- A fad or trend



#### **Mindset**

These principles inform a 'mindset'
We are participatory and inclusive
We value lived experiences
We show care toward people
We critique power including our own
We will create something together
We will make decisions together



# Who should (or could) be involved in co-design?

**Always...**People with lived experience (e.g., patients, consumers, service users)

Even better...add implementers (e.g., practitioners, clinicians, leaders)

#### Consider also...

- Advocates and activists (e.g., consumer groups, community representatives)
- Policy makers (e.g., government, peak bodies)
- Specialists (e.g., academics, thought leaders)
- Critical friends (e.g., curious allies and colleagues)

## **Benefits of Co-design**

Co-design benefits (1m37s): "Why Should We Co-design" by Co.Create.Training

https://www.youtube.com/watch?v=CyT3xDRunRM

## Benefits of co-design

- Improves the quality, relevance and impact of research
- Enables better healthcare experiences with potentially lower costs
- Efficiently brings research evidence, practice wisdom and lived experience together
- Collaboratively generates solutions that will be acceptable to both consumers and implementers
- Motivates and inspires professionals to make sustainable changes
- Contributes to positive emotional outcomes and capacity strengthening amongst participants
- Supports robust implementation and evaluation processes

## Challenges of co-design

- Requires harnessing multiple resources
- Time and funding constraints may not enable genuine co-design
- Keeping people involved and engaged over time can be difficult
- Power imbalances and tensions are ever present
- Risks lack of inclusivity and intersectionality (homogeneity, tokenism)
- Balancing rigour and uncertainty in funding and ethics applications

