2019 Submission - Royal Commission into Victoria's Mental Health System

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What are your suggestions to improve the Victorian communitys understanding of mental illness and reduce stigma and discrimination?
"Our groups core focus is raising awareness of PMDD (premenstrual dysphoric disorder) and PME (premenstrual exacerbation) as we believe awareness is key to dismanteling stigma and discrimination for people living with PMDD or PME (and the impact this has on their families and communities). As such, we do not believe that the Victorian mental health community addresses and understands PMDD or PME to an adequete level where sufferers recieve the best care they can.   Evidence-based research is what's best translated into the mind of mental health professionals and should Victoria's mental health community be able to conduct this research, we strongly believe that the results will be illuminating. The status quo is that there isn't enough reseach into PMDD, most people, including professionals, cannot recognise it and the mental health community are oblivious on how to treat it. Further, the mentrual taboo and general attitude of confusion and bewilderment surrounding cycles and hormones enhances the stigma and discrimination PMDD/PME sufferers face. Should the AFAB (assigned female at birth) body and its natural processes be focused on and regarded respectfully from school through to higher education, we believe general societal attitude towards these processs will follow form. Currently AFAB people often hide their mentrual cycles and its effect on their body through fear of shame, embaressment and discouragment. Should AFAB people feel safe and comfortable talking openly about their bodily anatomy from a young age, the symptoms of PMDD or PME can be more aptly identified and treated. "

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?
"There is currently no on the ground programs that focus on PMDD or PME or early prevention in Victoria.   However, there is an online effort to reach, connect to and inform PMDD/PME sufferers (or suspected sufferers) through peer support and education. This is done through Facebook groups and other social media platforms. Many PMDD/PME sufferers depend wholeheartedly on the anecdotal lived experiences of other sufferers to understand their illness and access the correct treatment. The International Association For Premenstrual Disorders (IAPMD) found at https://iapmd.org/ also attempts to prevent, educate and support PMDD/PME sufferers, but they are based in the U.S.   There are always greater health outcomes when treatment, support and care can be localised and provided in-person. With an estimated number of 5% at least of PMDD/PME sufferers of the AFAB population, it is not a lack of sufferers in one area that is keeping them isolated or untreated, but a lack of initiative and focus on a local level."

What is already working well and what can be done better to prevent suicide?
"The most recent findings of a global online survey by IAPMD found that 30% of PMDD/PME will attempt suicide during the tenur of their illness. Suicide is common theme for PMDD sufferers with the spectrum starting from suicidal idelation and ending at death by suicide. This symptom can be

exaccerbated by incorrect treatment, which is also a common experience by PMDD sufferers as they are often misdiagnosed with bipolar disorder (or another disorder), or symptoms can persist if they go undiagnosed. Correct treatment for a PMDD sufferer is also not a straight forward answer as there are sub-populations within the PMDD community that have intolerances, averisions or allergies to some treatment options - or they may react badly to another illness or disorder the sufferer has. In a crisis situation, if a PMDD sufferer is admitted to hospital because of their risk of self harm or suicide, little to no consideration is given to where they sits within their mentrual cycle or their mentrual history. The reason for this is because there are no proper guidelines or frameworks for crisis workers to refer to in relation to PMDD or PME. Should workers be informed, educated and trained to better understand PMDD and PME then PMDD sufferers at high risk of suicide can be adequently treated and cared for. "

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.

