

Co-Design Living Labs

# A HANDBOOK *BY* AND *FOR* WORKING WITH CO-DESIGNERS



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**THANK YOU**

## Thank you and Acknowledgements

This handbook has been co-designed by members of the Co-Design Living Labs Network. We acknowledge the following people who have contributed:

[NAMES HERE]

The members of the network would like to thank Vicki and the Co-Design team at Melbourne University for the opportunity to Co-Design research from a lived-experience perspective.

Welcome! We hope this journey is enjoyable and exciting for you as it has been for us at Melbourne University.

# NOTE AND TERMINOLOGY

## A note on language and terminology in this Handbook

It's important to acknowledge that everyone experiences and expresses their life stories, day to day activities, and identities differently. In mental health research this can be complicated. Some people are comfortable with the use of the term consumer or carer to define their experiences or roles, while other people prefer to talk about living with a mental illness, or having lived-experience, or lived-expertise.

For other people the wording of psychological distress, mental distress or emotional distress are preferred. Some people feel strongly about not using the term illness in their explanations and sharing of their experiences. Here, we have adopted the wording of people living with ongoing distress and mental ill-health to incorporate the reference to having direct lived-experience and to acknowledge the living expertise that people in the Co-Design Living Labs program bring. This includes referring to carers with the broader terminology of carers, family and kinship group members.

In the Co-Design Living Labs program, we view everyone as members. We hope that you come to feel ownership of the program and as members will support the development and direction of the work going forward. What we mean here is that you are not research participants, or enrolled in a study, but you are an integral, central and valued part of a dedicated Co-Design Living Lab program. It means when we talk about members taking part in co-design, you will see that we use the wording 'co-designer'. When we talk about doing co-design together with the researchers in the program, we call the researchers working with us in co-design, 'conveners' who help to guide the process and support achieving co-designed outcomes.

Enjoy your foray into our program of work and as always we welcome the opportunity to co-create with you.

### Please Cite this document as:

The ALIVE National Centre Co-Design Living Lab Network. (2022). A co-created handbook by and for working with co-designers.

The ALIVE National Centre for National Mental Health Research Translation. The University of Melbourne.

**WELCOME**



## Welcome to our handbook

Hi. Welcome to our co-designers' handbook which has been co-created through conversations convened with co-design leads for the national centre's living labs network over 2021 and 2022.

We are excited to share the journey of the Co-Design Living Labs program of work with you and the next steps as we become a national network.

If you've got some suggestions from reading this too that you would like to contribute, you are always welcome to get in touch to share that with the team.

In this handbook, you'll find some background to the whole Co-Design Living Labs program, who is in the team and who are our co-design leads.

But, you'll also find some information about what to expect at co-design sessions, ways people engage with the online co-design or face to face, and different tips and messages about co-designing together.

We have found that meeting virtually is an effective way of carrying out co-design. Connecting online has also allowed people from rural and regional areas to be part of the co-design process.

Togetherness is an important concept within the Co-Design Living Labs program of work – being together matters for support, collaborating, being creative and getting to know each other and what's important for working with people with lived-experience in co-design and transforming mental health care in the future.

**Thanks for joining and getting involved!**



# OUR BEGINNINGS

*"My involvement with Co-design Living Labs has given me an opportunity to share my experiences with others who have had similar times in their life where everything wasn't as "rosy" as it should be. As a group, we have discussed what worked and what we considered could be improved in the treatment of mental health. It has been a wonderful opportunity to get to know many people from different walks of life and we have had the chance to share our stories and opinions in a safe and caring environment. Mental Health is a difficult problem insofar as there isn't a physical sign such as a rash or bruise to show you are suffering. People often hide their problem for fear of being labelled."*

*– Co-designer with lived experience of mental ill health*

## Our beginnings - The Co-Design Living Labs Program

By Victoria Palmer

*“Well firstly I do love the idea of ‘Living Labs’ (LL) as it provides a very, unique way to engage people to participate in any way about a broad range of topics that mental health covers or touches.”*  
(Co-Designer 2020)

This is one of our member's feedback when we asked for people to share their experiences (it might be yours even!) of being a part of this work. I started with this quote because when the program was set up in 2017 we intentionally wanted to create a flexible approach to foster participation in any way possible. It's warming to hear that people do feel that sense of being able to participate in any way about a broad range of topics.

The world in 2022 is somewhat changed since we started out and while some parts of our Co-Design Living Labs program have stayed the same, many have changed too. Some of the changes reflect new ways of thinking in research and, we hope, greater ways of engaging in conversations with people in the community.

I hope this Co-Designer's Handbook which has been co-created by and for co-designers to work with co-designers, shares a bit of our story for you as a member. You might find it interesting to learn about the program a little more. Our goal in putting it together is that it helps future members to feel their own sense of belonging and orientation to what we do.

For me though, what I connect most with in this quote is that I too love 'the idea of Living Labs' – I realise though it is not a term widely used and people may wonder what it is, so, let us give two explainers before we fully begin this story.



# WHAT AND WHY



## So, “What’s a Living Lab”?

Living Labs have a long tradition and began in the innovation sector with people seeing the benefits of open structures for working together. Alongside this, there has been growing acceptance and recognition that to make something or develop a solution, involving people with direct experiences who may be future users is essential. The early work in Living Labs was largely technology focused, but there are all kinds of examples of living labs now in housing, health, ageing and environment.

The main part of a ‘Living Lab’ is that just that, living, it is about the everyday, our lives and where we live, work, learn, and play. Living Labs are about exploring and creating what’s needed together in live settings dependent on the context – for me that makes our Co-Design Living Lab an ‘anywhere-everywhere lab’.

## So, why the “Co-Design” Living Lab?

The addition of the word Co-Design to our Living Labs program was in recognition that co-creation and collaborative processes are one part of change, but they don’t offer a guarantee of staying focused on sharing power, collaborative decision-making, being intentionally creative in what we make or valuing and honouring lived-experience.

That’s where co-design comes in – it provides a way to be explicit that we honour lived-experience and always attempt to work from an experiential space through co-design methods and actions. Co-design was also important for us because in 2017 a big project called the CORE study was finished. The CORE study looked at a method called mental health experience co-design to improve psychosocial recovery in community mental health services in Victoria. In that project 287 people had been involved and a smaller group completed co-design within the services – setting up a Co-Design Living Lab meant that we could bring those experiences learned in the CORE study into this program and have a group of people who had had experience in taking part in co-design activities.



# CO-DESIGN LIVING LABS NETWORK

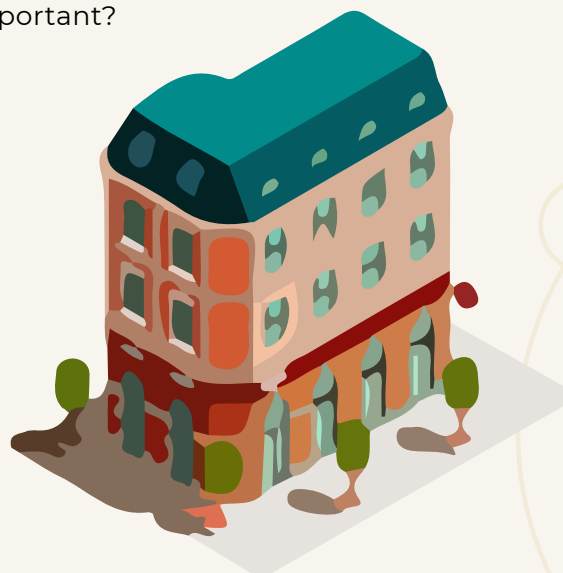
## And, now a Co-Design Living Labs Network?