Dimopoulos-Bick et al., 2019; Domecq et al., 2014; Slattery et al., 2020

## **Q&A** pause



## Doing co-design

Guiding frameworks

**Example activities** 

Case studies

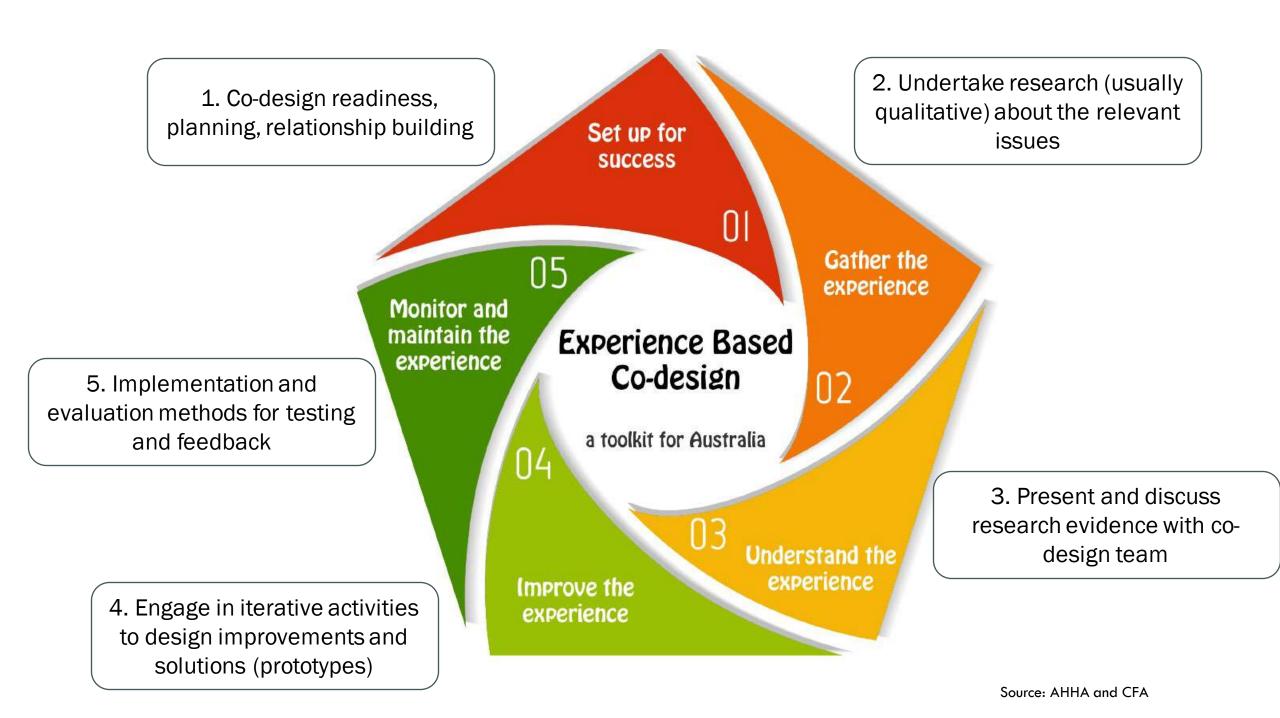


## **Guiding frameworks**

Double Diamond (UK Design Council)
Inspiration, Ideation, Implementation (IDEO)

Experience-based Co-design (Points of Care)





## **Activity examples**

- Personas
- Journey maps



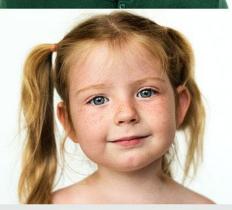
#### **Personas**

- Fictional characters
- Based on evidence exemplifying relevant consumer groups
- Provide validating representations of lived experience
- Use as a lens to understand the research problem and design solutions















#### **PERSONA TEMPLATE**





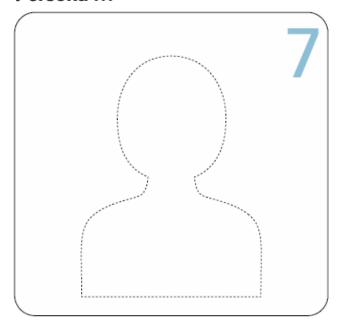
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What they say about themselves...

What friends and family say about them...

We were surprised that...

Persona ...



Details relevant to our challenge...

Details ...

Family and Work details...

2

Life Goals and Dreams...

Health Goals...

4

## Journey map

- Provides insight into consumers' (participants or personas) experiences through a service/system
- Can be used to map and compare the current experience and a future improved experience
- Identifies 'touchpoints' (emotional reactions) that signify potential areas to address when designing solutions

Mould et al., 2010; Reay et al., 2017



#### **JOURNEY MAP EXAMPLE**





High Level Stages	REHAB								
Doing	Rehab plan is organised	Finally able to go home with Jean	At home with Jean getting settled	Looking through rehab plan	Heading off to rehab - 3 appointments today	Heading off to rehab - everyday for 4 weeks	Rehab team check in - at least 2 months to go	Chatting with son who wants to help	
Thinking and saying	So much work to do - not to sure how we will be able to organise it	I feel so weak and old - this was not the plan  Can't want to get home and start life again  I'm still not so good - I don't want sympathy	We can do this together - but I worry about Jean having to do too much	All planned with well oiled military precision I hope gardening is part of the rehab	Thank god Jean is still driving	God I am meant to be the strong one Jean looks exhausted Why do we have to travelled between places	Jean and I can't do this - we don't need your help! I'm missing playing with the grandkids		
Interacting with	Allied health team	Jean and car	Jean	Jean	Jean and Rehab team	Jean and Rehab team	Jean and Rehab team	Son - James	
Feeling	Overwhelmed	Excited, relieved and scared at the same time	Concerned for Jean - ashamed	Determined	Determined	Tired, over it	Frustrated, sad	Ashamed and angry at self	
Emotional Map									
	×	×	×	×	×	×	<b>X</b> Pain	×	

Source: NSW ACI

## **Prototyping**

- A draft solution that intends to improve the experience.
- Evoke discussion, put ideas on the table.
- Developed further to create an output (policy, program, process, etc.)

