



National Community Consultation Program Final Report

Lived Experience leading the exploration of how digital products
and engagement change the way people experience
mental health care and well-being.

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Table of Contents

Background	01
The National Community Consultation Model	02
The voice of lived experience	02
Guiding principles	03
Intended outcomes	03
Where we went and what we asked	04
What do people want from a digital mental health solution?	05
People do search online for mental health information and support	05
Language is important	05
Person centred solutions are essential	06
Access to digital solutions is not a reality for all	06
People have data privacy concerns	07
People trust lived experience	07
What we learned along the way	08 - 09
In summary	10

“**Lived experience, alongside clinical, professional, industry and academic experience is fundamental for co-producing service improvement.**”

Guiding principle agreed at the
inaugural Lived Experience Advisory Board, meeting October 2017

”

Background

The Australian Government Department of Health provided funding to InnoWell Pty Ltd for the conduct of Project Synergy, a research project, to ensure the further development and refinement of the InnoWell Platform. The InnoWell Platform aims to support the delivery of right mental health care, at the right time.

InnoWell is committed to redefining how people with a lived experience of mental ill health are involved in the development and design of digital mental health products, services and research. This commitment is shown in the Project Synergy National Community Consultation Program (NCCP) designed and led by lived experience to explore and gain insight into the overarching question:

**How might digital products and engagement
change the way people experience their mental health care and wellbeing?**

The InnoWell National Community Consultation Program (NCCP) is lived experience led community consultation that uses both digital and face-to-face strategies to engage with individuals with a lived experience of mental ill health and their support networks, across the Australian community, in an effort to optimise diversity, reach and inclusion and thus ensure a rich tapestry of experience and input to inform the building and implementation of the Platform.

Community consultation is genuine partnership between community and service providers, and whilst research regarding the benefits and importance of community engagement varies, several key opportunities are identified in organisations that demonstrate meaningful community consultation and engagement. Among these are:

- **Increase in the likelihood that projects or solutions will be widely accepted.** People who participate in these community consultation and engagement processes show significant commitment to help make the projects happen.
- **Creating more effective solutions.** Drawing on local knowledge from a diverse group creates solutions that are practical and effective.
- **Empowering and integrating people from different backgrounds.** When people from different areas of the community work together, they often find that they have much in common.
- **Creating local networks of community members.** The more people who know what is going on and who are willing to work toward a goal, the more likely a community is to be successful in reaching its goals.
- **Increasing trust in organisations and governance.** Working together improves communication and understanding. Knowing what government, community citizens and leaders, and organizations can and cannot do may reduce future conflict.

(Adapted from Bassler,
A. et al, "Developing Effective Citizen Engagement:
A How-to Guide for Community Leaders." Center for Rural America, 2008).

Underpinning the model is a co-design framework that is governed by the Lived Experience Advisory Function (LEAF) model, a collaboratively refined model of engagement to better support co-design. The LEAF is comprised of a diverse group of lived experience champions who work together to identify issues while sharing advice, guidance and recommendations to InnoWell and Project Synergy from a lived experience perspective. Co-design is about working together. It is based on the simple acknowledgement that consumers, carers, families, and community know what works best for them.

