

# A GUIDE FOR ENGAGING IN LIVED EXPERIENCE OF MENTAL HEALTH



## WHO THIS GUIDE IS FOR

Organisations, project leads and staff wishing to engage with lived experience individuals to inform the design and delivery of programs related to mental health.

## HOW THIS GUIDE WILL HELP

Applying best practice when working with lived experience individuals can not only ensure they are kept safe and well throughout the process, but also help you maximise the benefits of having lived experience individuals inform the design and delivery of your work, and help you make a genuine impact.

These guidelines will take you through how best to engage with lived experience in a safe and effective way.

## ABOUT MENTAL HEALTH LIVED EXPERIENCE

Mental health operates on a continuum, with it being a natural part of life that will ebb and flow, up and down the continuum as we experience different situations or events that may occur in our lives.

In this way, all of us experience mental health in some way, shape or form, whether that is a difficult time in life, or whether that is a mental health condition that an individual may need to manage throughout their life.

No matter the experience, this is what we define as lived experience of mental health.

## WHAT IS LIVED EXPERIENCE?

Lived experience is defined as personal knowledge about an experience gained through direct, first-hand involvement in an event<sup>1</sup>.

When engaging with lived experience individuals it's important to be aware of best practice so that you can ensure they are kept safe and well throughout the process.

No matter the experience, this is what we define as lived experience of mental health.

## WHY YOU SHOULD WORK WITH LIVED EXPERIENCE INDIVIDUALS

As organisations look to create workplace mental health programs, the ability to engage with individuals who identify as having lived or living experience is critical in the successful design and delivery of workplace programs.

This can help enable genuine change for mental health in the workplace. Engaging with lived experience can have several benefits in a workplace setting, such as:

- Identifying key problems to solve.
- Informing delivery and design of services.
- Ensuring programs and resources address user needs.
- Understanding how employees can be best supported during events that might affect them at work.

<sup>1</sup> [www.oxfordreference.com/display/10.1093/oi/authority.20110803100109997](http://www.oxfordreference.com/display/10.1093/oi/authority.20110803100109997)



## GETTING STARTED: THE THREE Ps

When an organisation is looking to engage with lived experience of mental health issues, it is important that a considered process is followed to ensure that individuals remain well throughout the experience. The best way to approach engaging with lived experience is following the **three Ps**:



### 1 PURPOSE

As a first step to any engagement process, it is important to set a clear purpose to understand specifically why you're engaging with individuals with lived experience.



Having a **clear purpose** in why you're engaging is pivotal, both to define your work and to ensure the safety of the lived experience individual.

### Ask yourself the key question, 'What are you hoping to achieve through this engagement process?'

There are many reasons an organisation may want to engage with lived experience of mental health distress. Some common examples include:

- Gathering feedback to identify key issues and co-designing solutions for specific experiences at work.
- Engaging individuals to share their stories via an awareness campaign that will be shared across an organisation.

Once you've defined your purpose you can create a clear purpose statement. This statement can be used to help you communicate and engage with lived experience individuals.

### What is a Purpose Statement?

A purpose statement can be as simple as one or two sentences that clearly summarise the objective that you're hoping to achieve through the engagement process and identifying the specific lived experience that you'd like to engage with.

#### Some examples include:

- The objective is to develop a specific and targeted workplace program to support employees working from home by collating feedback from individuals about how working from home has impacted their mental health.
- The objective is to support employees to speak up about their mental health by sharing stories of other individuals speaking up about their experience of mental health conditions in the workplace.

The more specific the purpose statement is, the easier you'll find the planning process on how best to engage. You may find throughout the process that your objective may shift as you begin to learn from individuals, and that's okay, as long as you adapt the plan to be fit-for-purpose.

Understanding and setting a clear purpose from the beginning will allow you to define the parameters and scope of the program of work and will help guide the development of the next two Ps.

**A great way to remember 'fit-for-purpose' processes is to think about the work you're doing with lived experience individuals as 'with you, for you'.**

In other words, you can co-design programs with lived experience individuals to produce outcomes for your intended audience. The value comes from the unique perspective the lived experience individual can offer.

Many lived experience individuals will have experienced some level of trauma in their stories. It's therefore important that you familiarise yourself with trauma-informed principles and incorporate them in your work.

Regardless of the type of program you're developing, these principles provide a foundation to come back to when making key decisions and formulating how the engagement process will work.

The most important thing to remember when engaging with individuals with lived experience is the significant personal investment that they are providing, and how that could affect how they think and feel within the workplace.



## About Trauma-Informed Engagement

**Trauma-informed engagement is a method of approach that promotes a culture of safety, empowerment, healing, trust and choice.**

Many individuals with lived experience will have some element of trauma within their story – whether that is intergenerational, historical, direct, or indirect. Regardless of the type of trauma, it is important to understand that any type of trauma can bring about unexpected responses and processing of sharing their story. To ensure an engagement process is trauma-informed, the key principles include:

### Trauma awareness

**It is important to approach lived experience with a foundational level of understanding about the experiences involved with trauma.**

Individuals who have experienced mental health conditions, or trauma related to a specific event, may experience unexpected, heightened emotions when sharing their story.

An individual is unable to necessarily predict when their emotions might be triggered, so it's important to understand the key signs of an individual's body language that may indicate an individual is escalating or experiencing heightened emotions during the sharing process, such as:

- Fastened pace of speech.
- Raised tone.
- Stuttering or broken speech.
- Avoidance of eye contact.
- Fidgeting – for example, hands fidgeting or shuffling in their seat.
- Crying / tearful.
- Use of emotive language.

Being aware of when individuals may be feeling emotionally elevated during the sharing process allows you to offer pauses throughout the process, as well as understand that compassion and comfort is required to ensure that the individual feels OK before proceeding.

