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Formal Submission from:
The Australian Centre for Behavioural Research in Diabetes – a partnership for better health between Diabetes Victoria and Deakin University

1. What are your suggestions to improve the Victorian community's understanding of mental illness and reduce stigma and discrimination?
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2. What is already working well and what can be done better to prevent mental illness and to support people to get early treatment and support?
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3. What is already working well and what can be done better to prevent suicide?
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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.
   Living with a chronic condition makes it hard for people to experience optimal mental health. There are currently 330k people living with diabetes (type 1, type 2, gestational) in Victoria (5% of the general population). We have conducted a number of large-scale, national, population-based surveys to investigate the mental health of people with diabetes. We have found that 17% of adults with diabetes have been diagnosed with a mental health problem at some point in their life. Moderate-to-severe symptoms of anxiety and depression affect 36% of adults with insulin-treated type 2 diabetes, compared with 24% and 21% of those with type 1 diabetes and non-insulin-treated type 2 diabetes, respectively. Moderate-to-severe anxiety symptoms affect 21% of adults with insulin-treated type 2 diabetes, compared to 16% and 13% of adults with type 1 diabetes and non-insulin-treated type 2 diabetes, respectively. Adults with type 1 diabetes are more likely to experience diabetes-specific distress (24%), compared to adults with type 2 diabetes (insulin-treated: 20%; non-insulin-treated: 11%). The most commonly reported emotional problems related to diabetes are worrying about the future and the development of diabetes-related complications (reported by 1 in 4 people), and feeling guilty/anxious about 'getting off track' with their diabetes management (reported by 1 in 5). 23% of adults with type 1 diabetes report that feeling 'burned-out' by the constant effort need to manage diabetes is a somewhat serious or serious problem for them. As one man with type 1 diabetes (aged 29) put it, "managing diabetes is tough. I worry about burning out from having to manage it full time". Other research shows that diabetes distress can put people with diabetes at greater risk for diabetes 'burnout' and depression. In addition, our data show that the impact of (type 1 and type 2) diabetes upon emotional well-being is greater than for other aspects of quality of life, e.g. financial situation, work, leisure activities, relationships.

   Younger people living with diabetes experience higher rates of mental health problems. For example, 28% of adolescents with type 1 diabetes report impaired general emotional well-being, while 36% report high diabetes-specific distress and 18% report moderate diabetes-specific distress. Young adults with type 2 diabetes are another priority population, with 63% reporting severe diabetes-specific distress and 27% reporting impaired general emotional well-being.

In addition, we have recently identified that diabetes-related stigma (perceived or experienced) is common. For example, 67% of adults with type 1 diabetes endorse the following statement: 'Because I have type 1 diabetes, some people judge me if I eat sugary food or drinks'; and 50% of adults with type 2 diabetes endorse the statement: 'Because I have type 2 diabetes, some people assume I must be overweight or have been in the past'. The social stigma surrounding diabetes is palpable, evidenced in the media and in the frequent reports (of stigma/discrimination) reported to Diabetes Victoria's Advocacy team. As we already know from other areas of work, social stigma has implications for disclosure, help-seeking, self-care, and mental health.

What can be done to improve this? 1) Improve the health system: Health professionals need to have better understanding of the mental health issues faced by people with diabetes, and to provide support and/or signposting to relevant services and resources, i.e. those with expertise in, and integrating, both diabetes and mental health. Many health professionals indicate that they do not have the time, skills or confidence to do this. They are also constrained by rigid health systems, which do not allow sufficient flexibility (e.g. appointments) or easy referral pathways. There is also a distinct lack of psychologists and other allied health professionals with expertise in both diabetes and mental health.
2) Improve peer support (access and reach): Only 1 in 10 people with diabetes are part of a diabetes peer support group or community (and the majority of those have type 1 diabetes). Of the 89% who are not currently part of a peer support group or community, 38% would like to be. Of those who are currently participating in peer support, 69% found that it was helpful for their emotional well-being, and 67% found that it was helpful in connecting them with relevant healthcare services.
3) Reduce the stigma surrounding diabetes: One of the key ways to reduce perceived and experienced stigma is to ensure that we address myths and misconceptions about diabetes. Having realised the (sometimes) unintended consequences of well-intended messages, diabetes organisations are now doing their part to ensure that campaigns include positive, supportive messaging and correct commonly-held misconceptions. We also need the general media and other stakeholders to stop stigmatising and sensationalising diabetes.

5. What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?
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6. What are the needs of family members and carers and what can be done better to support them?
   Supporting a family member with type 1 diabetes can impact on the mental health of the carer (e.g. parent, spouse). Family members and loved ones face numerous challenges when caring for a person living with diabetes. We have shown that depressive and anxiety symptoms in parents with a child with type 1 diabetes are common. There are also the diabetes-specific emotional concerns related to being responsible for the managing the child's diabetes (including insulin treatment, blood glucose monitoring, etc), and the risk for hypoglycaemia. Fearing hypoglycaemia while the child is asleep is a key concern for parents, having a serious toll on the parent's quality of sleep. Consistent care is financially, emotionally and physically burdensome and parents can experience impaired emotional health and decreased quality of life.

   What can be done to improve this? Currently, there is very little support for the carers of (young) people with diabetes. Improving the health system as recommended above for a person with diabetes, is also needed for a carer. Feeling understood and supported is a first step in this process. There is emerging evidence that psychological interventions are effective in developing/strengthening carer's coping skills to better care for themselves and their loved ones living with diabetes.

7. What can be done to attract, retain and better support the mental health workforce, including peer support workers?
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8. What are the opportunities in the Victorian community for people living with mental illness to improve their social and economic participation, and what needs to be done to realise these opportunities?
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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?
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10. What can be done now to prepare for changes to Victoria's mental health system and support improvements to last?
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11. Is there anything else you would like to share with the Royal Commission?
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