

## Royal Commission into Victoria's Mental Health System

The Florey Institute of Neuroscience and Mental Health welcomes the opportunity to provide a submission to this important inquiry. We thank the Victorian Government and Commissioners for their leadership on a topic which affects so many members of our community.

With more than 500 research and support staff, the Florey is the largest brain research centre in the Southern Hemisphere. Our mental health research areas of focus include depression, anxiety, schizophrenia, bipolar disorder, addiction and neurodegenerative disorders which affect cognition. The Florey's mission, to change lives through brain research, extends to other conditions including dementia, epilepsy, motor neurone disease, discovery science and more. While our submission focuses specifically on the mental health research that we undertake, we recognise that these are often diagnosed as a precursor, co-diagnosis or occur after diagnosis, of one of the other serious conditions that we study.

As part of our commitment to ensuring a thoughtful and well-rounded mental health research workforce of the future, three early career researchers have been involved in the drafting of this submission, adding their perspectives, ideas and experiences to the document. We recognise Dr Robyn Brown, Dr Leigh Walker and Dr Sarah Ch'ng for their input and co-authorship of this submission with us.

Our submission focuses on the questions where we believe our experience offers a unique perspective. We would welcome the opportunity to host a site visit for Commissioners, or to discuss our submission further.

Yours sincerely



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## 1. What are your suggestions to improve the Victorian community's understanding of mental illness and reduce stigma and discrimination?

Over the past ten years, the excellent work of advocacy organisations in Australia has had a remarkable impact in improving the understanding and acceptance of some mental illnesses. Episodes of depression or anxiety are increasingly recognised as being a health condition which can be identified, discussed and treated. While recognising the enormous efforts that it has taken to reach this point, this same community recognition lags in other mental illnesses like schizophrenia, bipolar disorder or substance abuse where stigma and discrimination unfortunately remain pervasive.

International evidence suggests biological explanations can reduce stigma of mental health disorders<sup>1</sup>. The global anti-stigma alliance and other studies also consider that evidence and contact-based approaches are the most effective strategy in countering stigma and discrimination associated with mental illness<sup>2</sup>.

With these evidence-based frameworks in mind, we believe that research organisations and universities can play an important role in destigmatising mental illnesses through communicating the biological processes that underpin these conditions. Meaningful interactions between members of the community, expert researchers in mental health disease and people living with mental health conditions can enable people to openly discuss their experiences with mental health, share both similar and differing opinions on these conditions and reduce stigma and discrimination in mental health, to facilitate understanding of biological aspects that cause mental health disorders.

The Victorian community's understanding of mental health may be improved through engaging community groups like schools with researchers and individuals living with mental health disorders in shared learning opportunities. Evidence suggests educational approaches may be more effective for adolescents, as their beliefs are unlikely to be as firmly developed as adults and so there is a greater potential for understanding and attitudes to be changed in response to education initiatives<sup>3</sup>. For this reason, we believe that interactions with school groups are an important aspect of providing long-term perception changes related to mental illnesses.

*Case Study: Reducing stigma through engagement of high school students in art and scientific research.*

*The Dax Centre in Parkville, housed within the Melbourne Brain Centre and part of SANE Australia, is a gallery comprised of artworks made by people with an experience of mental illness. The Florey has been involved with the education program Mindfields run by the Dax Centre since 2011. This program engages high school students from years 9 – 12, with an aim to develop their knowledge and understanding of the complexities of mental health disorders. Aligned with the high*

<sup>1</sup> Andersson MA, Harkness SK (2017) When do biological attributions of mental illness reduce stigma? Using qualitative comparative analysis to contextualise attributions. *Society and Mental Health*.

<sup>2</sup> Corrigan, P.W., Morris, S.B., Michaels, P.J., Rafacz, J.D. and Rüsck, N., 2012. Challenging the public stigma of mental illness: a meta-analysis of outcome studies. *Psychiatric services*, 63(10), pp.963-973.

<sup>3</sup> Borschmann R, Greenberg N, Jones N, Henderson RC (2014) Campaigns to reduce mental illness stigma in Europe: a scoping review. *Die Psychiatrie*, 11 pp 43 – 50.

