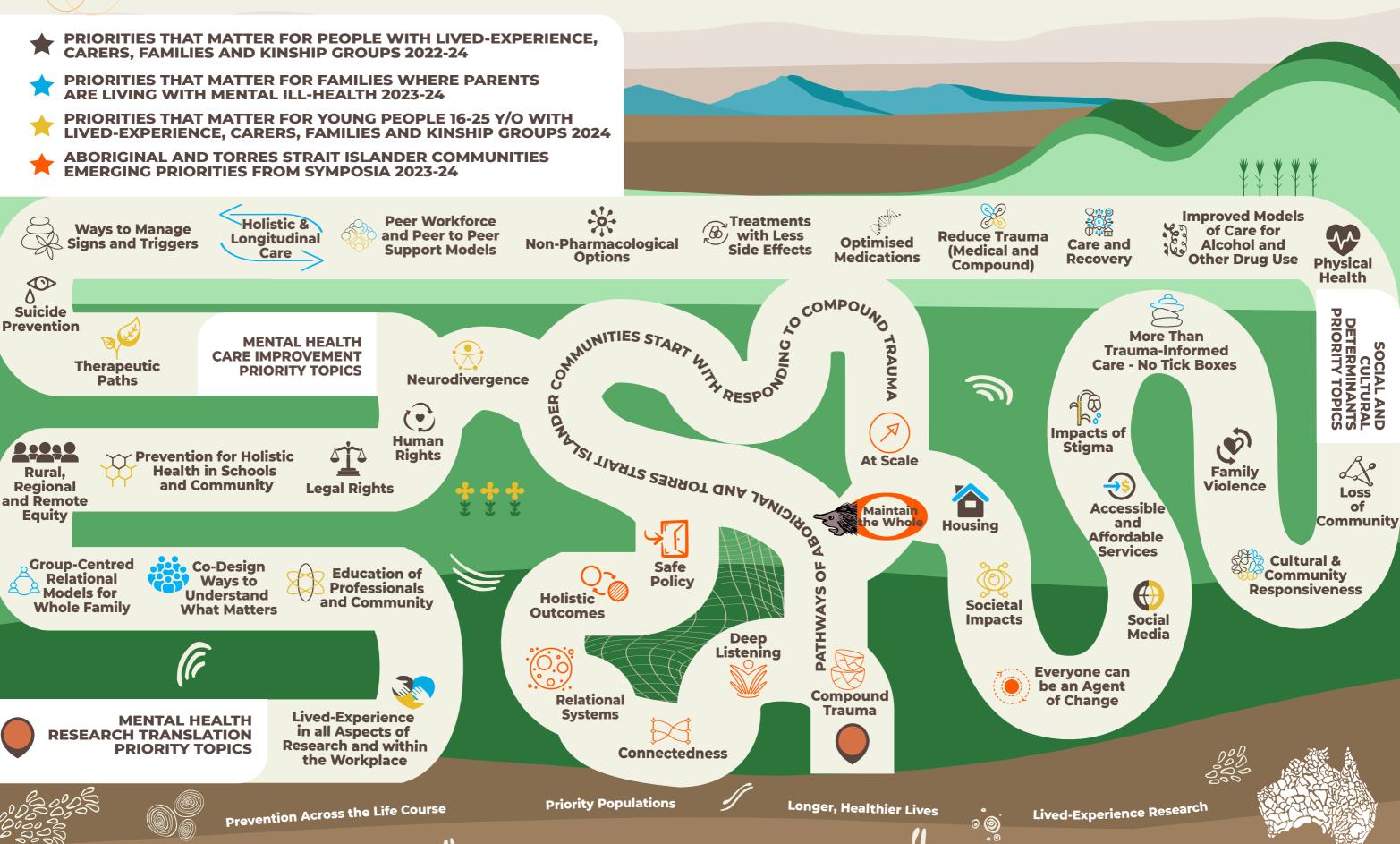


The ALIVE National Centre Pocket Map of Priority Topics for Mental Health Research Translation



2022: 365 survey contributions from people with lived experience of mental ill-health and carer, family and kinship groups. 88 emotion maps for prioritisation. 27 co-designers of Phase 1 Implementation Actions.

2023: 78 survey contributions from parents living with mental ill-health, and their partners, family members and adult children. 33 co-designers of Phase 2 Implementation Actions.

2024: 52 contributions of people aged 16 to 25 years to surveys, interviews and emotion maps.