The National Community Consultation Model

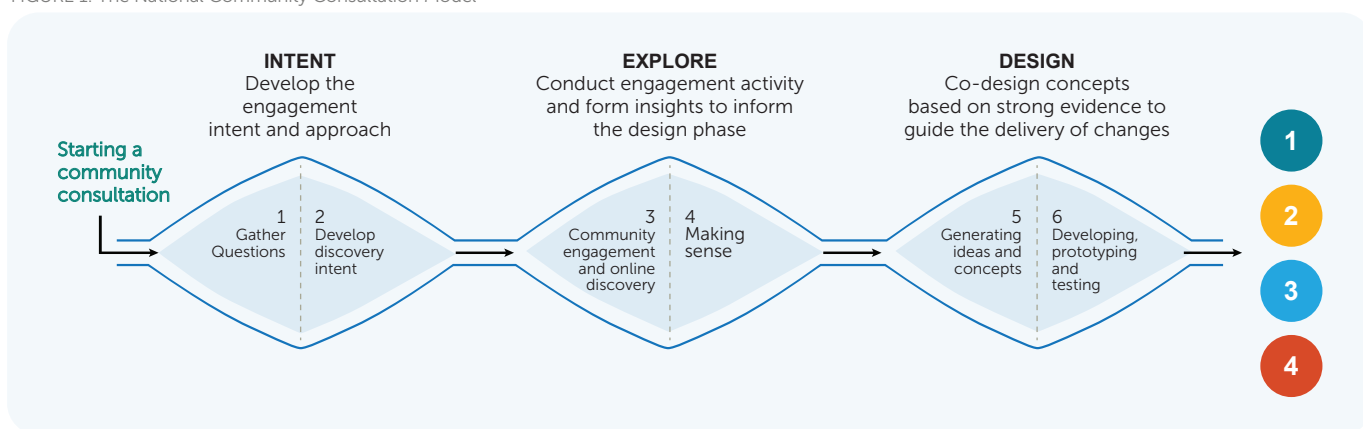
The National Community Consultation Program (NCCP) is led by lived experience and utilises a co-design framework, and includes both digital and face-to-face strategies with individuals with a lived experience of mental ill health and their support network, to ensure a rich tapestry of experience and input. The Program is conducted by lived experience for lived experience and aims to advance knowledge, challenge assumptions and test hypotheses.

The NCCP has two objectives:

1. Deliver on the needs of Project Synergy by engaging and supporting a community network of people with a lived experience of mental ill health to inform the building and implementation of the Innowell Platform
2. In the longer term, the NCCP can inform mental health service reform, one that uses technology as a vehicle to providing better long-term outcomes for people, families and services – ‘right care, at the right time’.

The activities of the National Community Consultation Program are designed and led by the InnoWell Lived Experience Advisory Function (LEAF) working group utilising the National Community Consultation Co-Design Framework.

FIGURE 1: The National Community Consultation Model



The voice of lived experience is embedded in each stage of the co-design framework that guides the NCCP and utilises a six-step process:

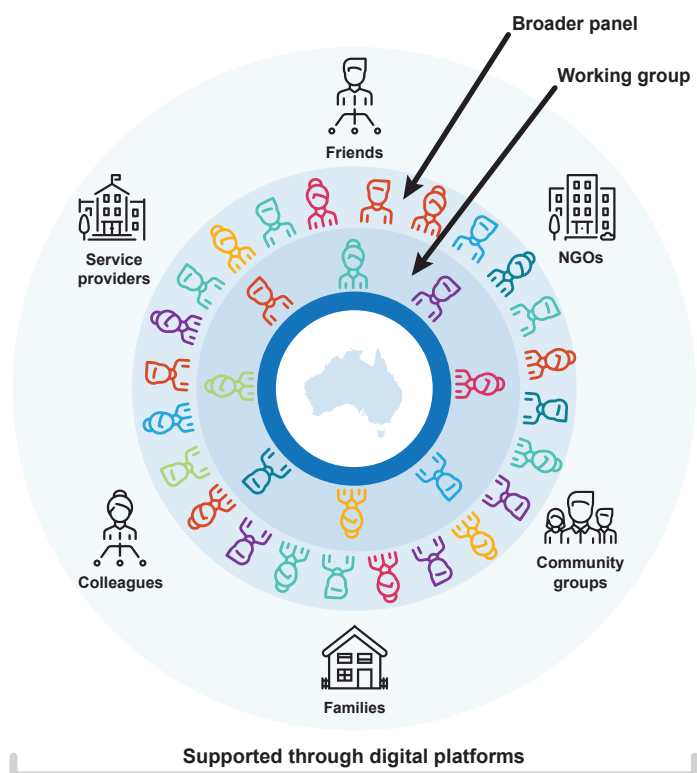
1. Gather questions
2. Develop discovery intent
3. Community engagement and online discovery
4. Making sense
5. Generating ideas and concepts
6. Making recommendations that inform one of four key outcome streams (see intended outcomes on the right)

All information gathered through consultation activities is fed back through the co-design framework and into one of four outcome streams:

- 1 Digital product development (improvements, enhancements and/or new features).
- 2 Implementation related service level improvements.
- 3 InnoWell governance, process and procedures improvements.
- 4 Presentations, reports or publications that contribute to the broader mental health policy reform agenda.

