

“I have always wanted to do work like this but felt it was out of reach”: Hopes and expectations of participating in a co-design storytelling project

Presented by Dr Kate D’Cruz ^{1,2}

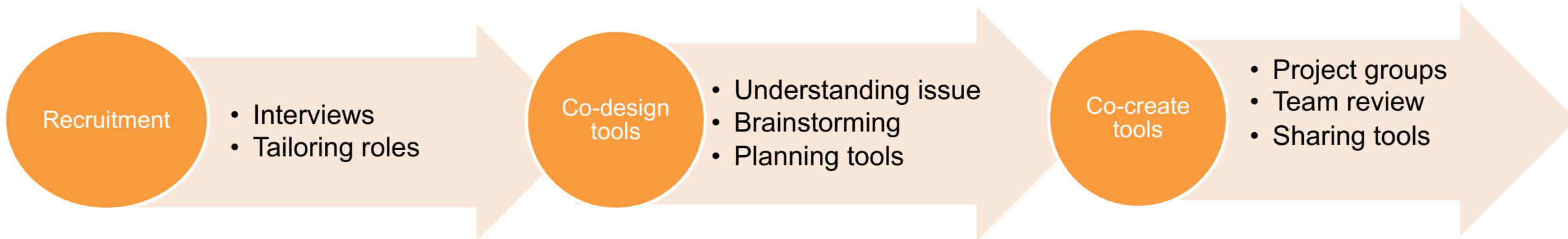
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Co-design project

Aim: To design and create tools to build the capacity of people with disability to take action to move out of aged care into inclusive housing



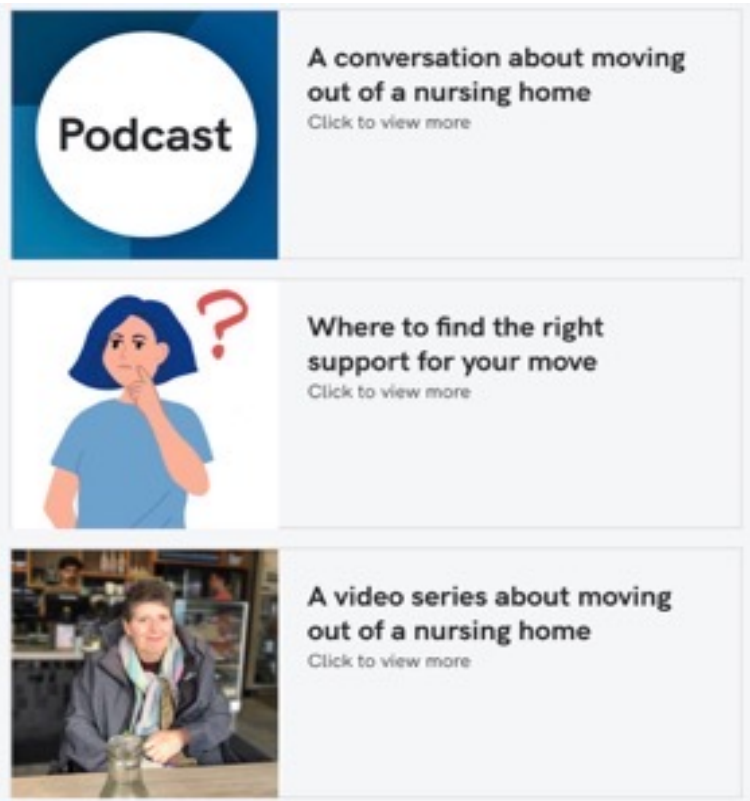
Lived Experience Partners (5), Lived Experience Contributors (5), Co-design Facilitators (3)

Produced tools

Three-part podcast series: A conversation about disability and leaving a nursing home

Three-part audio series: Choosing and managing your own support

Four short videos: The experience of moving out of a nursing home into my own apartment



The first card features a blue square with a white circle containing the word "Podcast" and the text "A conversation about moving out of a nursing home" with a "Click to view more" link. The second card shows an illustration of a woman thinking, with the text "Where to find the right support for your move" and a "Click to view more" link. The third card shows a photograph of a man sitting at a table, with the text "A video series about moving out of a nursing home" and a "Click to view more" link.



The screenshot shows a SoundCloud player for a track titled "Where to find support" by "Housing Hub". The player includes a play button, a progress bar, and a duration of 38 minutes. A "Cookie policy" link is visible at the bottom left of the player interface.

Aim: To explore the experience of participating in a co-design project from the perspective of partners/contributors and facilitators with and without lived experience of disability

- Enablers & barriers to co-design engagement
- Potential capacity building benefits
- Potential peer connection benefits

Methodology

- Qualitative study utilising constructivist grounded theory methodology (Charmaz, 2013)
- In-depth interviews conducted with lived experience partners, contributors & co-design facilitators
- Reflective journals completed by co-design facilitators
- Constant comparative process of data analysis; open & focused coding