Some people might wonder how this has all come to be a part of a Co-Design Living Labs Network. Well, back in 2020 the National Health and Medical Research Council had a funding call for the Special Initiative in Mental Health. This call was to set up a national research translation centre to improve experiences in care, outlooks and outcomes for people and in particular to address known gaps in life years due to unmet physical health needs going unaddressed. The call asked for a focus on capacity building of the next generation of mental health research leaders and multidisciplinary approaches with people with lived-experience professionals and all stakeholders to conduct implementation research.

As part of our existing Co-Design Living Lab program and the activities conducted within this (see figure on the next page) we asked co-design members what a national mental health research translation centre could look like – what would be important?

What topics would be researched and what kind of involvement might people want? We did this as part of what we call priority setting which forms one of the central activities of the Co-Design Living Labs program. In priority setting, we try to work out what's important for people with lived-experience and carers/kinship group members to ensure that the research questions and the grant reflect these.

We had 115 co-designers share their answers via email to the question and these were organised by researchers into thematic areas. We then co-designed ideas for the national centre further with another 27 co-designers; some of those who took part in co-design were named as leads in the proposal to take co-design work forward. Out of this, the ALIVE National Centre was formed. As part of being funded as the national centre we can now set up the Co-Design Living Labs as a nationally focused Network.



# CO-DESIGN TRAINING AWARD

*The Alex McLeod Co-Designer Training Award will provide support for two Co-Design Living Labs network members to be appointed to a training position for a year role. The aim is to foster co-design skills development, and grow the capacity within the membership base of the Co-Design Living Labs Network for co-designers to gather more experience about co-designing for service improvement and systems change and to become engaged in leading the co-design research, convening and facilitating groups, and research activities, and learning about the operations of the ALIVE National Centre Co-Design Living Labs Network.*



## The Alex McLeod Co-Designer Training Award

As part of the training award appointment we encourage Awardees to support communication of co-design activities and updates to members of the network, and engage with the membership base about what's happening in the program and network.

This Award is named in honour our long standing co-design member, Bev Harding, whose son sadly left the world in 2021. Bev shares, "Alex was someone who had a vibrant personality and loved life, however his mental ill-health prevented him from living life to its fullest. Tragically twenty years of struggling with mental torment, and minimal professional assistance, led to his premature death in 2021 at the age of thirty four." Bev Harding brings her own experiences of mental health needs and providing support as a family member over the course of Alex's life and navigating this major gap in mental health services.

As one of the first members in the Co-Design Living Labs program, 2023 will mark a 20-year relationship with the University of Melbourne program team. Bev first joined a ten year project exploring experiences of depression and service use in 2003 (the diamond study) with the Primary Care Mental Health research team and then, joined the Co-Design Living Labs on its establishment in 2017.

This annual Award marks an important moment in the next steps of the Co-Design Living Labs program as it becomes a national network and strives to support the member base to become leaders within the network through the National Health and Medical Research Council funded Special Initiative in Mental Health - The ALIVE National Centre for Mental Health Research Translation.

The Award is one very small way the research centre members and co-design team can honour the contributions of co-designers to the program. Bev's journey with the team has been long. She has been a member and then a lead in what was first the Collaborator Hub for the burgeoning program, to what is now a carer co-lead group for the Co-Design Living Labs National Network.

The team stands alongside Bev Harding's commitment to improve the mental health care system, to hold the large gap and space left in Bev's life with Alex's departure and to grow co-designer roles for implementing substantive changes in the mental health care system.

# DESIGN CO-DESIGN MODEL

*“The co-design sessions are a real opportunity to have a conversation with other carers, all of whose experiences vary from my own; to share an interest in the supports that might help; to clarify my individual understandings and be influenced by those of others; and to have hope that there will be useful changes.”*

*– Co-designer with lived experience of caring for someone with mental ill health*

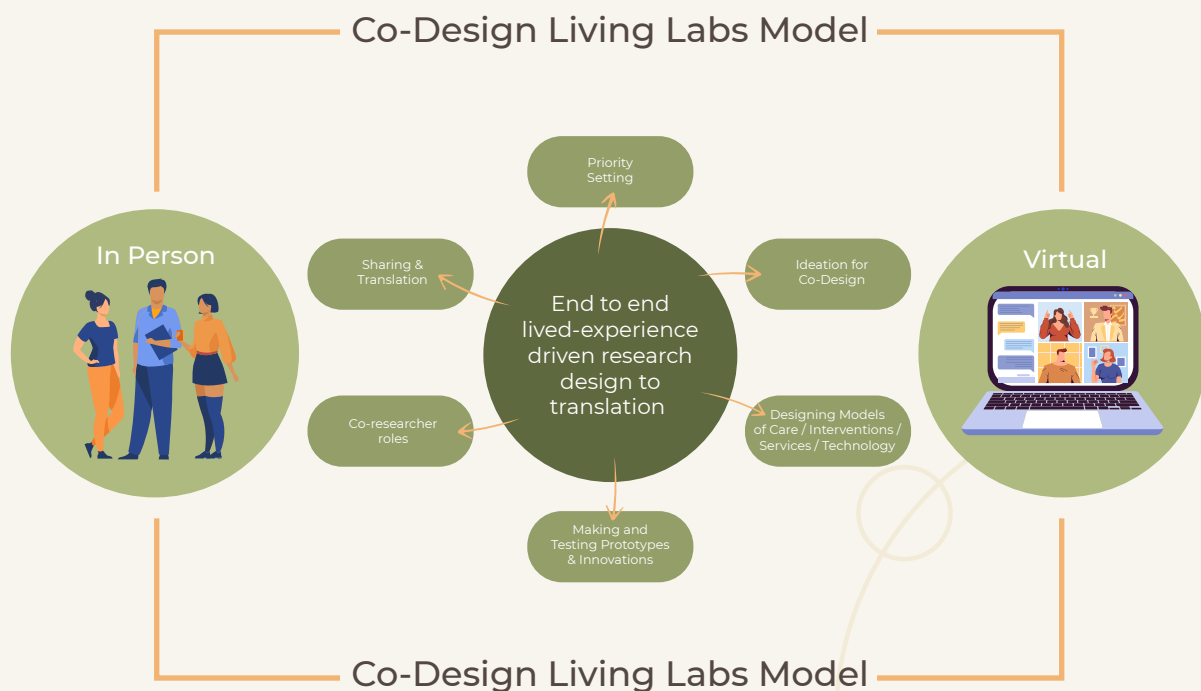
## How do the Co-Design Living Labs work?

The Co-Design Living Labs bring people together from community, industry, government and research and use experienced co-design methods to:

- Collaborate on research project development and materials;
- Co-design new health models, systems and processes for primary care;
- Co-produce methods to embed research outcomes into policy and practice;
- Test out prototypes, technologies, new interventions and pilot;
- Build sector capabilities for co-design;
- Develop and support co-researcher models.