*school curriculum, students attending the program receive a multifaceted perspective on art, have direct interactions with advocates who speak about their personal lived experience of mental illness and presentations by neuroscience researchers from The Florey about the biological causes of mental illnesses and research currently underway.*

*Over the past 8 years this education initiative has provided high school students with greater understanding of different lived experiences and the biological mechanisms of mental health disorders to help reduce stigma and discrimination surrounding mental illness.*

We also recognise and appreciate the approach taken by the Victorian mental health commission to consulting broadly and empathetically with individuals and organisations that span the full extent of the mental health system. We believe it to have already generated significant know-how and methodology for how organisations in the mental health sector can integrate many viewpoints into their ways of operating with a view to collectively working to destigmatise mental illness. We would encourage those involved in the commission to consider ways to communicate and integrate the valuable knowledge developed during this process to organisations in the sector.

- 2. What is already working well and what can be done better to prevent mental illness and to support people to get early treatment?**
- 3. What is already working well and what can be done better to prevent suicide?**

The work of advocacy organisations in Australia has had a remarkable impact in changing the willingness of Australians to seek medical advice for mental illnesses, with the General Practice: Health of the Nation report for 2018 finding evidence that mental health issues are the most common single reason patients are visiting their general practitioner<sup>4</sup>.

Despite this very positive indicator, for many individuals and their families navigating the mental health system and finding the right care at the right time remains challenging. Early diagnosis and timely treatment are critically important in order to optimise the overall health and well-being of those affected by mental illness.

As an example, individuals with bipolar disorder wait on average almost 10 years until correct diagnosis and adequate pharmacological treatment are in place<sup>5,6</sup>. Further, up to 70% of individuals who have bipolar disorder are misdiagnosed and require on average 4 consultations prior to correct diagnosis<sup>7</sup>. These delays to diagnosis and treatment have vast

<sup>4</sup> The Royal Australian College of General Practitioners. General Practice: Health of the Nation 2018. East Melbourne, Vic: RACGP, 2018.

<sup>5</sup> Hirschfeld R, Calabrese JR, Weissman MM, Reed M, Davies MA, Frye MA, Keck Jr PE, Lewis L, McElroy SL, McNulty JP, Wagner KD (2003). Screening for bipolar disorder in the community. *The Journal of Clinical Psychiatry*, 64(1), 53-59.

<sup>6</sup> Berk M, Dodd S, Callaly P, Berk L, Fitzgerald P, De Castella AR, Folia S, Folia K, Tahtalian S, Biffin F, Kelin K (2007). History of illness prior to a diagnosis of bipolar disorder or schizoaffective disorder. *Journal of Affective Disorders*, 103(1-3), pp.181-186.

<sup>7</sup> Hirschfeld R, Calabrese JR, Weissman MM, Reed M, Davies MA, Frye MA, Keck Jr PE, Lewis L, McElroy SL, McNulty JP, Wagner KD (2003). Screening for bipolar disorder in the community. *The Journal of Clinical Psychiatry*, 64(1), 53-59.

implications for individual outcomes, unnecessarily adding pressure during what can already be a difficult period for both individuals and their families or carers. There is evidence to suggest that delays to diagnosis and treatment can double the number of suicide attempts for individuals with both bipolar disorder<sup>8</sup> and schizophrenia<sup>9</sup> (Ran et al., 2018).

Improvement of diagnosis and treatment of serious mental illnesses including schizophrenia and bipolar disorder would have dramatic impacts on the lives of people living with these conditions, as well as the Victorian healthcare system. These improvements can only come through research which improves our understanding of the biological functions that are involved. Improvements could come through discovery of diagnostic biomarkers or precision medicine that can advance tailored diagnostic and treatment options to individuals.

While this type of research requires commitment, collaboration and partnerships between researchers, industry and community groups, there are examples of transformational changes being made in other health domains like cancer or HIV/AIDS through these means. The Parkville Biomedical Precinct and the Austin Hospital Precinct have provided Victoria with a strategic advantage in biomedical collaborations of the nature needed to undertake the significant challenge of improving diagnosis and treatment options for serious mental illnesses. We note that the 2013 Federal Strategic Review of Health and Medical Research (“The McKeon Review”) recommended the establishment of integrated health research centres that combine hospital and community care networks, universities and medical research institutes. We believe this model could be enacted in Victoria with a focus on mental illnesses.

Below we provide a case study that highlights how research is already changing our understanding of the biological mechanisms of schizophrenia and the impact this could have on diagnosis and treatment options.

*Case study: Improvements in diagnosis or predictors of treatment response in schizophrenia*

*Schizophrenia is a complex condition which laboratory researchers think may be caused by a number of different underlying biological mechanisms. Clinically this can mean that people who are diagnosed with schizophrenia may have very different responses to prescribed therapeutics. Similar issues exist in the treatment of bipolar disorder with delays in optimisation of treatment sometimes occurring due to overlapping symptom presentation between bipolar, schizophrenia and major depression. These have major implications for treatment schedules, improving quality of life and reducing the risk of suicide.*

<sup>8</sup> Altamura AC, Dell’Osso B, Berlin HA, Buoli M, Bassett R, Mundo E (2010). Duration of untreated illness and suicide in bipolar disorder: a naturalistic study. *European Archives of Psychiatry and Clinical Neuroscience*, 260(5), pp.385-391.