The voice of lived experience

The InnoWell Lived Experience Advisory Function (LEAF) model is a collaboratively refined model of engagement to better support co-design. The LEAF is made up of a diverse group of lived experience champions who work together to identify current and emerging issues while sharing advice, guidance and recommendations to InnoWell and Project Synergy from a lived experience (LE) perspective.



LEAF Working Group members act as champions and bridges to their communities to maximise reach of the project and in order to bring back the most current information of the views of their communities. This model of engagement and framework was co-developed during Phase I of Project Synergy in order to produce genuinely lived experience designed and led engagement activities, thus maximizing potential to provide input into Project Synergy activities, while ensuring meaningful engagement with people within the mental health space.

The LEAF Working Group meet monthly and use the co-design model to prioritise and co-develop engagement activities at each phase of the timeline. NCCP engagements and questions are prioritised, designed and executed by the LEAF Working Group with the support of the broader LEAF Panel.

These activities are ongoing throughout the NCCP to develop the engagement intent and approach and ensure the meaningful contribution from those with

lived experience. All information gathered through consultation activities is fed back through the co-design framework and into one of four outcome streams. The iterative process meant that we could be agile and responsive to the identified needs of different communities.

The identified community and stakeholders for the NCCP activities includes all Australians, particularly individuals with a lived experience of mental ill health and their support networks. We focused on gaining the perspective of a broad cross-section of the community, including those who live in urban, rural and remote areas, Aboriginal and Torres Strait Islander people, those who identify as LGBTI, Veterans, refugees and those from culturally and linguistically diverse backgrounds.

Guiding principles

The principles of the LEAF at InnoWell and they extend to everything that we do as part of the NCCP.



Intended outcomes

The intended outcomes of the National Community Consultation Program are to:

- Use a model that enables those with lived experience to ask others with lived experience; **“How might digital products and engagement change the way people experience their mental health care and wellbeing?”** and to use their findings to inform the co-design of the InnoWell Platform and its implementation in Project Synergy trial sites.
- Use the voice of lived experience to improve and identify what is needed in order to deliver an effective digital mental health solution, one which is fit-for-purpose and will be utilized – **‘right care, at the right time’**.

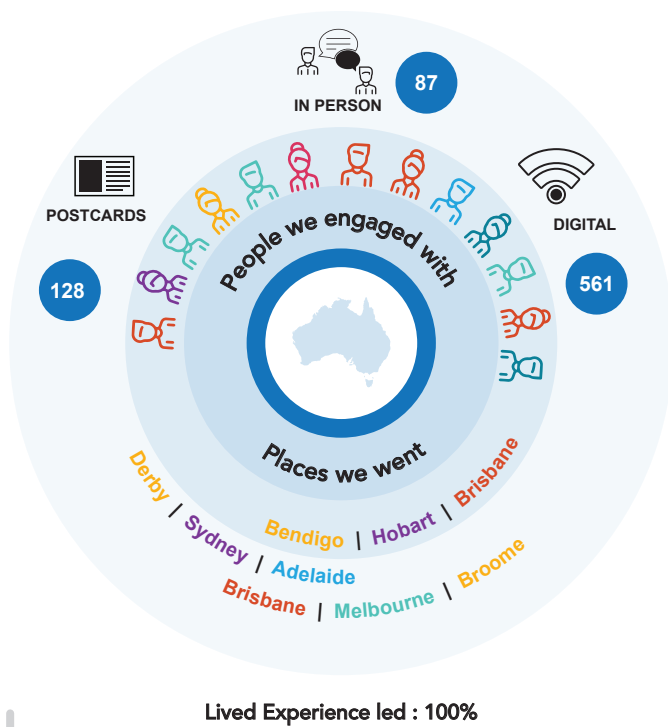
Where we went and what we asked

The LEAF working group co-developed several communication tools to explore how might digital products and engagement change the way people experience their mental health care and wellbeing.