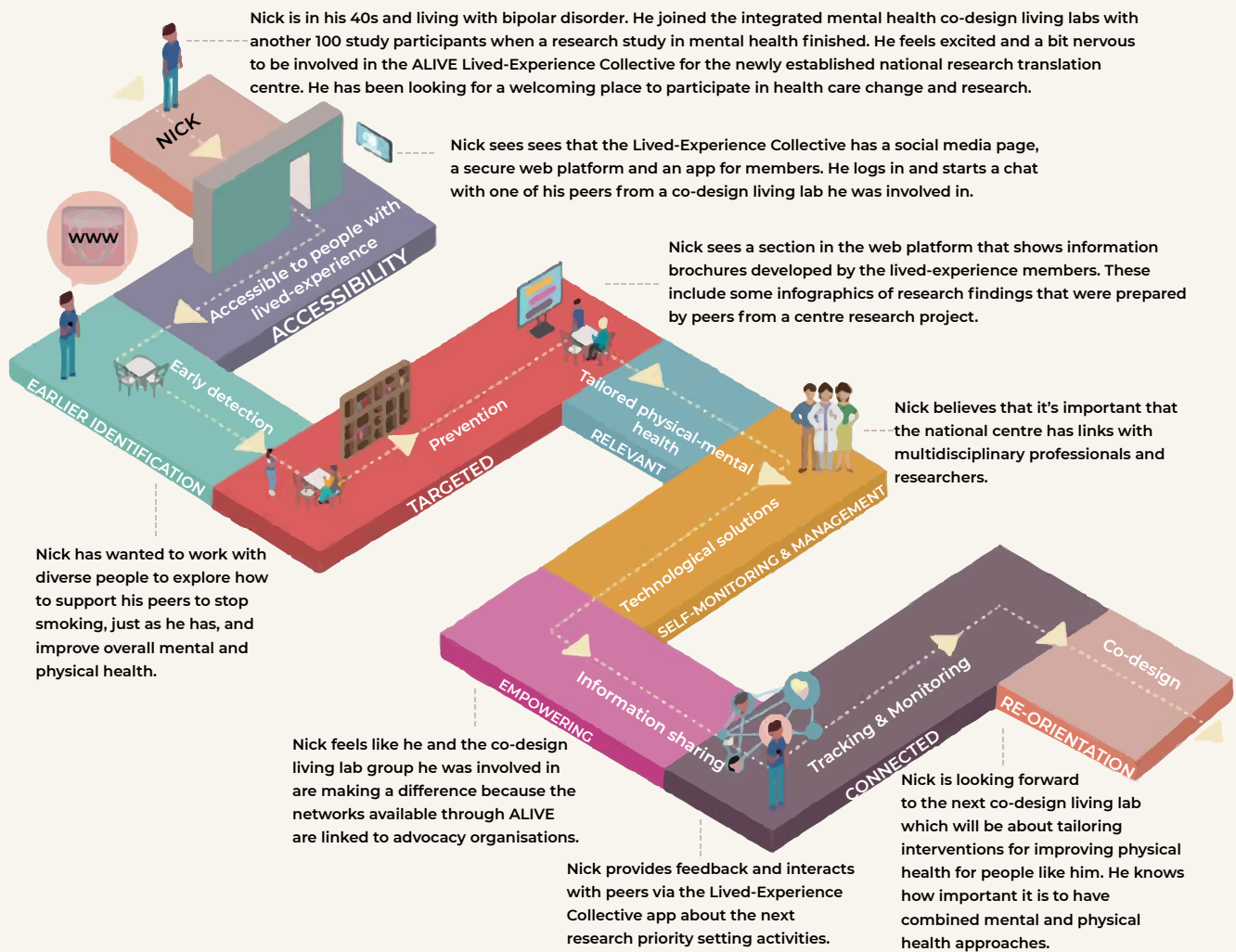
We use an 'opt in' approach where participants are invited to be part of a database and are sent information about opportunities to participate in co-design for research design to translation. Participants can choose what they participate in, they can take part one year and take a break the next, and are always reimbursed for their time.

Here is a diagram of the Co-Design Living Labs journey that highlights different co-design activities we undertake.



# PRIORITY SETTING EXAMPLE

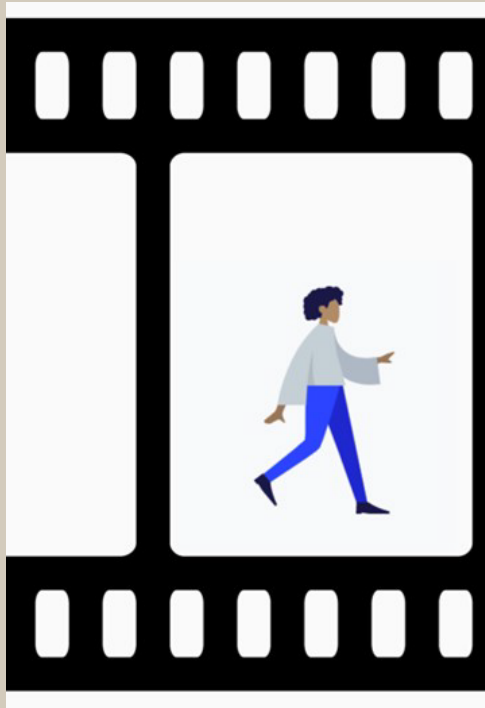
## An example of priority setting



Priority setting is about ensuring that the priorities of people who are most impacted by the focus of co-design are front and centre. It is also about ensuring priorities within experiences shape what is co-designed. Priority setting activities can vary and include understanding priorities about people's experiences before coming together to codesign. For this kind of exploration, we might use a method such as photo interviewing where co-designers take a photo to represent their views. Photos can then be used to provide different insights to experiences.

In this example we asked co-designers to share what was important to them for a National Mental Health Research Centre. We used an email dialogue approach to gather views from co-designers. There were 115 people who shared views. We then identified common themes or touchpoints from people's contributions. These touchpoints and themes shaped our vision for the ALIVE National Centre for Mental Health Research Translation pathways.

# IDEATION EXAMPLE



## An example of ideation for co-design

Below is an example of an ideation session for a project with carers who had participated in an online support program. The co-design objective was to explore potential improvements that could be made to the program. Co-designers were asked to explore interactivity within the groups, and the type of language they would use to describe the program. Co-designers were first reminded of the program's content and focus areas through a video 'play back' board.

This was to support content recollection and recognition of topic areas within the online program meetings. The conveners facilitated discussion as the sessions were played back and comments and ideas that related to increasing interactivity were added to digital post-it notes and the session playbacks. This was completed together as a group.