<sup>9</sup> Ran MS, Xiao Y, Chui CH, Hu XZ, Yu YH, Peng MM, Mao WJ, Liu B, Eric YHC, Chan CLW (2018) Duration of untreated psychosis (DUP) and outcome of people with schizophrenia in rural China: 14-year follow-up study. *Psychiatry Research*, 267, pp.340-345.

*Research being undertaken at The Florey by Professor Brain Dean is focusing on the discovery of biomarkers for sub-types of schizophrenia. The ultimate aim of this research is two-fold – tests that can be used for diagnostics, and/or tests which can be used as predictors of treatment response in people with schizophrenia.*

*A method of accurate and rapid diagnosis of sub-types of schizophrenia would make it possible to firstly rule out other mental health disorders with overlapping symptoms, such as bipolar disorder, and second, optimise treatment intervention required for individuals. Assessment suggests implementing optimal, evidence-based diagnostic tools and tailored treatment could increase the quality of life and social function of individuals living with schizophrenia, while reducing suicide (Ran et al., 2018).*

#### **4. What makes it hard for people to experience good mental health and what can be done to improve this? This may include how people find, access and experience mental health treatment and support and how services link with each other.**

A major challenge for those experiencing mental health problems is that many do not receive timely treatment. Up to 54% of people with mental illness do not access any treatment, and only a minority ever receive specialised mental health care. Initial treatment can often be delayed for many years due to personal reasons (avoiding seeking help or perceiving that treatments will be ineffective), misinformation, lack of knowledge, and stigma surrounding mental illness<sup>10</sup>. For example, a study on treatments received for mood and anxiety disorders in Australia indicated that 39% of individuals with mood/anxiety disorders sought professional help, 26% received evidence-based treatment, but only 16% received minimally adequate treatment<sup>11</sup>.

At a fundamental level, the quality of treatments for mental disorders hinges on the successful translation of basic science research to clinical interventions. Yet the translational gap in realization of findings at the bench to implementation at the bedside remains a significant issue, with a mere 10% of new drug research receiving likelihood of approval from phase I clinical trials<sup>12</sup> and an average time gap of 17 years for moving a drug into clinical practice<sup>13</sup>. A major impediment between the bench and bedside is the cultural and academic divide between basic and clinical research, and the resultant difficulty in successfully translating research through to the point where it is available for use by the public.

To render advances in basic research commensurate with therapeutic progress, the promotion of translational research is critical. Translational research depends not just on integrating basic research into clinical applications; it relies equally on feedback from clinical outcomes to drive the focus of basic research. This iterative and reciprocal approach will help to improve the validity of preclinical models and ensure that they reflect the human

<sup>10</sup> Kohn R, Saxena S, Levav I, Saraceno B. The treatment gap in mental health care. Bulletin of the World Health Organization. 2004;82:858-66.

<sup>11</sup> Harris MG, Hobbs MJ, Burgess PM, Pirkis JE, Diminic S, Siskind DJ, Andrews G, Whiteford HA. Frequency and quality of mental health treatment for affective and anxiety disorders among Australian adults. Medical Journal of Australia. 2015;202(4):185-9.

<sup>12</sup> Hay M, Thomas DW, Craighead JL, Economides C, Rosenthal J. Clinical development success rates for investigational drugs. Nature biotechnology. 2014 Jan 9;32(1):40.

<sup>13</sup> Morris ZS, Wooding S, Grant J (2011). The answer is 17 years, what is the question: understanding time lags in translational research. Journal of the Royal Society of Medicine. 104(12):510-20.

condition as closely as possible to reduce the disconnect between basic science discoveries and true clinical impact.

For this to be possible, there needs to be improved conversation at various levels of the translational landscape: between preclinical and clinical researchers, as well as between medical researchers and health care professionals involved more directly in providing treatment, and community and advocacy groups who provide valuable perspectives.

## **6. What are the needs of family members and carers and what can be done better to support them?**

The onset of mental illness can be a distressing experience not just for the individual directly affected, but also their family members and close friends. The evidence base for positive impact of family involvement in care is well documented, with research consistently indicating that the best treatment outcomes, including reduced rates of relapse and increased recovery, are achieved when family members and/or close friends are involved in providing care and support for individuals with mental illness.