Key themes explored included:

1. What motivates people to use a digital solution?
2. What barriers do they face in accessing one?
3. What keeps them engaging once they are there?

These themes underpinned all consultation activities - whether that was digital (survey, postcards, quick online polls) or face-to-face engagement (community event or focus group).



Engagement methods used

Recruitment strategies included a mix of:

- LEAF member networks and communities
- Social media
- Sector and stakeholder networks
- Other channels specific to local communities/ target audiences, ie. Aboriginal Elder's groups

Between November 2018 and April 2020, the LEAF working group held 13 in person meetings and round table forums with the four voices of co-design. Utilising the NCCP co-design framework, LEAF designed, planned and ran five digital engagements, eight face-to-face consultations and two community engagement events across Australia.

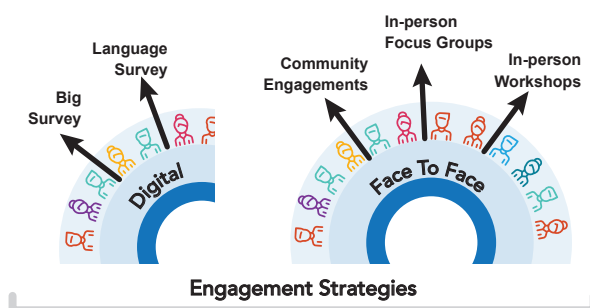


We had varied success with these engagement tools and consistently reviewed and adapted according to reach and impact.

Planning and recruitment of the digital and face-to-face activities were designed and led by members of the LEAF working group.

The nine face-to-face engagements were facilitated by a LEAF working group member, with understanding of the community being represented. The group co-developed the appropriate recruitment strategy, information and consent forms, and Participant Evaluation form. All focus group participants were paid for their time and expertise.

The contact details for a clinical psychologist was offered to all participants to ensure their emotional safety on and after the day. We fed back a snapshot of the initial findings to each community and continued to inform them via email of the progress and outcome of the broader community consultation.



These findings were used to inform the co-design of the InnoWell Platform, its implementation in Project Synergy trial sites in real time, and to identify the following key principles. Ideally, these key principles are addressed by organisations and in broader mental health policies in order to deliver an effective digital mental health solution, one which is fit for purpose and will be utilized - 'right care, at the right time'.

What do people want from a digital mental health solution?

People do search online for mental health information and support

A high proportion of those we engaged with, those with a lived experience of mental ill-health and their support networks, had explored online mental health information and support. The survey showed the following:

- 81% of respondents are comfortable sharing mental health experiences online, with 94% of those having done so
- 90% had searched online to learn about mental health, and 89% of those were confident in finding what they needed
- 55% had been online to see or speak to someone about their mental health

Language is important

We found that language must be simple – not using 'top down' language, jargon and cliched language and not deficit-based. Digital solutions are best received when they work to provide practical support; support that is easy to navigate and is culturally sensitive and appropriate. The use of language was found to be a significant barrier to access and resulting engagement.

We conducted a poll, via social media, to explore the use of sector language and test assumptions using three 'common' phrases in mental health prevention and treatment – person-centred care, digital mental health service and lived experience.

"Words like anxiety don't translate."

Participant, Broome workshop

"Beware of toxic positivity"

Participant Tasmania

"Aim at connection... inviting but not patronizing"

Peer workforce participant (Bendigo)

"[A digital solution should enable] good communication between everyone involved in care. Good communication with the service provider, and them understanding that they need to include the family."

Support person participant Melbourne

"Knowing how to navigate the system on your own is a nightmare"

Peer workforce participant (Bendigo)

"[A digital solution] should not be one size fits all. Know your demographic and understand the language that works for them."