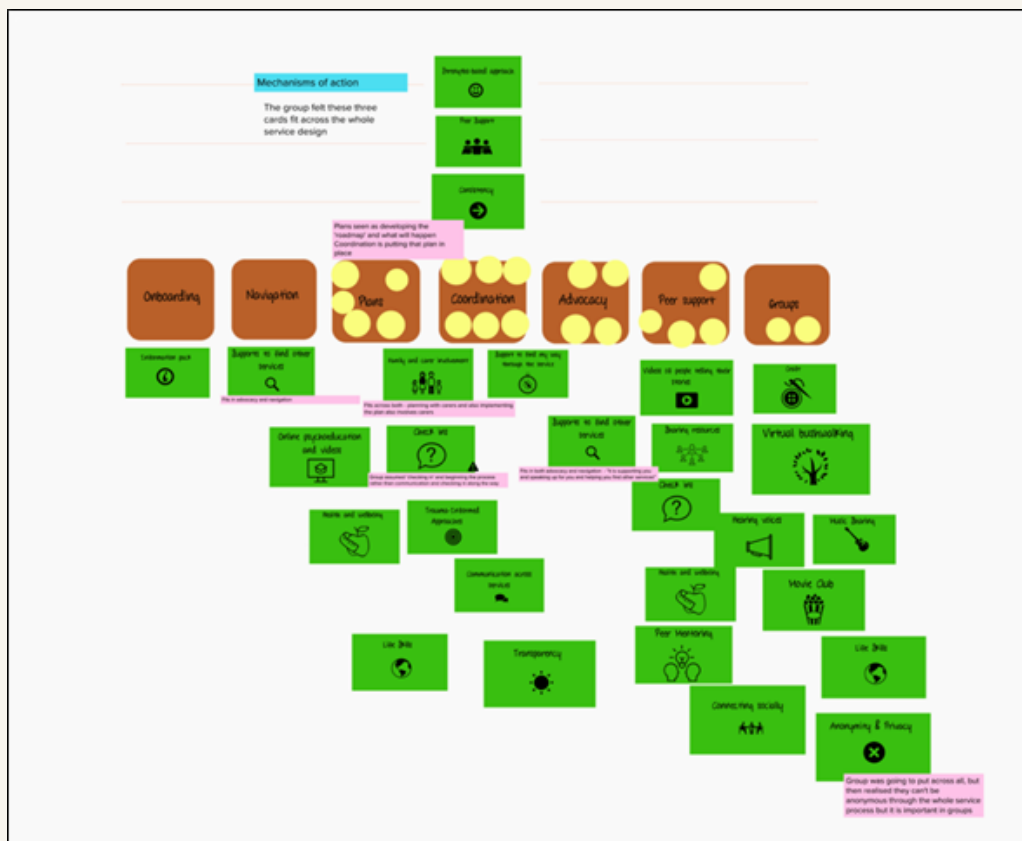
# MODEL OF CARE EXAMPLE



## An example of co-designing a model of care

Below is an example of an activity with co-designers who were involved in a co-designing a new model of care. The co-design objective was to understand what was important in a new digital service model for people with complex mental ill health experiences. The example image below shows a card sorting activity that was used to understand what was important to people. The group worked together to move the green cards (preliminary service concepts) underneath the brown cards (preliminary service structure). The group was then asked to indicate the three brown cards that they valued the most.

These votes are represented by the yellow dots. Through undergoing this process with a number of different participant groups, the key service concepts and structure for the service became apparent. A number of key aspects that were viewed as mechanisms of action (that is, what is needed to make this model successful and lead to the greatest benefits and outcomes) were also identified through this process. These were concepts that the groups thought fit across the whole service design and underpinned the entire service. These later developed into the service values within the final model.



# WHO IS INVOLVED

*"To be able to participate was important to me, as it gave me the chance to give feedback into an area of health research where I believe my "lived experience" may be able to help people in the future."*

*– Co-designer with lived experience of mental ill health*

*"The co-design sessions are important to feel a part of a team all working together to achieve better outcomes for all of us dealing with mental illness. It helps to overcome the stigma I still feel when mentioning my mental illness. Being in groups of people with shared experiences is very comforting in opening up discussions."*

*– Co-designer with lived experience of mental ill health*



## Who is involved in the Co-Design Living Labs Network?

[information will be included here about current members that gives a national overview of who is in the program and range of experiences people bring]

*“Participation in the Co-design Living Labs Program gives meaning to my journey. It gives me a voice and the hope that my contribution may: inform research; influence attitudes to health and wellbeing; change treatment models; assist policy makers; ease stigma and change community attitudes; cause medical professionals to consider their approach; and ease pain and provide the best quality life for all. (Not in this particular order.) Put simply, participation allows me to be heard and to feel that I count.”*

*– Co-designer with lived experience of mental ill health*

## Why this co-created handbook?



By now we hope our journey to getting here is clear for you. As we go national with the Co-Design Living Labs Network across universities in Australia, we will have new members joining and we will also continue to invite people from our research studies in the University of Melbourne too. As more people join, we think a Handbook by and for co-designers to co-design with who have been a part of this program (some since its very early beginnings) is important.

# OBJECTIVES

*"This too shall pass"*

*This quote relates to the temporal nature of all emotions.  
It helps with the difficult ones.*

*– By Dani*

*"I went along with an open mind, really interesting, more of an insight into what goes on, it was interesting to hear from different people who have similar problems, but come from totally different backgrounds, yet we all have similar problems. And knowing that you're sort of not in isolation which can sometimes be a bit of a problem when you get down and out, you can feel like you're the only one in the world but you're not."*

*– Co-designer with lived experience of mental ill health*

## Objectives

The specific objectives of this handbook by and for co-designers is to:

- Share the Co-Design Living Labs story with you all
- Provide some orientation and tips for new members (and existing ones!)
- Ensure any new co-designers know the importance of their role in the Co-Design Living Labs
- Outline what to expect when you co-design for the first time

Most importantly though, our co-design lead group have said that this Handbook is best as a living document – we want it to continue to be adapted and updated by co-design living lab members over time – just like the Living Labs model.

You are always welcome to make new suggestions or identify an area that you think could be covered and share your views to be included in the Handbook.

Contact us

([livinglabs-imhr@unimelb.edu.au](mailto:livinglabs-imhr@unimelb.edu.au)) to share something. If you are still thinking about taking part in a co-design session, on the next page we have shared what some of our co-designers have said about their experiences. From here you'll find some helpful tips and guides from our current co-design leads and members. There are also some inspiring quotes shared by co-design leads and members spread throughout the Handbook that help them through difficult times.

Now you have a bit of an idea about what the program is all about, we will introduce some of the advice and tips our co-design leads have shared so far....



# WHAT TO EXPECT

*"I went along with an open mind, really interesting, more of an insight into what goes on, it was interesting to hear from different people who have similar problems, but come from totally different backgrounds, yet we all have similar problems. And knowing that you're sort of not in isolation which can sometimes be a bit of a problem when you get down and out, you can feel like you're the only one in the world but you're not."*

*– Co-designer with lived experience of mental ill health*



## What to expect when attending a session

The main parts to attending a session are feeling prepared personally, consideration of the technology (if attending online) and feeling safe in the co-design space.

### Prior to the session

- When people sign up to attend a co-design session, they are sent a preparatory questionnaire prior to the workshop (see appendix). The questionnaire has been developed by previous co-designers who have shared their own preferences around what might be helpful to ask before sessions. By asking co-designers about any additional needs in advance, we can prepare and ensure your needs have been considered and addressed.

