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

Organisation Name
Genetic Support Network of Victoria Inc

Name
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What are your suggestions to improve the Victorian communitys understanding of mental illness and reduce stigma and discrimination?
"Education is key but it must be accessible and relatable and it isn't enough. The UK experience would suggest that a major turning point has been the involvement of Patrons such as the Royal Family members speaking of their own person experience which has changed the conversation. There is a consistent message of communication. This has been a strategic campaign that has a pragmatic approach. It's a living case study that has resonated with the general community. The media are also being engaged in a strategic process, rather than a reactive and story' driven way. It's a campaign of recognition and awareness that embraces reality, choices and hope ? without judgement. We would like to see some existing living case studies of high profile Australians across life stages, diversity of culture and backgrounds. In Victoria, we work on highlighting mental illness through sport generally? this is important but not relatable for everyone. We also need high profile examples that clearly inform that being mentally unwell is a spectrum ? everybody has days where they feel mentally unwell, this needs normalisation. It's not illness ? it's the normal flow of life. I think the language is also critical, mental illness can be an isolating and suggestive term - is it avoidable, could you have done anything about it, it must be externally treatable etc. It suggests you have caught something' ? this contributes to an environment for judgment. For the perception to change, the language must change. We are not mentally well or mentally ill, there are so many permutations in between. When talking specifically about mental illness, definitions are important. Generally we use the term broadly and this is also problematic. Is mental illness referring specifically to a wide range of mental health conditions disorders that affect mood, thinking and behaviour at any level or is mental illness conditions such as depression, anxiety disorders, schizophrenia, eating disorders and addictive behaviours. The general community doesn't understand these nuances of definition, let alone for impact and treatment. The segregation between health and mental health also contributes to confusion. We are overwhelmed with physical health messaging ? fitness, nutrition and the delivery of physical health services is overt and easily accessible. In general, genetic health professionals are totally focussed on the physical health of their patients and unless there is an acute presentation of a mental health issue, this would not even be discussed as part of an ongoing health plan. Lack of integration also allows the general community to compartmentalise in a totally non-realistic fashion. Recommendations to address a)Create a communication strategy focussing on high profile diverse people talking about: i) How they focus on and maintain their mental health ii) How they have managed and been impacted by mental illness' iii) How they continue to manage mental Illness' b)Integrate mental health and health at a policy level ? focussing on health and social needs for wellbeing and integrated care. "

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?
"The UK study previously referenced reveals the relationship between rare disease and mental

health: -Living with a rare condition can have a huge impact, including anxiety, stress, low mood, emotional exhaustion and suicidal thoughts. -Many of the drivers of poor mental health reflect issues that are specific to managing a condition that is rare, and that patients/carers face challenges at many points during their journey from the onset of symptoms onwards. -Patients and carers can experience not being taken seriously by healthcare professionals, and sometimes being misdiagnosed with psychiatric illness, when trying to access support for their physical condition. This can have both physical and mental health implications. So, what is working well: In the genetic, undiagnosed and rare disease communities, there are existing support networks, including individual condition specific condition organisations and the GSNV who support those organisations. That means there is somewhere to begin for people. It is still self-generated support. These support organisations are also able to provide peer support through State, national and international networks if required ? for some very rare conditions, an international connection may be the only possible support. What can be done better: Clarity of responsibility is an important beginning ? this is partly driven by the existing silos of physical health and mental health. The GSNV study showed that both health professionals and support services are aware that patients and families are not receiving the appropriate level of mental health support however responsibility was less clear: -mental health issues identified by health professionals differ from those identified by support group leaders; -peer support services do not feel equipped to deal with severe mental health concerns and are of the belief that individuals and families are often not receiving appropriate support for mental health when they engage with support services; -health professionals have mixed feelings regarding whether identifying mental health issues is within the scope of their role, however most believe they should be referring patients on. Already pressured GP's with varying knowledge and skill levels in the field of mental health are charged with being the gate-keepers, with responsibility for the development of mental health plans. It is clear from anecdotal evidence that a medical response is most often recommended, rather than a holistic approach. Take this prescription and when you feel better, if you still need it, I can refer you to a mental health professional. This is a direct result of asking people to perform at a level beyond their knowledge and skill and growing mental health issues would suggest that this approach is not working. In 2018 and again in 2019, the GSNV has funded a very small number of support group leaders (due to our own budget constraints) to undertake the Mental Health First Aid program to upskill the sector to recognise mental health issues presenting ? in themselves and the people they support. This is an excellent program and would be of great benefit to all support group leaders We support the finding of the Genetic Alliance UK as entirely relevant to Australia, Rare Disease Research and include our own below. Recommendation Healthcare professionals should be provided with the skills, knowledge and capacity to: -demonstrate awareness of the emotional challenges of living with a genetic, undiagnosed or rare disease; -handle discussions about mental health sensitively -recognise developing mental health challenges. Recommendation Patients and carers should be routinely signposted to sources of support by healthcare professionals. Recommendation Coordinated genetic, undiagnosed and rare disease services should include assessment of mental health needs and access to mental health services. This should be extended to families, carers and support organisations Recommendation GP surgeries and clinics should have mental health specialists as part of the team of doctors. Medication should not be prescribed without clear evidence that other avenues have been sought (unless there is a diagnosis of mental illness, psychosis where evidence informs that this is the best' course of action). Recommendation Greater access to free Mental Health First Aid for not for profit organisations and a mandate that health service organisations must have staff trained in this specific area ? mirroring general first aid mandating in high risk sectors. If effectively implemented, these changes could do much to address some of the mental health issues patients,

