Position Paper

Enhancing Psychosis Research:

Addressing Gaps in Knowledge, Lived Experience Inclusion and Implementation

March 2025: This paper has been developed to support national advocacy for enhanced investment in psychosis research. It summarises themes from the October 2024 Psychosis Australia Symposium presented in partnership with Mindgardens Neuroscience Network: *Insight to Impact: Translating Psychosis Research into Practice and Policy*.

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Enhancing Psychosis Research: Addressing Gaps in Knowledge, Lived Experience Inclusion and Implementation

This paper is the outcome of the October 2024 Psychosis Australia Symposium presented in partnership with Mindgardens Neuroscience Network: *Insight to Impact: Translating Psychosis Research into Practice and Policy*.

About psychosis

Psychosis refers to a collection of symptoms that affect the mind, where there has been some loss of contact with reality. During an episode of psychosis, a person's thoughts and perceptions are disrupted and they may have difficulty recognizing what is real and what is not.

Psychotic *disorders*, such as schizophrenia, involve experiencing psychosis for at least a month, and can cause significant distress and negative impacts on someone's ability to function. Psychotic symptoms can also accompany other mental health conditions including depression, bipolar disorder, post-traumatic stress disorder and borderline personality disorder.

At any given time about 0.5% of Australians – or 100,000 people – are living with a psychotic disorder. Over a lifetime there is roughly a 3% chance an individual will be diagnosed with a psychotic disorder. (Many more people may experience passing symptoms that do not reach the threshold for diagnosis or treatment).

The impact of psychosis

Psychotic disorders are often severe and enduring and can lead to significant disability and disadvantage. They represent a high proportion of public mental health services expenditure in Australia. Some estimates suggest as many as 80% of people admitted to acute mental health wards are there for psychosis. Many people with psychosis do not receive appropriate support, which exacerbates the impacts of the condition. The total economic cost is estimated at almost $5 billion annually.

People living with psychosis are at higher risk of developing preventable medical conditions, such as cardiovascular disease and diabetes. The lifespan of individuals with psychosis remains 10 to 20 years shorter than the general population.

The impact of psychosis on a person's family is often immense. Family members may experience stress and depression, social isolation, employment and financial difficulties, anxiety and feelings of helplessness as they focus on their caring role.

Despite these devastating impacts, psychosis research remains under-funded compared to other health conditions.

This disparity needs to be eliminated. Only through dedicated research can we improve the lives of people living with psychosis, through development of better treatments and services.

Recommendations to the Government for psychosis research and supports

Research plays a critical role in advancing understanding and improving outcomes for people living with psychosis. However, gaps remain in our understanding of the needs of under-represented groups, there is a need for greater investment, barriers exist to incorporating lived experience, there are challenges in applying research findings in real-world settings, and obstacles to effective collaboration between researchers and clinicians.

This paper provides actionable advice to support psychosis research that can readily be translated into better treatments and services.

The recommendations are provided for the Government to enhance its support of psychosis research, fostering an environment where innovative solutions improve outcomes for individuals. They aim to address systemic challenges and are grouped into four domains:

1. **Establish targeted research funding for people living with psychosis** (p4)
   Develop research programs that focus on people living with psychosis from marginalised and minority communities, youth, older adults, and individuals with co-occurring conditions. This funding should prioritise participatory research practices that directly involve these groups.
2. **Integrate lived experience into all stages of psychosis research** (p5)
   Prioritise co-production of research with people living with psychosis, and their families, carers and kinship groups, requiring lived experience leadership in the design, implementation, and evaluation of research projects.
3. **Invest in research to improve psychosocial services and biomedical treatments for people living with psychosis** (p6)
   Allocate dedicated funding streams to support both psychosocial and biomedical research, ensuring that innovation in psychosocial interventions, rehabilitation, and community integration is prioritised, complemented by advances in understanding psychosis and treatment at the molecular level.
4. **Accelerate the translation of research into practice** (p7)
   Fund initiatives that address the average 17-year lag in research translation through ongoing evaluation and quality improvement, research capacity building with practitioners, and investing in implementation science to bring evidence-based interventions into practice faster.