Families and carers have both subjective and objective needs when a relative or individual is experiencing poor mental health. In our experience, it is unfortunately common for family members to express feelings of grief, guilt, anxiety or shame. As outlined in our response in regard to stigma, much of this unnecessary emotional burden can be alleviated through the individual developing an understanding of the underlying pathology which may be driving some aspects of changed behaviour and considering what this means within their own individual circumstances. As an example, relapse in alcohol seeking by an individual can be challenging or disheartening for family members however an understanding that neurocircuitry and neurotransmitter systems play a role in stress-induced relapse can alleviate some of the distressing emotions associated with these events. Similarly, in conditions like dementia where behaviours of concern or psychosis can occur, an understanding of the biological processes which underscore Alzheimer's disease can help to shift the frame of reference for a family away from apportioning blame or having unrealistic expectations, and instead encourage early help-seeking for the entire family unit.

In our view, there is clear and consistent demand for scientific education about the evidence base and latest research into understanding, preventing, treating or curing mental illness. The Florey's public outreach program is focused on increasing awareness and knowledge of the neurobiology underpinning mental disorders to reduce stigma and promote understanding. The Florey hosts a public lecture series in which researchers speak directly to the public about the mental disorders being researched in the Institute. From January 2018 to June 2019, public lecture attendance (15 events) was 3,750 in person. The popularity of the lecture series, which regularly reaches capacity of the Melbourne Brain Centre, has led to the Florey now producing video capture of the event and posting them on YouTube for broader viewing, with ~40,000 views each year.

The active public engagement of researchers at the Florey serves as a critical interface between individuals with a diagnosis of mental illness, their families, and researchers. This dialogue is important as it serves as a platform to hear different perspectives, provide hope

and inspiration to all parties involved, and equip those affected with the knowledge and skills necessary to navigate the landscape of mental illness.

**9. Thinking about what Victoria's mental health system should ideally look like, tell us what areas and reform ideas you would like the Royal Commission to prioritise for change?**

Achieving the “right” mix of funding between awareness raising and advocacy, clinical care and preventive or treatment measures is a difficult task in the mental health area. Each area is critically and inextricably linked, and each area requires resourcing to meet the needs of the people living with mental illnesses.

From the perspective of a scientific organisation which seeks to change lives through brain research, we recognise that our work, our science and our impact is improved when we actively engage with and seek to understand the individuals and communities that we aim to benefit. For this reason, the Florey partners where possible with universities, health care providers, community groups, industry and international collaborators.

We believe that collaborative and innovative research is needed to make long-term, significant impacts on mental health outcomes. For fundamental shifts in the way that we can prevent, diagnose or treat mental illnesses, government and community support is required for research which starts with discovery science, and progresses right through to clinical trials and interventions.

On a purely economic argument, medical research is an investment which has consistently paid dividends for the community and investment in mental health research is no different in this respect. A report prepared by KMPG for the recent productivity commission inquiry indicates that for every dollar invested in Australian mental health research, a return of \$2.70 is delivered to the broader economy<sup>14</sup>. In addition, evidence suggests that for many areas of mental health research priority, innovations have the potential to greatly increase this rate of return. For example, early intervention in psychosis has been estimated to have a long-term ROI of 8.6 per person, yet this remains a challenging area without means of accurately and rapidly diagnosing the condition and being able to predict the best treatment options for an individual<sup>15</sup>. Currently unknown biomarker or other diagnostic approaches could improve the outcomes for individuals, while simultaneously easing the pressures on the healthcare system. Similarly, innovations which can improve effectiveness of existing treatments such as precision medicine approaches could have a large impact on the ~\$1.38 billion that the Victorian State Government provided for clinical mental health services in 2017/18<sup>16</sup>.

Victoria is facing a trajectory of increasing healthcare costs; Federal treasury forecasts that government expenditure on healthcare alone will increase from 4% of GDP in 2009–10 to 7%

<sup>14</sup> KMPG & Association of Australian Medical Research institutes (2018), Economic impact of Medical Research in Australia

<sup>15</sup> KPMG & Mental Health Australia (2018) Investing to save: The Economic benefits for Australia of investment in mental health reform.

<sup>16</sup> Victoria's mental health services annual report 2017 – 2018 (2018), State of Victoria, Department of Health and Human Services.

of GDP in 2049–50. Given the sharp increase in the incidence of mental health concerns, particularly within the youth category<sup>17</sup> and the escalating costs of providing healthcare it is imperative that government leverages research to increase the efficiency of health services and ensure health system sustainability.