families and carers currently face; and to ensure that mental health is considered as important as genetic, undiagnosed and rare disease patients' and carers' physical health. "

What is already working well and what can be done better to prevent suicide?
This is outside the knowledge and expertise of the GSNV

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 ability of a person and family living with a genetic, undiagnosed and rare conditions to live the best life possible depends upon access to the knowledge and services they need. Services are most often operating in total isolation ? education, GP's, allied health services, specialist health services, social supports including NDIS, financial supports, childcare and sibling support, carer's allowances and pensions and insurance certainty. The stress for families is totally compounded by the lack of coordination between these structures and often the individuals or families are given responsibility for navigating this maze. It is useful to reference the UK genetic, undiagnosed and rare disease research as it represents the Australian environment very well from a patient experience. The GSNV receives anecdotal support for all the following findings across all conditions. The research states that very little has changed for genetic and rare disease patients in the last 5 years. Patients are still experiencing difficulties in getting a diagnosis, accessing information about their condition, receiving appropriate coordinated care, accessing treatments and finding out about research and clinical trials. The reality is that changes in the lives of patients, as a result of awareness, are not living up to our expectations. Research highlights areas impacting mental health for patients are: -Patients and families are given very little information about their condition. 70% of respondents did not feel they were provided with sufficient information following diagnosis. -Patients are frequently left to research their condition alone. Patients often become an expert in their own condition and are often left to inform and educate the medical professionals they encounter. -Patients face significant delays on their journey to secure a diagnosis. 45% of all respondents waited over a year. -The majority of patients (52%) receive at least one incorrect diagnosis/diagnoses, and visit numerous doctors, before they receive a final diagnosis. 37% receive 3 or more incorrect diagnosis. -Patients can experience issues in persuading medical professionals to believe their symptoms and describe how their condition is initially written off as psychological' or, parents are described as neurotic'. It is acknowledged that a number of these items will need technological or scientific advancement, or increased volume of expertise to change however, the system places responsibility with the individual to recognise and seek out support for mental health. This is a significant contributor to the reported decline in mental wellness for people with genetic, undiagnosed and rare conditions and those who support them. Shifting the onus to be with the health professional would significantly impact early intervention and support. Anecdotal evidence would support the assertion that early intervention in emerging mental health challenges will also provide a health economic impact by interrupting the relationship between deteriorating mental health and deteriorating physical health. Anecdotal evidence suggests it is very difficult to achieve acceptance of evidence and therefore mental health support to improve functionality for people with genetic, undiagnosed and rare conditions through the NDIS. This places individuals and families under increasing pressure. Health professionals communicate with each other primarily through the patients themselves or their parents. This lack of an integrated care approach without question is having a negative impact on the mental health of Victorians engaged in the genetic health system. Our health system's patient