Notes:
1: Some symposium delegates preferred the term 'altered states' over 'psychosis' to describe the experiences addressed in our discussions. Language is important and dialogue about these terms should continue. In this paper, we use the term 'psychosis', as this terminology is currently employed by government entities. This facilitates engagement with policymakers and other stakeholders, ensuring our message is effectively communicated.
2: Similarly, some delegates preferred the term 'consumer' while others favoured 'person with lived experience'. Both terms are commonly used in mental health policy, and both are used in this paper.
3: This paper focuses on psychotic disorders, which are generally severe and ongoing. It does not address transient episodes of psychosis, for example delirium in the context of dehydration. It is essential that clinical staff are trained to recognise different forms of psychosis in acute settings.

1: Establish targeted research funding for people living with psychosis

Psychosis research often overlooks the needs of specific sub-groups, resulting in interventions that may not adequately serve all affected people. Some critical under-served groups include:

- **Priority communities**: Aboriginal and Torres Strait Islander people, culturally and linguistically diverse communities, people who identify as LGBTQI+, people from rural and remote communities, people experiencing homelessness and people in contact with the criminal justice system face additional challenges, such as systemic barriers to accessing care and cultural stigmas.
- **Youth and aging populations**: Research has focused disproportionately on youth and younger adults, with limited consideration of the particular challenges faced by older adults.
- **People with co-occurring conditions**: About half of individuals with psychosis also experience additional mental or physical health or psychosocial issues, including metabolic syndrome, anxiety, depression and suicidality, and alcohol and other drug use, which exacerbate distress and increase the complexity of treatment, leading to worse outcomes.
- **People with transdiagnostic experiences of psychosis**: Psychosis impacts people with a variety of conditions - including schizophrenia, mood disorders, post-traumatic stress disorders, personality disorders and neurodegenerative conditions – but research has focused on some diagnoses and not others.

A national research agenda for psychosis should recognise these under-served groups, their distinct experiences and intersecting needs, across the whole lifespan.

This requires targeted studies, inclusive methodologies, and participatory research practices that directly engage these groups, ensuring research is relevant and able to be implemented. It is also essential that research outcomes are applied equitably in interventions and support practice.

2: Integrate lived experience into all stages of psychosis research

The historical exclusion of and continuing discrimination against people living with psychosis has resulted in policies, services and research programs that are not always well aligned with their needs and priorities.

Lived experience leadership to incorporate the insights and experiences of people living with psychosis, as well as those of their families, carers and kinship groups, is essential for shaping a research agenda that genuinely addresses community needs.

Meanwhile the inclusion of people with lived experience expertise as co-investigators in research studies is important to ensure work remains aligned to lived experience values.

- **Emphasise lived experience in scoping of grant schemes:** Lived experience leadership in priority setting and the assessment of grant applications can ensure psychosis research addresses the things that matter most.
- **Promote opportunities for research participation**: Stronger pathways to facilitate involvement of people living with psychosis as co-researchers are needed and could be required by Government within grant schemes.
- **Encourage lived experience participation in research**: The Government can empower individuals to contribute important insights by strengthening the role of national consumer and carer national peak bodies to build networks of potential research participants.

The Government's investment can be directed to better align research to community needs and the real-world priorities of people living with psychosis and their families, carers and kinship groups. Individuals with lived experience of psychosis should be included in research not only as participants but also in research governance and priority setting and as co-researchers.

3: Invest in research to improve psychosocial services and biomedical treatments for people living with psychosis

Research into psychosis is critically under-funded in comparison with other health conditions, and in consideration of its immense impact on individuals, families and communities.

Increased investment is needed in all types of psychosis research including:

Psychosocial services research

Services designed for the wider community may be less accessible for people living with psychosis, who can benefit from specialised support for their wellbeing. In domains including education, employment, housing, nutrition and physical activity, services designed specifically to meet the best interests of people with complex mental health challenges are likely to be more effective. Research is required to scope, design, pilot and evaluate such services and interventions.