We have a specific version of the questionnaire which is sent to co-designers who identify as being from Aboriginal or Torres Strait Islander communities. This has been co-designed with the specific needs of co-designers from these backgrounds in mind.

- An agenda of the topics to be discussed in a workshop and a co-design objective is sent in advance so that co-designers can feel prepared. Any reading for the workshop or in between workshops is also sent in advance with as much notice as possible.



# GETTING STARTED

*"By being part of the Living Labs Co-designers program I am able to share the many years of experience of caring for my son with mental ill-health, so that in some small way this may assist in improving the plight of others so they have a more supported and inclusive future".*

*– Co-designer with lived experience of caring for someone with mental ill health*



## Getting started in the session

By Tricia | Creating safety and a welcoming environment

The convener of the workshop provides a safe space for expressing views and experiences.

- At the beginning of the session facilitators provide an Acknowledgement of Country prior to the session commencement. Facilitators include the Aboriginal name of the 'country' where they are joining the group from in their online name label (if the workshop is online). Co-designers are invited to share where they are joining from with the group.
- A culture of safety is fostered within the session by talking about principles of participation (see Attachment Working Together Agreements). These lay foundations for listening respectfully and working collaboratively. This is solidified by the completion of a matrix for group agreement at commencement of sessions that has been designed purposefully for group practices by Atkins et al. (2019). The convener of the workshop reiterates that all perspectives are valued and will contribute to research outcomes.

Other important points to note during the session:

- Time efficiency in the co-design sessions is important and the convenor will be mindful about sharing time together and keeping people on track.
- Sometimes feelings come up when you don't expect it. If feelings come up for you during a session, it is okay. Co-designers can always have a break when they need to or have a de-brief with a convenor.
- The aim of the workshop is to produce for difference, share differences in viewpoints and create resources that are alternative to the status quo.
- When attending a workshop, you are going to be asked about information that leads to an outcome or direction - you might need to give feedback or comment on something after the session. There is no pressure to contribute if you don't have time.



# WHAT TO PREP

*“Up until being involved in the Living Labs workshops I had only understood what my situation is and how my conditions impact me... I am also incredibly lucky to have internet access and proficiency in using online aids and services. It seems that not everyone is so lucky or their anxiety may not allow them to seek adequate assistance. It also made me understand that there is no one size fits all in how we can approach the idea of getting services to the people that need them.*

*The workshops I have been involved in allowed me to be a voice for the experiences that I see each day. It is always challenging to have an honest and open conversation especially when in a male dominated workforce. These experiences help me to inform the workshops as to what may be required for these areas. Having people with lived experience inform programs that can support is a crucial part of making sure the right services are being developed and implemented where they are required and where they will have the most impact. I have enjoyed attending and engaging in safe, open conversation and look forward to being involved in future programs.”*

*– Co-designer with lived experience of mental ill health*

## What could help to prepare for coming to a session?

Feeling prepared for a co-design session can be a different feeling for everyone. Some people may just simply need to know the day and time they need to attend, while others may need to spend time preparing in other ways.

We have included some strategies that help us prepare for sessions which might be helpful for others. We can continue to build on these strategies over time as our network grows. You can share anything you find helpful with us too!



*"What enables me to participate and not feel hassled/pressured is the regular scheduling, the communications as time for a session approaches, and having an idea of the agenda. As a carer, I'm used to being busy, and that is always more manageable if the timing is clear, the communication is good and the purpose/agenda is known"*

*- Tricia, co-design lead*

# ONLINE COUNSELLING

*“Meaning in life can get blurry at times, but Co-Design living labs can help with this.”*

*– Co-designer with lived experience of mental ill health*

# Online Meeting Etiquette

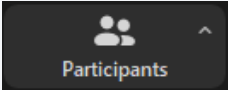
By Jarrad

To make sure this online session is run as best it can, we ask you to take a few moments to read through these tips for attending an online meeting. Specific examples for using different online software programs are included in the Appendix.



**Name/Pronouns:**

To change your name, and include your preferred pronouns or any other identifier, click on the

 **Participants**

participants button on the bottom of the page. Next, place your mouse over your name on the participants list on the right side of the Zoom window.

Your name here

More >



Click More, then select Rename.

Your name here

Rename

**Using the Mute function:**

We ask that you conduct these sessions in a quiet place, but sometimes noise is inevitable, especially when living and working with others. If you need to mute yourself, for whatever reason during the session, click the Mute button on the bottom of your screen. A red line will

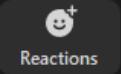
indicate you are muted.


**Lighting:**

Make sure there is enough lighting when you set up your computer/tablet/phone. It is best to sit near a light source, either window or electric light, so all participants can clearly see each other.


**Raising your hand:**

If you want to ask a question while someone else is speaking, please use the raise your hand function. To do so, click on the Reactions button at the bottom of the page, then select Raise Hand.

 **Reactions**

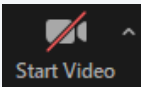
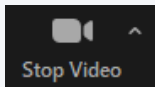
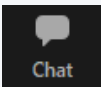
 **Raise Hand**

Once your question has been answered, you can lower your hand by again clicking the Reactions button and selecting Lower Hand.

 **Lower Hand**

**Keeping Your Video On**

We ask that you keep your video on during discussions. You can check if your video is on by clicking either Start Video or Stop Video at the bottom left of the screen.

 **Start Video**  **Stop Video**  **Chat**

If at any stage, you would prefer to turn your video off please let the convenor know by writing a message in the chat. To access the chat function, click the Chat button at the bottom of your screen.

# SELF-CARE

*"Being a member of the carer co-design group allows me to try to make a difference by expressing the barriers we experienced for decades to get help for someone we love after diagnosis of a serious, lifelong mental illness. Hopefully my contribution can improve the journey and support services available for loved-ones towards better outcomes. For me, this process has facilitated open and honest discussions, respectful sharing of ideas and a format for hope and change to mental health services in Australia. Talking with key academics and researchers who can guide government policy and funding into areas that our consumers and carers feel are important to facilitate worthwhile support and programs for recovery and well-being."*

*– Co-designer with lived experience of caring for someone with mental ill health*

## Self-care strategies

By Nargis

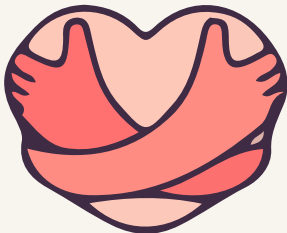
Co-designers shared the following things they've learned from being engaged in activities and the program over the years. Co-designers said, when attending a session, it is important to look after yourself first. Self care means slowing down and looking after ourselves a little bit more. Having a designated time before and after a session can be helpful to reflect and allow yourself time to have a mental break.

This can include preparing some strategies for the session and using some strategies for afterwards.

These tips were provided by Nargis in one of the conversation groups to co-create this handbook.