Research participants

Three co-design facilitators

Skills/experience: physiotherapy, occupational therapy, stroke

Six lived experience partners / contributors

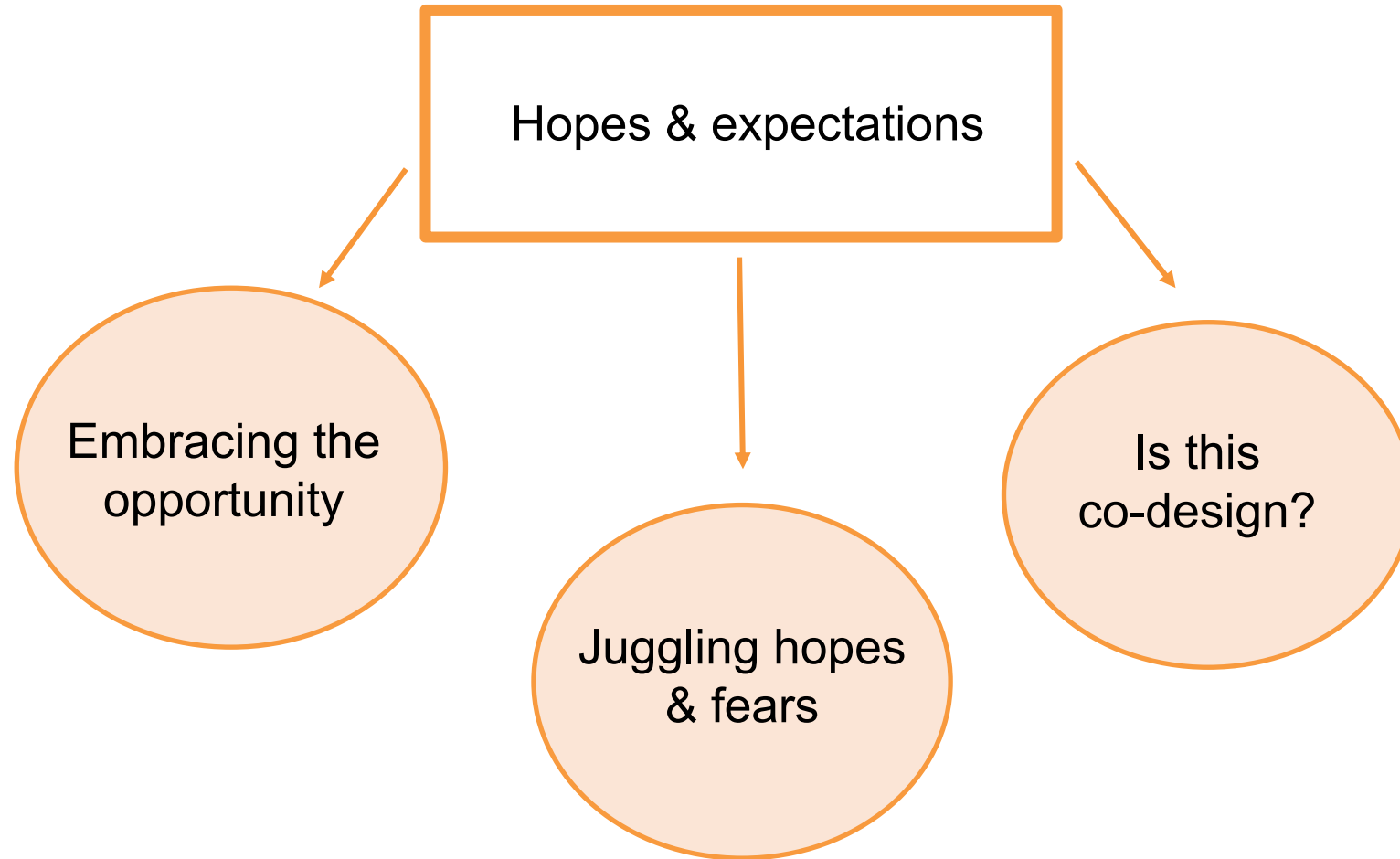
Skills/experience: accountant, teacher, artist, acquired brain injury, muscular dystrophy, MS, stroke, dystonia

Inclusion criteria for lived experience partners/contributors

Lived experience of disability

Lived experience of moving out of aged care

Findings



Embracing the opportunity

Helping others

I want everyone to have the same experience [moving out of aged care] (Christine)

Being employed

Wow- this is me (Christine)

Contributing in a new way

*Moving on from the storytelling a bit to **making a difference** (Holly)*

- Idea generation & problem solving
- Drawing upon lived experience and other skills/experiences

*Lived experience partners have **so much more to give** than what we have given them the opportunity to do*

Juggling hopes and fears (lived experience partners)

Contributing & having impact

It will be fantastic to give my opinions and suggestions and have them listened to (Christine)

- Is the project worthy of personal investment?

Testing work capacity

My main goal is to see whether or not I can do it (Deidre)

- Fatigue
- Availability of support
- Work tasks

Building social connections

- Hopeful but cautious

Looking forward to working with others who have a similar life to mine (Ingrid)

Worried about communication

I'm a bit worried about other people understanding me and my speech and communication (Gabby)

Juggling hopes and fears (Co-design facilitators)

Doing co-design well

- More than consultation
- Shift or change in power relationships
- Trusting the process- tightening & loosening the structure

Being true partners also means contributing to the process- Feeling comfortable to share knowledge (co-design facilitator)

Enabling growth & capacity building

Having more time to invest in each other and process but will it be enough?

- Role of facilitator with lived experience of disability?

Creating meaningful process & tools

If the lived experience partners are the decision makers then the tools will be great (co-design facilitator)

What value are people looking for? Employment or being paid? What does this look like for people?

Is this really co-design?

*Is this what we can do and how we can do it? **Is it OK if it isn't co-design?***

*I just really like the opportunity to **work with other people***
(Gabby)

***Bringing skepticism** about the co-design process (Billie)*

*As a concept [co-design] sounds fantastic. It is **a great movement on**.
When I have provided my lived experiences... I haven't really looked at, not so much a more positive thing*
(Christine)

*Team effort of coming together, people from Summer, people with disabilities coming together **collaboratively working** to design their tools* (Deidre)

Conclusion



Co-design was identified as a strengths-based opportunity to contribute



Excited to use lived experience knowledge in addition to other skills such as listening, discussing and problem solving



Appreciative of and motivated by the opportunity to be employed; payment does not suit everyone



Hoping to build new connections



Worried about the impact of communication difficulties

Thank you

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