"The process to be diagnosed for PMDD or PME is not an easy one.   Firstly, anyone who experiences mentural cycles may or may not have negative experiences associated with this. This is called PMS (premenstrual syndrome) and is generally regarded as a natural experience as it effects up to 80% of the population. People are taught to soldier through these symptoms when exercises, tools and support can be given to alleviate these symptoms early on, rather than encouraged to dismiss. People who experience a menstrual cycle are not actively taught how to distinguish a normal menstrual cycle to one that might need medical intervention or lifestyle management. They are also not encouraged to talk about their experience with their menstrual cycle. If they were, we believe this would be beneficial for mental health outcomes and makes it possible to be diagnosed early if something is amiss. Most sufferers overlook the link between their cycle and mental health and assume any symptoms are due to character flaws. This inability to discern what is expected of a cycle and what is abnormal is a huge barrier with women often being treated as unreliable narrators of their menstrual experience by professionals, friends and families and sometimes themselves. Once the menstrual experience becomes problematic and interfering with the quality of ones life, a person either make the connection independantly, another person makes the connection for them, or they are forceably admitted into care. Often times mental health professionals dismiss the relation of the menstrual cycle to mental health as they are not trained to recognised the link and misdiagnose the patient with a mental health condition that has similar symptoms (often bipolar). Not many people are aware that PMDD or PME exists. On in June 2019 did the World Health Organization's include PMDD in the ICD-11 (see https://iapmd.org/position-statements-1/2019/6/11/world-health-organization-adds-premenstrual-dysphoric-disorder-pmdd-into-the-icd-11). This goes to show that PMDD exists as an illness in the genitourinary system as well as a psychiatric one as defined in the DSM-5. Once a link has somehow been made, a person must track their cycle and symptoms for 2 months to be diagnosed with PMDD. It is also difficult to distinguish PMDD from PME and this is another process of elimination that the sufferer needs to go through. They must then go through the trial and error of finding the correct medication.   All in all, it can take years for a person to be properly assessed, diagnosed and treated - with experiences sometimes taking up to 20 years. This lapse in time can severly degrade ones mental health and morale, especially if the medical system has let them down or made mistakes, misdiagnosis or bad treatment. Currently 90% of PMDD sufferer remain undiagnosed. For this reason we believe that the PMDD/PME population is one of the most at risk population.   To resolve this we recommend that the link between mental health and the menstrual cycle including PMDD symptomology, be taught early to dismantel shame and stigma around it, people are encouraged to talk about their cycles and mental health professionals understand how hormonal and menstrual cycles effect mental health. This will require training, guidelines and a review of the current practice."

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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What are the needs of family members and carers and what can be done better to support them?
"Many PMDD or PME sufferers have dependants (children) and need to negotiate their roles as mothers and sufferers. Sometimes their partners or husbands must learn how to take a more active parental role when a PMDD episode hits while also taking on the role of a carer. There is currently no support in place for carer or family members of PMDD/PME sufferers outside of support groups created by other family members and carers (on social media). These groups are often discussing topics such as how to find the right treatment for their loved one, how to not exacerbate symptoms when they present and how to maintain their own mental health when exposed to symptoms or an episode.   Again, focus, resources, booklets and in-person support groups will be beneficial for these people and the medical community can put an emphasis on the effects of PMDD/PME."

What can be done to attract, retain and better support the mental health workforce, including peer support workers?
"More research then training, awareness and education in the form of easy to follow guidelines would be a good place to start. At the moment the UK has begun including guidelines for PMDD for their doctors to learn and practice.   Other options could be: - workplace training for employers in how to make accommodations and adjustments for employees living with PMDD. - Access to additional sick days to reflect the chronic and recurrent nature of the condition."

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?
Accessible workshops could be developed on topics such as managing PMDD at work.

Thinking about what Victorias mental health system should ideally look like, tell us what areas and reform ideas you would like the Royal Commission to prioritise for change?
"We certainly feel the inclusion of PMDD/PME can do nothing but improve the current system. However we understand that care needs to accurate and well-founded, and while there is a growing body of research around menstrual health, endocrinology, PMDD and PME, it is not nearly as impressive as other mental health conditions such as depression. If there is more research, care can be more effectively deployed. One thing that many PMDD sufferers speak of is their inability to locate effective care. This is often due to their local GP not knowing about PMDD or being limited to the little research they've completed overnight. There are a range of treatment for PMDD and we believe it's important to present each treatment alongisde their potential risks/dangers and benefits and how the medication is supposed to work. It would empower the mental health professionals if they better understood PMDD and the various treatment options."

What can be done now to prepare for changes to Victorias mental health system and support improvements to last?
At the very least make sure every mental health professional has a preliminary understanding of PMDD and PME

Is there anything else you would like to share with the Royal Commission?
N/A