Sometimes it's good to think about what you need personally for self care during a session, some ideas are:

- Use a fidget toy
- Wear a weighted blanket
- Have a warm beverage with you
- Sit in a comfortable seat
- Have water with you
- Step away and take a break if you need to



*"We can't help everyone, but everyone can help someone"*

*- John Lennon*

*(chosen by a Co-Design Living Labs member as a way of describing what the program means to them)*



# SELF-CARE

*"This is so important. I feel like I'm doing something purposeful in these times when I'm feeling so shit all the time. Doing these sessions makes me feel like I'm contributing."*

*– Co-designer with lived experience of mental ill health*



Self care is as important following a co-design session – sometimes the conversations we have and the activities we have worked in stay with us and it can be important to think about how to wind down and relax. Ways you can check in with your well-being can include:

- Journaling
- Meditating
- Yoga
- Going for a walk
- Listening to a podcast
- Watching TV
- Having a nutritious meal
- Just sit for a while and get thoughts clear for about 10 or 15 mins
- Reaching out to a friend for support or catching up for a coffee



*"Remember; self care is not self indulgence, it is self preservation"*

*- Audre Lorde*

# GLOSSARY



## Glossary

By Elise

ALIVE	“The centre is a collective effort that harnesses the creative potential and research excellence of individuals, universities, primary and community care organisations to improve experiences of care and address life expectancy gaps of priority populations. We bring research, implementation and translation together.” (from <a href="https://alivenetwork.com.au/about-us/">https://alivenetwork.com.au/about-us/</a> )
Carer	A person who cares for and supports a person with mental illness or distress. This includes family and kinship group members.
Co-Design	Bringing people together who have an interest in a particular topic, to discuss and design outcomes for that topic, and to make change. A key component of co-design is about sharing power and knowledge while challenging the power imbalance between people who may traditionally have made decisions over others.
Co-Design Living Labs Coordinator	The person who organises and contacts people to arrange the co-design living labs.
Co-Design tools and techniques	The methods used in co-design sessions that are applied with particular intended outcomes.
Collaborate	Work jointly on a co-design activity.
Convenor	A person leading the co-design session who helps to guide the process and supports achieving co-designed outcomes.
Co-designer	A person taking part in co-design who is a member of the program.
Co-produce	Create an outcome together using co-design.
Co-researchers	Researchers with lived-expertise of a particular issue or condition.

## Glossary

End to end research process	Research from the beginning (including designing the research and setting priorities) to the end (including translating and implementing the research findings into practice).
Evaluation	“The process of judging or calculating the quality, importance, amount, or value of something.” (From the Cambridge dictionary)
Ideation	“The process of forming ideas and images.” (From <a href="https://dictionary.apa.org/ideation">https://dictionary.apa.org/ideation</a> )
Implementation	Putting the decisions into effect. In a health context this means putting the outcomes of research into practice. This can be through policies, programmes or services.
Innovation	“Innovation is the creation, development and implementation of a new product, process or service, with the aim of improving efficiency, effectiveness or competitive advantage.” (From <a href="https://drkenhudson.com/best-way-define-innovation/">https://drkenhudson.com/best-way-define-innovation/</a> )
Living Labs	A ‘Living Lab’ is about the everyday - our lives and where we live, work, learn, and play. Living Labs are about exploring and creating what’s needed together in live settings dependent on the context. Working together, a Living Lab offers the potential for private-public-partnerships to co-create new technologies, solutions and co-design research projects and materials.
“Opt in”	An approach where participants are invited to be part of the Co-Design Living Labs database and are sent information about opportunities to participate in co-design sessions. Participants can choose what they participate in.

## Glossary

Power sharing	Power sharing is a key aspect of co-design. Sharing power involves all people who are part of the co-design process being considered equal. If the power between researchers and participants (or healthcare workers and people with lived experience) is shared, this contributes to a richer experience and more genuine research outcomes. When co-designers contribute a variety of different perspectives to research and when these perspectives are valued as equal, the outcomes can be more useful to the wider community.
Prototype development (Intervention/Apps/Tools/ Technology)	A working draft of the final product.
Research priority setting	Brainstorming and setting the priorities for the research. In co-design this involves working out what important for people with lived-experience and carers/kinship group members to ensure that research being conducted reflects this.
Stakeholders	People who have an interest in the co-design process or service development.
Service Users	Someone who uses health services.
Study Design and material development	Selecting the materials needed for the study.
Togetherness	Being together through co-design where researchers and people with lived experience collaborate, support each other and be creative by co-creating knowledge about a topic.
Translation	Research translation is putting research outcomes into the real world. For instance, GPs putting into practice the newest research outcomes. .

# KEY CONTACTS

## Key Contacts

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# APPENDICES

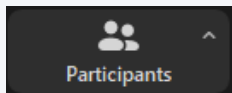


## Appendices

### Tips for Using Zoom Online Software to Attend a Virtual Meeting

#### Name/Pronouns:

To change your name, and include your preferred pronouns or any other identifier, click on the



participants button on the bottom of the page. Next, place your mouse over your name on the participants list on the right side of the Zoom window.



Your name here

More >

Click More, then select Rename.



Your name here

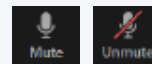
Rename

#### Lighting:

Make sure there is enough lighting when you set up your computer/tablet/phone. It is best to sit near a light source, either window or electric light, so all participants can clearly see each other.

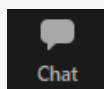
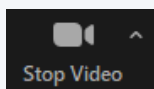
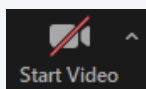
#### Using the Mute function:

We ask that you conduct these sessions in a quiet place, but sometimes noise is inevitable, especially when living and working with others. If you need to mute yourself, for whatever reason during the session, click the Mute button on the bottom of your screen. A red line will indicate you are muted.



#### Keeping Your Video On

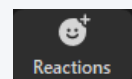
We ask that you keep your video on during discussions. You can check if your video is on by clicking either Start Video or Stop Video at the bottom left of the screen.




If at any stage, you would prefer to turn your video off please let the convenor know by writing a message in the chat. To access the chat function, click the Chat button at the bottom of your screen.


#### Raising your hand:

If you want to ask a question while someone else is speaking, please use the raise your hand function. To do so, click on the Reactions button at the bottom of the page, then select Raise Hand.



 Raise Hand

Once your question has been answered, you can lower your hand by again clicking the Reactions button and selecting Lower Hand.

 Lower Hand

# PRINCIPLES

IN ALL OF THE CO-DESIGN LIVING LABS PROGRAM OF WORK WE ACKNOWLEDGE THE TRADITIONAL CUSTODIANS OF THE LANDS ON WHICH WE MEET AND PAY RESPECTS TO ELDERS PAST AND PRESENT.

THIS IS OUR WORKING TOGETHER AGREEMENT FOR THE CO-DESIGN SESSIONS THAT THE PRIMAY CARE MENTAL HEALTH RESEARCH PROGRAM CONVENE (ETHICS APPROVAL NO: 1954193.2). THESE ARE REVIEWED TOGETHER AS A GROUP AT THE START OF A SESSION AND we encourage everyone to share additional PRINCIPLES they feel are important BEFORE WE GET STARTED.

THESE HAVE BEEN FORMULATED FROM OUR establishment in 2017 AND ARE BASED ON AN EXPLANATORY THEORETICAL MODEL FOR CO-DESIGN AND CO-PRODUCTION (SEE LINK BELOW). WE HAVE ADAPTED THESE MECHANISMS OVER TIME – we see this as central to setting THE TABLE FOR CO-DESIGNING TOGETHER.