centred focus includes the expectation that an individual has the capacity or the support to advocate for themselves, to understand and respond to information and to manage navigation through services. This is not true for all, leading to an inequity of service provision and support. What can be done to improve this: Recommendation Healthcare professionals should be provided with the skills, knowledge and capacity to: -demonstrate awareness of the emotional challenges of living with a genetic, undiagnosed or rare disease; -handle discussions about mental health sensitively -recognise developing mental health challenges. Recommendation Patients and carers should be routinely signposted to sources of support by healthcare professionals. Recommendation Coordinated genetic, undiagnosed and rare disease services should include assessment of mental health needs and access to mental health services. This should be extended to families, carers and support organisations. Recommendation Ensure integrated policy on mental health and health to ensure a living the best possible life person centred focus Recommendation Support the education of NDIS planners and area coordinators through support organisations in the development of mental health impact information around clusters of genetic, undiagnosed and rare conditions such as neurological, mobility, blood, cardiac, cancers etc Recommendation GP surgeries and clinics should have mental health specialists as part of the team of doctors. Medication should not be prescribed without clear evidence that other avenues have been sought (unless there is a diagnosis of mental illness, psychosis where evidence informs that this is the best' course of action). Recommendation Greater access to free Mental Health First Aid for not for profit organisations and a mandate that health service organisations must have staff trained in this specific area ? mirroring general first aid mandating in high risk sectors. "

What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?

"This submission refers specifically to the genetic, undiagnosed and rare disease community and focusses on their experiences and needs. Within this community there are also specific cohorts who are experiencing poorer mental health outcomes. These cohorts include: -The Time of Diagnosis At the time of diagnosis, individuals and families potentially have the most access to support. This support is from genetic health professionals including counsellors (who are not trained in mental health). As research has demonstrates, understanding of mental health needs and potential needs, support services and networks is inadequate. It is this period which often introduces families to self-advocacy, to self-awareness and the frustration of isolation. This can become a familiar place. This is a time where relationships are under significant pressure as uncertainty and blame and shock are common. Extended family may also need to be involved increasing potential for blame as well as natural support systems to implode. -People in transition. Health -This is the group of people exiting the paediatric health system and entering the adult health system. Decision making shifts during this time from parents and health professionals to the young person. This is a particularly challenging time and experiences are much varied. There is, however, no question that this is a high risk group for mental health decline and anecdotal evidence suggests many young people fall through the cracks at this time. Experiences are varied but appear to depend upon individual health professionals rather than the health system in any way. Again, the focus here is on physical healthcare. Education ? Transition in education refers to children from childcare to primary school and primary to secondary school. This is a very stressful time for families, new people need to be introduced and educated about a child and their condition. There is a constant sharing and disclosure of private details and anecdotal evidence is clear that outcomes depend upon individual articulation and advocacy skills to get the best outcomes for their children. -Carers There is a large body of research presenting the increasing pressures on carers and mental health outcomes. Carers can become increasingly isolated