**Some techniques to use during engagement include:**

- Keeping your **body language open**, rather than closed, in either face-to-face or virtual environments – for example, avoid crossing your arms and keep your body relaxed. If you're on a video call, make sure you address whether you're taking notes on a separate screen, so the individual does not perceive your body language as distracted.
- **Responding with empathy**, for example, 'I appreciate this must be hard for you'.
- When you're interviewing the individual, **offering for the interview to be paused**, allowing them time to recalibrate how they may be feeling.
- **Reassuring them** that they can withdraw at any time.
- Above all else, the best thing you can do for someone who may be struggling to share their story is to **be patient**, show compassion and acknowledge that this may be a really difficult process for them.

When someone is experiencing heightened emotion when telling their story, you are not expected to take away someone's pain and the individual won't be expecting you to either. Sitting with them, holding the space, and acknowledging that this is part of their story can be incredibly powerful for that individual.





If you remain genuine, kind, and most importantly, honest, throughout the process, this will build trust with an individual more than anything else.



## Safety and trust

**To ensure the individual feels safe to share, it is important to build immediate trust for the individual who is sharing their story or experience.**

This will mean building rapport and getting to know the individual prior to jumping straight into the process. At the end of the day, you're a stranger to the individual who is sharing, and what they'll be sharing will be very personal. To build rapport and ease into the process, some recommendations include:

- ✓ Connect with the individuals prior to the engagement process if possible – to make them feel more comfortable and allow them to prepare for what to expect and ask any questions.
- ✓ Work to create a warm and welcoming environment.
- ✓ Share something about yourself to build a sense of connection.
- ✓ Provide the individual with as much information as possible about the process to create transparency.
- ✓ Ease an individual into the process by talking through their experiences at the pace they offer.
- ✓ Be patient as the individual may need breaks or pauses.
- ✓ Plan your time well to ensure the individual does not feel rushed. This means allowing yourself enough time to **not** end the conversation in the middle of a difficult part of the story. Overestimate the time required.

Trust isn't something that can be rushed, however if you remain genuine, kind, and most importantly, honest, throughout the process, this will build trust with an individual more than anything else.

## Choice and control

**Finally, throughout the process, it's best practice to ensure an individual has the opportunity to withdraw from the process, and understands how to do that if they choose not to continue.**

Having this option will provide the individual with a sense of control that will allow them to feel safer through the process.

It is important that this choice to withdraw is genuine and respected. It is therefore best for both parties to communicate upfront what the withdrawal process looks like.



If you've recommended an individual for a campaign where you are not involved in the engagement process, for example an interview with media, it is important to remind them of their rights and the importance of them speaking up if something doesn't feel right.



This document has been developed in collaboration with Camille Davey, an expert in engaging with lived experience of mental health within workplaces.

Find further information at [www.growtogethernow.com](http://www.growtogethernow.com)

## 3 PLAN

The final P to cover off before engaging with individuals is the plan. This means planning the methods in which you will engage, who you will engage with, and the key roles, responsibilities and expectations throughout the process.

### Don't forget...

As you move through the engagement process, it is pivotal to remember the reason that the engagement process was started in the first place.

Sharing lived experiences well can have a significant impact on workplaces. When done respectfully and genuinely, it can change the world for your employees by creating connections, encouraging individuals to speak up, and creating avenues for earlier access to support.

## FURTHER INFORMATION AND SUPPORT

**Engaging with Lived Experience (SIRA)**, a strategic framework for guiding our work impacting mental health.

**Reach out for support from your local GP**, health professional or your workplace Employee Assistance Program.

**Beyond Blue:** 1300 22 4636

**SANE Australia:** 1800 187 263

**Lifeline Australia:** 13 11 14

## Methods of Engagement

Engaging with lived experience can occur in many ways, and it is important to consider whether it is suitable to engage with a provider to facilitate this work with lived experience individuals. Different methods you may choose to engage the expertise of lived experience individuals can include, but are not limited to:



Administering a survey or poll



Individual interviews



Focus groups

Once you have determined how you're going to engage lived experience individuals, it's important to clearly define your plan, so that you can best communicate everyone's roles and responsibilities.

### Ensure your plan includes:

- The purpose** of the work.
- The key principles** you will follow in the work.
- The key messages of the work** – for example, if you're looking for lived experience of anxiety, make sure this is clear, so that individuals understand how and why lived experience individuals are selected to be part of the process).
- The time, effort and output you anticipate from the lived experience individual** – for example, will you have regular meetings, how long will they be for, what is their purpose. It's important to be as clear as possible here. You might also want to think about information you can share in advance, such as interview questions or reading materials.
- The review and approval process** – depending on the nature of work, make sure it's clear if and when lived experience individuals can review their contribution within the project timeline.
- The withdrawal process.**
- Acknowledgement of how the end product will be shared** and communicated, as well as agreement to ongoing post-engagement check-ins.
- An emphasis on the importance for individuals to have a self-care plan** for before, during and after their participation.

## Importance of Communication

**It is important to ensure that individuals involved receive clear, consistent, and honest communication throughout the entire process.**

The purpose of clear communication is to ensure the individual has clear expectations of what will be involved.

Make sure you communicate the purpose, principles, and plan to the individuals, and be prepared to repeat these as required. Please keep in mind that a lot of emotions can be experienced by an individual who is sharing their story for the first time and our memory can be affected when we are feeling nervous, stressed or overwhelmed.

The process of sharing their story publicly can be very different from sharing it one-on-one. It's important to be mindful of how you can support each individual prior, during and after they share their story. Remember, sharing a lived experience story takes great strength and courage from the individual themselves.