## Principles of participation statement

THINK OF THE eight PRINCIPLES/mechanisms WITH THE FOLLOWING IN MIND,  
“at all times we agree to”:

### 1. Recognise

- that we all bring lived-experience to contribute to the group, and we agree to value what you say, and always treat you with respect as co-creators.
- sometimes we hold a different point of view, and we will all listen respectfully to the views all people have for sharing in the group.
- acknowledge that conflict happens — and that diverse points of view all deserve attention and respect.
- fostering a free, but always respectful conversation. Though conflict is okay, conversations should always be conducted with civility and respect, everything talked about within a meeting is treated as confidential.
- that feeling safe is important, while there are different views these can be shared with consideration and sometimes we also may experience discomfort and it's okay to talk about that.

### 2. Dialogue

- that or roles in co-design meetings are a part of a dialogue, with multiple voices and backgrounds.
- accept that people will not always agree.
- that we commit to valuing all points of view as part of the conversation to foster healthcare improvement where ever possible.

### 3. Co-Operation

- is collaborative. We recognise that co-design meetings are a collective effort that can make a difference.
- to work together as equals and collaborators in research – knowing sometimes we might have to work on power differences as researchers and co-design members.
- to work together, alongside participants to change research and influence practice and policy using research to inform this.

### 4. Accountability

- to be accountable to each other.
- be transparent and open with co-designers about the outcomes of research and to value your co-productive efforts when contributed within research, service design or health care improvement studies.
- to share the outcomes of research and providing opportunities for participants to engage at all stages of the research cycle.

# PRINCIPLES

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## Principles of participation statement

### 5. Mobilisation

- to put what we learn, create and build in meetings into action in research and translate this to government and practice where applicable.
- to acknowledge that our program works primarily work to improve healthcare design, delivery and transformation and this can take time to implement and see change in.
- to acknowledge that these meetings are shaped by experiences, but we share these to help shape the research process and do not have to share our full stories in co-design meetings.

### 6. Enactment

- to use what co-design produces to change the mental health and healthcare system broadly.
- to implement (as much as we can) from the outcomes of meetings in order to improve the mental health research and, as a result, the mental healthcare system.
- to be collectively committed to implementation where ever possible.
- to recognise that we cannot change everything that we seek to change – sometimes important changes are smaller than the bigger ones and sometimes we do not have the resources to change the big issues.

### 7. Creativity

- to creatively engage in the meetings, to use explicit use of co-design techniques, tools and activities for ideation to creation.
- to producing creative and engaging ideas to be used in meetings.
- to find imaginative ways to run the meetings, so that meetings in turn spur your creativity.
- to thinking creatively alongside you.

### 8. Attainment

- to improve research and change in mental healthcare design, delivery and improvement.
- to do everything we can to improve the way research is done in Australia and around the world to honour lived-experience and collectively celebrate the strengths we all bring.
- to improving the mental health system in all its forms, and at all stages of care.
- to a space of co-creation, to ideate and share the things that we sometimes think are a good idea but may not be 100% possible.
- to encourage people to share ideas no matter how much they think they cannot be done because by working together we might find a way to do this—you never know?

# PARTICIPA QUESTION

# ATORY NAIRE

1

Everyone comes from different backgrounds. We want to ensure we refer to you and work in ways that you are comfortable with. What name would you prefer to be called during the session?

We recommend when online you just share your first name too.

2

Would you like to s

START

We'd love to hear more about why this co-design topic is of interest. Please share here:

12

## Preparing our ta work together as signers

To make our co-design table as space as possible, we'd love to know about you and your n  
Please pop in some answers to questions.

Thank you for giving your time a to co-design with use. We're looking forward to meeting. Your perspectives are and will help to co-create change in health care system. We value you and you will be reimbursed for your time.

Let's get started.

11

Sharing with other people who we do not know can feel different - is there anything else to share how about we can support you during co-design sessions?

10

9

We usually use a video platform for online co-design - do you need help to download the app or for logging on ahead?

☐ Yes please

☐ No, I should be fine on my own

Is English your first language?

☐ Yes

☐ No

If no, do you require an interpreter in meetings?

☐ Yes

☐ No



Share your pronouns? If so, please add these here:

Is there anything else we should know about how you identify?

3

4

Do you have any needs that help express yourself with confidence? (equipment or carers)

5

Are there people who you would like to involve? (Carers, Aunty, Uncle or Health Worker)

6

How can we best communicate with you during the session?

- ☐ I use a screen reader so I might need more time to respond;
- ☐ I am bringing a support person to help me communicate;
- ☐ I am non-speaking and prefer the chat function.
- ☐ I can communicate verbally and through text;
- ☐ Other (please describe your needs)

8

How would you prefer us to share information ahead of meeting?

- ☐ With large text print
- ☐ In a PDF or Word document
- ☐ In black/white not colour
- ☐ I use a screen reader
- ☐ I don't have a preference

Are you comfortable with communicating ...

- ☐ Speaking
- ☐ Using the video function
- ☐ Using the chat box
- ☐ I need a bit of time to think about things before I contribute
- ☐ I am fine with all of these

7

START

1

What is your name?

2

What is your mob?

3

What are you from?

14

We'd love to hear more about why this co-design topic is of interest. Please share here:

Sharing with other people who we do not know can feel different - is there anything else to share how about we can support you during co-design sessions?

We usually use a video platform for online co-design - do you need help to download the app or for logging on ahead?

☐ Yes please
 ☐ No, I should be fine on my own

Is English your first language?

☐ Yes
 ☐ No

If no, do you require an interpreter in meetings?


☐ Yes
 ☐ No

Preparing to work together

To make our co-design table as comfortable as possible, we love to learn a bit more about you. Please pop in some answers to the questions below.

Thank you for giving your time and expertise. We're looking forward to meeting. Your input is valuable to us and will help to co-create change in the health system. We value your time and you will be compensated for your time.

Let's get started!


 The ALIVE National Centre  
for Mental Health  
Research Translation

Funded by the NHMRC Special Initiative in Mental Health (2021-2026).  
 These questions have been adapted with permission from '5 Top Tips'  
[shops-2/?cookie-state-change=1633379779396](https://www.5toptips.org.au/shops-2/?cookie-state-change=1633379779396) | Thank you for the c

...

Would you like to share your pronouns?  
If so, please add these here:

4

How do you identify?

5

6

Do you have any needs that help express yourself  
with confidence? (*equipment or carers*)

7

Are there people who you would like to involve?  
(*Carers, Aunty, Uncle or Health Worker*)

## er as Co-Designers

able a space as possible, we'd  
you and your needs.  
these few questions.

periences to co-design with  
your perspectives are valued  
e in the mental health care  
be reimbursed for attending.

d...

10

8

How would you prefer us to share information ahead  
of meeting?

- ☐ With large text print
- ☐ In a PDF or Word document
- ☐ In black/white not colour
- ☐ I use a screen reader
- ☐ I don't have a preference

9

Are you comfortable with communicating ...

- ☐ Speaking
- ☐ Using the video function
- ☐ Using the chat box
- ☐ I need a bit of time to think about things before I contribute
- ☐ I am fine with all of these

WHO ARE THE  
CO-DESIGN  
LIVING LABS  
CO-LEADS?