Participant Tasmania

"Lived experience' is a western word"

Culturally diverse workshop participant. Adelaide

"Use language that makes people feel in control"

Focus group participant Sydney

"Make it strengths based! I'm not a 'poor thing'... I am incredibly strong, smart and resilient"

Participant Tasmania

Person centred solutions are essential

We found people wanted to actively participate in their own care, in collaboration with health professionals. They described a digital solution that is co-designed with lived experience and mental health professionals and provides accessible and available resources – ‘real stories from real people’.

The digital solution will be interactive, strengths-based and is customisable allowing for expression of the self (eg. design your own emoji, add mantra). A chat bot and/or live web chat option was desirable to enable the best support – one that is accessible ‘anywhere, anytime’.

“Answering multiple choice questions are impersonal and confronting – seek to gain this information through conversation.”

Participant Veteran community focus group
Melbourne

Access to digital solutions is not a reality for all

Not all Australians have access to the internet, primarily due to poverty, although NBN availability and mobile phone data usage were also barriers.

Low digital literacy, particularly understanding how to use search engines or the ability to evaluate online resources for accuracy of information, are also barriers to access. People spoke of the fear and absence of trust resulting from their low digital literacy. Survey participants responded overwhelmingly to having issues with trust (over 84% responded that they never or sometimes do not trust online advice).

“Guided support for mental health services is important for us... Everything has to be contextualised, because one word they may not know, will throw them and they won’t understand.”

Participant, Broome workshop

“Speak to people in a way that’s relatable – Simple language, short words, customise to local content and imagery”

Workshop participant, Broome

“I shouldn’t have to go through four pages on a website to find out where to go”

Peer workforce participant. Bendigo

“People need a holistic rather than a clinical model”

Peer workforce participant. Bendigo

“Words are only one way of giving information.”

Culturally diverse workshop participant. Adelaide

[Call centres and helplines are not useful] “I don’t want to call, call centres and talk to someone down south”

Workshop participant, Broome

“[It is] not obvious to refugees where to go for help - they sometimes look for years.”

Culturally diverse workshop participant, Adelaide

“People wouldn’t access anything online (or by phone) anything in crisis especially as the first point of call.”

Participant, Broome workshop

“You don’t come from a culture where you say what you feel.”

Culturally diverse workshop participant, Adelaide

People have data privacy concerns

People raised several issues related to privacy, particularly the potential access of their personal data by third parties, the perceived stigma, and anonymity concerns related to online webchat or forum.

People resoundingly state that they would be more comfortable providing personal information and engaging in online support if they trust its privacy and security. Plain English terms and conditions and other information statements are imperative.

"Understand that trust takes time"

Participant Tasmania

"Acknowledge the courage a person took to make contact and celebrate that small win"

Focus group participant Sydney

"Privacy and confidentiality in Tasmania is a big issue"

Participant Hobart

[Need a soft, relatable entry to engaging] "No good just coming in at pointy end."

Participant, Broome workshop

People trust lived experience

People trust products when their trusted networks and peers endorse and recommend them. People trust others who have had similar experience and are more likely to adopt the products when they see real people are involved and see themselves reflected and considered in the promotional material and the product itself.

People stated that peer support is of significant benefit to people with lived experience and should be used as a bridge to engage those who otherwise will not.

"Hearing someone else's story makes a difference, this is peer support."

"We need support workers who are culturally trained to support."

Refugee and culturally diverse workshop participant. (Adelaide)

[What makes it culturally sensitive?] it should be developed for community by community, using everyday language for community"

Adelaide culturally diverse workshop participant.

"The biggest challenge we have is people talking about their health. Mental health particularly, there is so much stigma around talking about it still. Even after all these years of advocacy, that's been out there and awareness building. So having someone with a LE getting up and actually facilitating a program and community consultation actually helps other people feel comfortable, and encourages a door opening so that if you share a little bit of yourself then others will share themselves too and their experiences. So it helps to humanise the whole issue of health and wellbeing, particularly mental health."