We provide two case studies below which illustrate how investment from the government can improve mental health outcomes for individuals, the community and the Victorian economy.

*Case study: New treatments to prevent relapse in alcohol use disorders*

*Alcohol use disorders represent a significant social and economic challenge to Australian society, resulting in over 400 hospitalisations and 15 deaths per day. Estimates from 2010 assess the economic impact of productivity losses associated with alcohol abuse at over \$6 billion per year<sup>18</sup>. Clinicians working with those affected by an alcohol use disorder can also experience difficulties in assessing and optimising treatment of their psychiatric complaints as these conditions can co-exist and sometimes co-contribute to the affected person's symptoms. Although approved treatments for alcohol dependency exist and are regularly used in clinical settings (with mixed success), currently around 90% of alcohol dependent individuals relapse following treatment<sup>19</sup>. Therefore, we need a suite of medications to improve outcomes at a population level.*

*In 2006, in work conducted at the Florey Institute in Melbourne and supported by an NHMRC Program Grant, Professor Andrew Lawrence was the first in the world to establish that the brain's orexin system played a critical role in the desire of people to seek and consume alcohol<sup>20</sup>. This fundamental change in understanding the underlying biological mechanisms that result in relapse during treatments has led to a global research effort in this system, now culminating in an FDA approved therapeutic Belsomra® being registered for use in Australia, the US and Japan. Commencing in 2019, a world-first study will be undertaken in Melbourne in partnership between the Florey Institute, St Vincent's Hospital and Merck to undertake a double blind placebo controlled trial of Belsomra® in people diagnosed with comorbid insomnia and alcohol dependency. This trial is supported by funding from two sources, the Percy Baxter Charitable Trust and the Victorian Government Medical Research Acceleration Fund, plus the in-kind support from Merck to gratis supply compound and matched placebo. A positive outcome would expand the toolbox for prescribing clinicians.*

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<sup>17</sup> Lawrence D, Johnson S, Hafekost J et al (2015) *The Mental Health of Children and Adolescents. Report on the Second Australian Child and Adolescent Survey of Mental Health and Wellbeing*. Canberra: Department of Health.

<sup>18</sup> Manning M, Smith C, Mazerolle P (2013) The societal costs of alcohol misuse in Australia, prepared for Australian Institute of Criminology.

<sup>19</sup> Sinha, R. (2011). [New findings on biological factors predicting addiction relapse vulnerability](#). *Current Psychiatry Reports*, 13(5), 398–405.

<sup>20</sup> Lawrence AJ, Cowen MS, Yang H-J, Chen F, Oldfield B. (2006) The orexin system regulates alcohol-seeking in rats. *Br. J. Pharmacol.*, 148, 752–759.

*Case study: Innovation in treatment resistant depression*

*Treatment resistant depression affects 20 – 30% of individuals diagnosed with major depressive disorder and is defined as non-response to two or more adequate course of consecutive antidepressant treatments<sup>21</sup>. Studies have shown that costs per depressive episode are approximately three times higher for individuals affected with treatment-resistant depression compared to those with non-resistant major depressive disorder<sup>22</sup>.*

*In such cases where psychological and pharmaceutically based options for treatment of depression have been exhausted, approved device based alternatives exist including electroconvulsive therapy, repetitive transcranial magnetic stimulation and vagus nerve stimulation. While these options provide benefits to those affected by treatment resistant depression, use can be hampered by lack of target specificity and/or lead to undesirable side effects.*

*Researchers at the Florey are developing 'optochemical' treatment avenues which target specific neural pathways suspected to be involved in treatment resistant depression. If proven usable in the clinic, this research has the capacity to revolutionise the way in which major depression is treated, using a device rather than a small molecule.*

As outlined in our response to item 3 of the inquiry, we believe that embedding research in and alongside healthcare delivery, as recommended in the 2013 McKeon review of Health and Medical Research, would be a positive step in improving the long-term trajectory of the mental health of Victorians. The Florey is interested and committed to exploring this approach and would be pleased to engage with government on this front.

A strong culture of continuous improvement is required in order to deliver optimal mental health outcomes for all Victorians. We believe that working in partnerships and collaborations across all areas of the mental health system will be necessary to continue improving outcomes for people who are experiencing mental illnesses.

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<sup>21</sup> Johnston KM, Powell LC, Anderson IM, Szabo, S, Cline S (2019) The burden of treatment-resistant depression: A systematic review of the economic and quality of life literature, *Journal of Affective Disorders*: 242:195-210.

<sup>22</sup> *ibid*