ANN  
ELISE  
GREGOR  
NARGIS  
BEV  
PAM  
TRICIA  
SARAH

ANN



I became involved with Living Labs following my participation in the Diamond Cohort Study. This study was undertaken by the University of Melbourne over a 10 year period. During this study participants completed surveys regarding their day to day lives, their depression, stress related problems, treatments, the support received and general involvement in the community.

My journey with the Co-designs Living Labs has been a wonderful opportunity to share my experiences with others who have suffered depression or been carers. Each participant is given an opportunity to contribute ideas and opinions about diagnosis, treatment and outcomes.

As a group we have opportunities to contribute information regarding what worked for us and what didn't meet expectations. I always feel safe and supported when with this group of people. Being part of the group has given me confidence and a feeling of not being alone in my journey to wellbeing.

ESTATE





Elise is a lived-experience collaborator in the ALIVE centre at the University of Melbourne. She has lived expertise of mental health for nearly two decades and she has been involved in the co-design living labs for six years. She joined co-design living labs in 2017, after being a participant in the CORE study at the University of Melbourne. The CORE study looked at service improvement of Mental Health services using co-design.

Elise loves the opportunity to be involved in something so much bigger than the individual. She finds it exciting to be involved in the co-design living labs because they bring lived expertise to the forefront of the discussion and decision making. People with lived expertise bring a diverse range of abilities to the co-design living labs and hopefully through the ALIVE network, people will not just feel listened to, there will be better health outcomes for all people with lived expertise. The roll-out of co-design living labs is exciting.

# CREGOR



I first became involved with the co-  
program through the CORE study. I  
accessed the Personal Helpers and  
program through Eastern Access Co-  
(EACH). After attending several of the  
became aware that there was to be  
called living labs. I jumped at the op-  
recognized that there needed to be  
people who identified as having a li

I am passionate in advocating change within the Mental Health system. I believe that the system needs to evolve to become a more user-friendly system, as well as breaking down the stereotypes, stigmas, and exclusion, which many people with a lived experience experience. I am also interested in utilizing Indigenous knowledge to provide a more caring system in which local connection to community and surrounds can be established for people with a lived experience. People with a lived experience can often feel excluded from community due to how they are perceived by the dominant society.

Although I never went through the whole Mental Health system, I did have friends who went through the system. This included being admitted and then released into a PARC facility. I also witnessed the struggles a close friend had through the private Mental Health system and visited the Melbourne clinic several times to visit him. After my recovery from my own experience, I have been working with National Disability Insurance Service (NDIS) and have had the need to visit clients in the Unit 1 Maroondah hospital and Murnong. This has given me an appreciation, as to the strengths and weaknesses of the present Mental Health system and gained knowledge from people with a lived experience.

My own experience has included recovery from several traumas. These include adopted, my parents' divorce and 10 years ago a Brain Hermitage, which led to me having to retrain and face my fears in the Academy. I would also express that I suffered from doubting my ability growing up, as I had a high achieving family member, who I did not feel able to achieve the same standard which he had set. I continue to suffer from social anxiety when placed in intimidating spaces. Usually this is when I feel inadequate to compete with others surrounding me. My permanent disability from my Acquired Brain Injury (ABI) also impacts me when I am tired, ill or trying to exercise high level cognitive activities.

design living labs  
At the time I had  
Mentors (PHaMs)  
Community Health  
the CORE sessions, I  
a follow up program  
opportunity, as I  
more input from  
lived experience.

**NARGIS**



I got involved years ago during a depression study that the university of Melbourne was conducting.

I love being able to share my insights as someone with lived experience and have those contributions honoured.

I have Post Traumatic Stress Disorder, Persistent Depressive Disorder and Borderline Personality Disorder.

BEV



I experienced depression after the birth of my second son; many years later because of this experience I was asked to be part of the Melbourne University 10 year Diamond Study of Depression. After this study finished, I was invited to be part of the Living Labs Program as by then I had considerable experience as a carer of my eldest son who was diagnosed with Obsessive Compulsive Disorder at the age of nine. In the ensuing years he endured other manifestations of extreme anxiety and mental ill-health.

It excites me to be part of the co-design program because our experience can help to make the changes desperately needed to develop better understanding, support and treatment for those with mental ill-health. Contributing our knowledge, and sharing our personal experience, puts us at the forefront of initiating change.

My son lost his battle with mental ill-health almost a year ago, and I want to assist in improving the lives of others who are suffering as he did.

In my experience supporting my son when he was suffering severe depression, and at other times when he was paralysed with anxiety, I could not access the professional help he needed. Often I was told the help needed was not available for days, weeks or months. At other times I was told to come back Monday to Friday 9 to 5pm which is not helpful when mental ill-health is with a person 24 hours a day 7 days a week. I felt so impotent as his anguish and pain increased.

# PAM



I became a carer 15 years ago when her 2 children came to live with us. 14 months and a new born. My step struggling to stay engaged with her going out at night, doctor shopping department and, pretty much, leaving care. We thought she might have p something similar – a while later sh serious, lifelong mental illness.



my step-daughter and  
The children were aged  
-daughter was  
r children and kept  
g, at the emergency  
ing the children in our  
ost-natal depression or  
e was diagnosed with a

So, with no support, just a brochure, we were looking after 2 children under 2 years old and an adult with many complex mental health needs. I reached out to a local carer support group to seek some advice and help. There was a longitudinal study being conducted by Melbourne University which was a survey on what carers' were experiencing and needed - so I responded and that began my involvement with Melbourne University.

I am fully aware of the difficulties faced trying to access specialised services let alone, in a regional area. As a family, we have been on a journey through many service areas to seek support and guidance and this has also made me very conscious of the barriers facing carers while they try to help someone with a life-long mental illness to stay engaged in programs tailored to assist them. I have enjoyed being involved in this project as I have had the opportunity to share my experiences and be part of a team who are trying to improve support services. In particular, my focus has been recognising and highlighting the role of the people who care for and about family members with mental illnesses while also trying to navigate such a complex system of agencies.

I hope my participation is useful and can continue.

**TRICIA**



I am retired from 35 years' lecturing and researching in applied linguistics. My lecturing focused on sociolinguistic and linguistic underpinnings to second language acquisition; my research focused on first language acquisition, on the adult talk addressed to young children with and without a speech delay, and its influence on their language development. During my lecturing years, I took time off to work in developing early intervention programs for young children with special needs.

I am also the wife of a small business man, and mother of two adult sons, one who is seriously disabled by cerebral palsy and Complex Trauma/PTSD. This experience has required me to become engaged in many of the mental health services offered to young adults in our region, northeast Victoria. My son has been unable to access these services without support because of the serious impairments caused by his cerebral palsy.

In the course of helping my son access mental health services, I joined a co-design project to evaluate services provided by a regional mental health support service. This introduced me to co-design. While I had been accustomed to being involved with services for people with disabilities, I had never been asked even for feedback from mental health service providers. Now, I welcome the opportunity to have a conversation with other carers, to have a voice, and I feel more hopeful that there will be useful and informed changes in services.