Ingrid Ozols AM (Lived Experience Working Group)

What we learned along the way

It is essential to listen to the voice of lived experience

Australians are significantly impacted by mental ill health, either as a person with a lived experience, or as a carer, family member, friend, or community member. Experiences differ from person to person and it is essential that the many voices of lived experience are heard and considered.

Co-design is based on the simple acknowledgement that consumers, carers, families, and community know what works best for them. Co-design seeks to combine lived experience and professional expertise to identify, develop and create a product or service.

Using co-design methodology is best practice and has potential to transform lived experience participation into an integral driver for change and transform the way in which mental health services are designed and delivered.

"Connect people to the community and community members" (peer to peer support models)

Participant, Broome workshop

"Work with community leaders and champions"

Community consultation is most effective when it is designed and led by lived experience

Effective community consultation requires a fundamental understanding of the causes and drivers of mental ill-health. Consultation that is designed and led by lived experience can facilitate active participation and frame and deliver sensitive complex subject matter in a mutually respectful way.

Despite this, it is not common practice for community consultation to be led by lived experience. Continued investigation is required to demonstrate its impact on the quality and effectiveness of product or service outcomes.

Matthew | Gold Coast QLD.



"The value in having the community consultation being LE led is the opportunity to link in with different voices from different communities and have that diverse range of experiences shared in an open and honest way with shared understanding with all involved. It gets much more rich and engaging information to come out to inform the work that we are doing."

Lived Experience Advisory Function Working Group member |
CEO of Australian Student Veterans Association, Medically retired
ADF, 2019 Winston Churchill Fellow.

Samuel | New South Wales



"It's so important to have the voices of lived experience at the table and leading a National Community Consultation because it amplifies the voices of real people having real experiences in mental health. Tell us about trust, tell us how an online solution could help make a difference. Connecting with people."

Lived Experience Advisory Function Working Group member |
Former National Mental Health Commissioner, National Ambassador for
Youth Mental Health, Associate researcher in youth mental health at the
University of Sydney

Shea | Brisbane



"When it comes to the NCC that we are undertaking at InnoWell I think it's really important to remember that members obviously such as I and the rest of the WG are involved because we are the ones who are able to make sure that people engage with us, tell us what's going on and give us the right feedback so that we can actually take that feedback and implement it in an appropriate way. As a member of the WG what's really important to me as an Aboriginal man is actually engaging through our community consultation framework engaging with members of the Aboriginal and Torres Strait Islander community to find out what could potentially make a digital mental health platform culturally appropriate"

Lived Experience Advisory Function Working Group member | Aboriginal man Brisbane PHD student and UN Youth ambassador

Leilani | Brisbane



"I think the whole point of having a national community consultation program is to engage broadly including diverse communities, but even more so, actually engaging those who aren't involved who might not necessarily had the opportunity to give their perspective and their opinions and when you include a diverse group of people with lived experience perspectives from communities they represent it means you are going to reach more people.

What our digital mental health strategy looks like moving forward in this country and people who are bringing something new to the table that hasn't been explored.

In valuing diverse communities and populations and making sure that our own personal communities as part of the LEAF group are included means we are hitting the mark and actually getting people who have not previously engaged and hearing what they have to say, potentially getting some really positive and powerful suggestions on how things could be done differently, and how to improve that and how to actually meet the needs of people at that grass roots level who struggle to engage and who are looking for alternatives that aren't necessarily always a face to face conversation with someone."

Lived Experience Advisory Function Working Group member | Advocate for cultural inclusion and practices for Aboriginal and Torres Strait Islander people and communities, Head of the Aboriginal and Torres Strait Islander Lived Experience Centre, Expert Advisory Group member to Christine Morgan, Prime Minister and Cabinet.

Ingrid | Melbourne



Why is embedding the voice of people with a lived experience so important in projects such as this?

Our stories provide an opportunity to connect to our common humanness. Though the 'content' of our stories differ, we all have one. They connect us to each other, they serve as messengers, door openers that encourage others to share their stories and develop relationships. Embedding, bringing these stories, life experiences and voices enriches projects and the end product."