Sanders & Stappers, 2014



#### **Prototype Mapping**

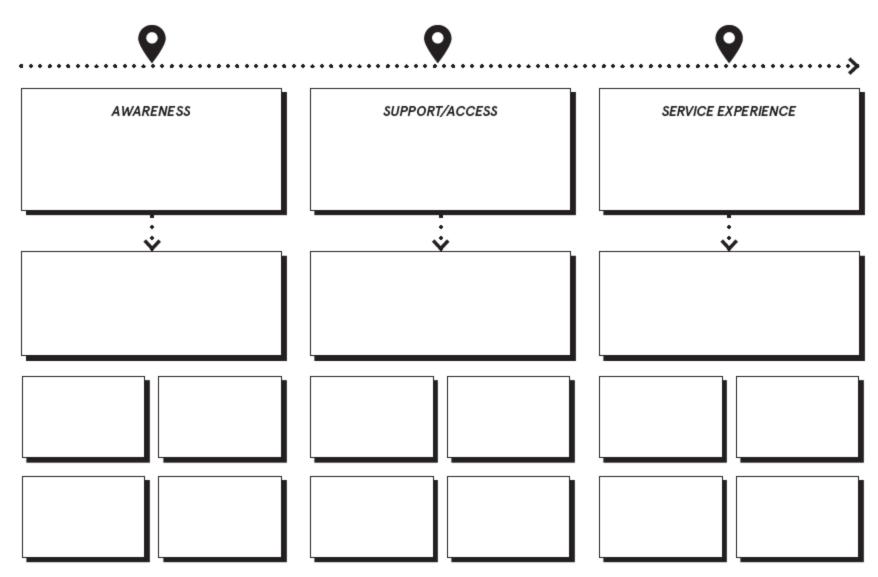
Map out the most important moments and milestones in your user journey.

#### What shift do you want to see in this moment?

Revisit your insights statements or impact ladder as you define these:

#### Map your solution concepts.

\*We've given you space for 4 concepts here—but you may have more



# Case study: Pediatric Exome Testing

- 1. Set up MISCH agreement, co-design plan, ethics, recruitment
- 2. Gathering info interviews with parents, paediatricians, and genetics services staff
- 3. Understanding 3 evidence feedback sessions to inform co-design
- 4. Improving 3 co-design sessions with persona, journey map, prototyping activities.
- 5. Implement Monitoring Evaluation 2 prototypes in development, review, implementation and evaluation to follow.



#### In the chat

How are you or could you bring co-design into the work you are doing?



## **Key tips**

- Readiness
- Budgeting
- Ethics



## **Key tip: Readiness**

- Do you know how your project relates to the engagement spectrum?
- Are you willing to apply and reflect on co-design principles and mindsets?
- Do you have the **funding, time and resources** to support co-design?
- Are you able to conduct qualitative research to prepare for co-design, or at least draw on prior **research and evidence** to inform the process?
- Are you and key stakeholders open to sitting with uncertainty and changing course?
- Do you have experience with facilitating participatory approaches and methods?
- Are you able to provide ethical care and resources to recruit, engage and support participation?

## **Key tip: Ethics**

Regularly examine your biases, power and privilege throughout the whole project.

Involve consumer representatives and community groups in early planning.

**Prioritise equity** in recruitment, processes, groups (size, number, configuration)

Practical considerations for renumeration e.g., payment, childcare, interpreters, transport.

Take the time to orient participants to co-design before you begin

**Keep checking in** – debriefing, feedback loops, offer support services

## Case study: Peri-menopause assessment tool

Recruit more women than GPs to prioritise lived experience

Check before if women know any of the GPs for safety and confidentiality

Prepare everyone – informed consent, readiness, roles and responsibilities

Co-create group agreements to support participation

Offer breaks, debriefing and service support with every engagement

Provide research evidence to inform co-design and increase knowledge of menopause

Use intersectional personas to overlay experience if they don't want to share directly

## **Key tip: Budgeting**

Planning and preparation of co-design (e.g., lit review, ethics, co-design methods)

**Recruitment and engagement** with inclusion and equity in mind (e.g., interpreters, transport, after hours)

Information gathering methods (e.g., qualitative, consultations, scoping)

Coordinating and conducting iterative separate and/or joint co-design sessions

Renumeration costs

Implementation and evaluation costs

Knowledge translation costs - dissemination, reporting and publication

#### How MISCH can help

#### **COLLABORATE WITH US EARLY!**

Grant development support

Consumer engagement or co-design planning and outputs

Literature review about relevant co-design or implementation research for your project

Qualitative research to inform co-design processes and implementation plans

Evaluating co-design processes, interventions, and implementation strategies

Mentoring and education about co-design and implementation

Multidisciplinary research with other MISCH nodes (e.g., biostats, health economics, etc.)







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