Currently co-designing Phase 3 & 4

Implementation Actions.

In 2019, 114 research priorities were shared by Co-Design Living Labs Network members (n=115) to establish research program areas within the ALIVE National Centre for Mental Health Research Translation as part of the grant preparation. These priorities were checked against research priorities identified in a separate study conducted by the ACACIA Lived-Experience Research Unit in 2013 which was updated in 2017 and resulted in a total of 87 priorities. Both projects worked with people living with mental ill-health or for people caring for someone as a carer, family or kinship group member to develop research priorities. There were 201 priorities when the two studies were combined.

ACACIA advisory group members and ALIVE National Centre Co-Design Network co-leads met to review the 201 priorities. They compared the 114 priorities from Co-Design Living Labs Network members with the 87 priorities from ACACIA. The group confirmed that while there were some language differences due to timing of the exercises and reforms underway in the Australian mental health system at the time of projects, there were many similarities. ACACIA priorities were mapped into Centre research programs.

For the emotion mapping we used a collaborative digital space called Mural. The priority topics were placed around a Compass with people directed to move clockwise from North (research topics), East (mental health care improvements), South (social determinants and social issues) and West (mental health care improvements). As the funding objectives in the Centre related to improving care experiences and addressing unmet needs, a larger number of priority topics were selected in mental health care improvements and mapped into two parts of the compass.

To establish currency and consensus within lived-experience groups, we then conducted emotion mapping of the 52 priority topics. Participants opted-in from the 2022 Annual Lived-Experience Priorities Survey (n=201) and self identified as either consumers, carers or someone with both consumer and carer experiences (using the terminology of the survey).

A final synthesis of all priorities was conducted by co-design co-leads and research team members. Priorities were then organised into 52 priority topics for roadmap development in the following three priority areas: 1) mental health research; 2) mental health care improvements; and 3) social determinants/social issues for innovations in models of care.

People in the emotion mapping process were advised to read a priority topic and then select a coloured dot that best corresponded with the emotion felt when reading it. Colours were provided for strong emotions (orange), not so strong (yellow) or mixed/uncertain emotions (blue). After determining a strong feeling or otherwise, people moved the relevant coloured dot to the priority topic. They were asked to type a word or a statement onto the dot to describe the strong or not so strong or mixed feeling and connection. People could opt to just place dots or place dots with added text.

A total of 88 people completed emotion mapping from 101/201 who opened the unique Mural board digital workspace link sent by email. Participants were provided with up to four weeks to complete mapping (with two email reminders sent) and asked to return the completed emotion mapping board by email.

Researchers downloaded 88 completed emotion mapping boards as PDF documents and stored these on a secure password-protected server. Completed responses (n=88) were received from consumers (n=51), carers (n=12) and people with both consumer and carer experiences (n=25).

As part of the second step for the emotion mapping analysis, the feelings words and statements were organised into a table matched to the priority topics. This helped to establish touch points (the places people have come in touch with priority topics that have shaped their experiences in positive and negative ways). An emotion board was created for each priority area to represent the priority topics where there was consensus and feelings about the topics. These were used in public co-design meetings.

To create focus for roadmap development we initially looked for shared consensus in emotions and how people felt for five priority topics in the three areas of mental health research, mental health care improvement and social determinants and social issues. Consumers, carers and people with both consumer and carer experiences shared consensus about most priority topics but there were some topics that different groups felt more strongly about than other groups. The consensus priority topics and the points of difference were outlined in the first Pocket Map (2022 Edition).

All 88 Mural boards were reviewed by co-design research team members. Only the priority topics that people felt strongly about (regardless of whether the feelings were positive or negative) were mapped into an excel spreadsheet. We used colour gradients to code the feelings that were shared. Negative feelings were represented as reds, oranges or lighter oranges depending on the feelings shared. Positive feelings were represented as greens for a very positive comment, mid-green for positive and light green for a generally positive comment.

Six public co-design meetings were held in 2022 to establish the Phase 1 Consensus Statement. These brought together 32 consumers, carers and people with both consumer and carers experiences to co-create the first set of priorities and implementation actions shared in the Phase 1 Consensus Statement. Renewal of the priorities continues year-to-year with our annual lived-experience priorities gathering and public co-design of new pathways in the roadmap. Pathways outline the nuanced priority topics for different groups and are used to co-create new implementation actions in new phases of the Consensus Statements. To date pathways for families were completed in 2023 with a focus on younger people for 2024 planned.