Lived Experience Advisory Function Working Group member | Workplace and Community Mental Health, Suicide prevention lived experience advocate, Educator and consultant, Expert Advisory Group member to Christine Morgan, Prime Minister and Cabinet.

Faith | Darwin, SA



"Where I grew up we never had the chance to talk and share our experience, especially coming from a diverse community. To be able to actually stand and talk about mental health itself from a Lived experience is a stigma that you're not able to talk about. But to have the opportunity from a cultural background to have the voice and to stand here and to talk about it and share my experience with other other people, the Australians. People who work in diverse areas not only make a difference to myself but also to other people that are out there. Because they are able to look at what I am doing and be like. Oh yes. If she can do it, i'm also able to do it. So I believe that to have a person that's able to speak on their own experience, the voice of people of Lived experience, is the most powerful thing."

Lived Experience Advisory Function Working Group member | Mental Health Commission Youth Advisory Group (YAG), National Mental Health Leader Fellowship NMHC, Disability support worker

Ken | Melbourne



Why is embedding the voice of people with a lived experience so important in projects such as this?
It ensures that ultimately the best effort to achieve the best outcome is achieved without duplication or gaps in service.

Lived Experience Advisory Function Working Group member | Veteran, Veteran and veteran family champion

In summary

The InnoWell National Community Consultation Program (NCCP) is lived experience led community consultation that uses both digital and face-to-face strategies to engage with individuals with a lived experience of mental ill – health and the support networks of people with a lived experience of mental ill health, across the Australian community, in an effort to optimise diversity, reach and inclusion, and thus ensure a rich tapestry of experience and input to inform the building and implementation of the Platform.

What we learnt via these engagements is then fed back through co-design framework and used to inform one or more outcome streams:

- 1) Digital product development (improvements, enhancements and/or new features)
- 2) Implementation related service level improvements
- 3) InnoWell governance, process and procedures improvements
- 4) Presentations, reports or publications that contribute to the broader mental health policy reform agenda.

Community consultation activities ran concurrently with the co-design of the InnoWell Platform and its implementation into trial sites. What we heard was synthesised into key recommendations, separated into one of the above streams and used to inform these activities across the breadth of Project Synergy.

We asked the question **“how might digital products and engagement change the way people experience their mental health care and wellbeing?”** and this is what we heard

We heard that:

- People do search online for mental health information and support
- Language is important
- Person centred solutions are essential
- Access to digital solutions is not a reality for all
- People have data privacy concerns
- People trust lived experience

The community consultation enabled us to determine the above community-minded set of principles that contribute to broader mental health policy reform. Of upmost importance is the building of digital mental health products and services that are safe, seamless, trustworthy and fit-for-purpose.

The role that lived experience plays in community consultation cannot be underestimated. We were able to give real people the opportunity to speak to peers in a manner that was solution focused and environment that was safe and respectful. If we are to reform mental health experience and outcomes in Australia, we need to include as many voices in the conversation as possible.

“**“Things will change, but only if our voices are amplified! We will do it together.
Many voices, one purpose – better outcomes for people, families and communities”.**

Jackie Crowe 2017

In loving memory of Jackie Crowe (1968 – 2017)

National Mental Health Commissioner
Inaugural Chair of the Lived Experience Advisory Board

Acknowledgments

We would like to acknowledge the following people for their contributions to the National Community Consultation and Final Report.

Lived Experience Advisory Function (LEAF) Working Group members: Leilani Darwin, Matthew Wyatt-Smith, Ken Tsirigotis, Ingrid Ozols, Shea Speirings, Faith Abio and Samuel Hockey for their leadership, expertise, commitment and passion for improving mental health outcomes and representing their communities.

The broader LEAF Panel members for their support throughout.

All of the people who so generously shared their stories, experiences, insights and perspectives either online or in person across Australia in order to amplify the voices of lived experience and inform this report.

Maria Tchan from Iota Consulting for her assistance, especially her analysis skills.