Biomedical research

Scientific understanding is progressing rapidly in:

- the structure and functions of the brain
- the genetics of mental health conditions
- how medications and other interventions influence mental health

Basic science that extends knowledge of the brain and mental health disorders, and discovery research that applies this knowledge to prevention approaches and new treatments, may benefit people living with psychosis provided it appropriately considers their experiences and concerns.

Implementation and evaluation research

For both psychosocial and biomedical approaches, ongoing review is required to assess the real-world impact of research findings and adjust intervention protocols to keep them aligned with clinical and consumer needs. Investment in adaptive implementation of research results enables more responsive and meaningful application of research and better outcomes for consumers and their families, carers and kinship groups.

4: Accelerate the translation of research into practice

Translation of research into action – in the form of innovative treatments and service responses – is unacceptably slow, with an average lag time of around 17 years from discovery to practical application.

Funders are well positioned to ensure that psychosis research not only advances scientific knowledge but also leads to practical solutions, so people living with psychosis can benefit sooner. Opportunities include:

- **Invest in implementation studies**: Implementation research and evaluation should be prioritised and include support for essential clinical-research liaison roles, staff training, resources and equipment.
- **Bridge professional divisions and silos**: Research funding should prioritise collaboration between researchers, clinicians and people with lived experience to promote research literacy, cultural competency and formal implementation approaches. This would promote shared understanding between research, clinical practice, and psychosocial support and remove obstacles to real-world application of findings.
- **Diversify research workforces:** Many workforces support people living with psychosis, including psychiatrists, psychologists, nurses, occupational therapists, exercise physiologists, dietitians, social workers, youth workers and the peer workforce. Despite their critical role, many of these professionals are infrequently involved in psychosis research. Research investment should prioritise their inclusion to broaden the scope of research and promote wider implementation of findings in a greater variety of settings.

CONCLUSION

Psychosis research must receive additional investment and evolve to include under-served groups, integrate lived experience, embrace diverse research topics and approaches, and overcome systemic barriers to timely implementation.

By supporting inclusive methodologies, emphasising collaboration, and investing in the transition from research to practice, the Government can empower psychosis research to deliver on its potential, transforming outcomes and improving the lives of people who experience psychosis and their families, carers and kinship groups.

The recommendations in this paper provide a blueprint for how this can be achieved.

APPENDIX: About the 2024 Psychosis Australia/Mindgardens Neuroscience Network Symposium: *Insight to Impact: Translating Psychosis Research into Practice and Policy*

This one-day meeting took place in Sydney on 16 October 2024. It included presentations, panel sessions and audience discussions. Both the speakers and the audience represented diverse interests in psychosis research including lived experience as consumers and carers, clinicians, researchers, health system planners and managers, advocacy professionals and policy-makers. Video recordings of some presentations are available on Youtube.

The program can be accessed here.

Co-chairs	
Prof. Jackie Curtis AM	Executive Director, Mindgardens Neuroscience Network
Prof. Dan Siskind	University of Queensland
Speakers	
Dr Sophie Davison	Australian Government's Chief Psychiatrist
Prof. Cyndi Shannon Weickert	Psychosis researcher, Neuroscience Research Australia
Dr Tertia Purves-Tyson	Psychosis researcher, Neuroscience Research Australia
Prof. Phil Ward	Psychosis researcher, UNSW
Kerry Hawkins	President and carer representative, Western Australian Association for Mental Health (WAAMH)
Amanda Habermann	Mental health peer worker and lived experience educator
A/Prof Alexis Whitton	Associate Professor and Psychologist, Black Dog Institute and UNSW
Dr Barry Geheran	Trainee psychiatrist and carer
Prof. Michelle Banfield	Head of Lived Experience Research, ANU Centre for Mental Health Research
A/Prof. Julia Lappin	Psychiatrist and researcher, South Eastern Sydney Local Health District & UNSW
Mark Orr AM	CEO, Flourish Australia
Prof. Nick Goodwin	Director, Central Coast Research Institute Co-Founder, International Foundation for Integrated Care
Dr Geoff Lau	Director of Therapies and Allied Health, Metro South Addiction and Mental Health Services (Brisbane)
Carolyn Nikoloski	CEO, Mental Health Australia

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It was shared in draft form with all speakers and delegates and this final version includes feedback from these groups.