increasing their risk of mental health issues. Financial hardship is also increasingly common as parents become full-time carers impacting stress levels and potential mental health. -Regional and Rural Victorians Access to health professionals with specific expertise can mean that families are travelling long distances for hours regularly to meet health appointments. This places enormous pressures on families. Supporting services are also less likely to be available or accessible outside large metropolitan centres. Many support groups in rural and regional Victoria report feeling isolated themselves and that the people they support are more reliant on them than we experience in metropolitan centres. European research reports that one-third of people have inadequate access to community supports. This is higher in regional centres. If care is available locally, waiting lists can be longer and privacy less assured. The internet is more likely to be the major source of information in regional and rural centres rather than health professionals themselves which can be overwhelming and not always easy to find accurate information. -Lifestage People with genetic, undiagnosed and rare conditions can move between presenting very well and being very unwell at different times of life and in fact each day. Lots of people are very ill but don't look ill and have conditions that no-one has ever heard of. This can lead to a lack of empathy, lack of belief and constantly explaining and disclosing personal information. It can also mean that employment can be extremely difficult. 70% of people have to reduce or stop professional activities due to their condition. As milestone life stages are approached, this is often a time of re-ignited grief for what might have been, for lost possibility. For example a 30 year old diagnosed at 6 years of age may not even think about the reproductive implications of their condition until the reality becomes meaningful. They may have always known but not grieve the loss of children until they feel its relevance. The shared drivers for these cohorts in experiencing disproportionately high mental issues are: -Lack of access and referral to professionals skilled in the area of mental health -Lack of information and communication leading to increased stress levels and perceived lack of choices -Real or perceived lack of understanding and support leading to feelings of isolation And, what can be done to address this: Recommendation Healthcare professionals should be provided with the skills, knowledge and capacity to: -demonstrate awareness of the emotional challenges of living with a genetic, undiagnosed or rare disease; -handle discussions about mental health sensitively -recognise developing mental health challenges. Recommendation Patients and carers should be routinely signposted to sources of support by healthcare professionals. Recommendation Coordinated genetic, undiagnosed and rare disease services should include assessment of mental health needs and access to mental health services. This should be extended to families, carers and support organisations. Recommendation Ensure integrated policy on mental health and health to ensure a living the best possible life person centred focus' including lifestage. Developed in liaison with people with genetic, undiagnosed and rare conditions and relevant stakeholders ? schools, local communities, grief counselling experts "

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

"The UK research clearly reports the experience of family members and carers. Family members and carers reported that there is a huge emotional impact when living with rare disease, negatively impacting on mental health and wellness. 93% of carers reported feeling stressed 90% have felt low 80% have felt emotionally exhausted 70% have felt at breaking point 95%+ worry about the future for their child 15% have had suicidal thoughts The major contributors to mental health stressors identified in research were: -Lack of information and support from health professionals -Being made feel like you are imagining things -Even when services where reasonably coordinated (Paediatric) mental health support is never considered -More than 70% of carers and individuals

living with conditions believe that their health professional is not interested in their mental health state -46% of patients and 57% of carers reported that their health professionals never asked them about their mental and emotional wellbeing -78% of patients and 68% of carers stated that they had to seek out support organisations themselves, they were not referred or recommended by health professionals. Families and carers are also impacted when participating in clinical trials or research projects which are seeking knowledge and medical advancement. I am unaware of any project that currently requires an exit strategy for participants so that they are supported through the transition out of the project and its potential result. This is again the result of a lack of integration between physical and mental health. What can be done to support change?: Recommendation Undertake a similar study in Australia to the UK based study and develop a better understanding and evidence base for the Australian environment and the systemic issues we face. Recommendation Healthcare professionals should be provided with the skills, knowledge and capacity to: -demonstrate awareness of the emotional challenges of living with a genetic, undiagnosed or rare disease; -handle discussions about mental health sensitively. -recognise developing mental health challenges Recommendation Patients and carers should be routinely signposted to sources of support by healthcare professionals. Recommendation Coordinated genetic, undiagnosed and rare disease services should include assessment of mental health needs and access to mental health services. This should be extended to families, carers and support organisations. Recommendation Support the genetic, undiagnosed and rare condition support organisations to be sustainable and to ensure the safety net of networks and support are firmly in place and well known by all. Recommendation Mandate that all research projects involving patient or carers in the health sector must include an exit strategy that ensures minimisation of mental health risks through the transition out of the project and into the next phase ? which may be treatment or nothing. Recommendation Develop a patient participant panel that informs research projects, health professional practice and the support sector on the real and everyday' mental health impacts arising from living with a genetic, undiagnosed or rare condition. "

What can be done to attract, retain and better support the mental health workforce, including peer support workers?

"Peer support workers (voluntary through peer support groups) as previously identified are approaching their threshold in the support of people with genetic, undiagnosed and rare conditions. A clear trend in the support sector which is also disturbing is that this is an ageing sector. Our support groups are often still running 20, 30, 40 years later with the same people leading them. They self-report as tired, burnt out, wishing they could move on and terrified by the uncertainty of what happens without them to drive. People have tended to self-select to these roles through personal experience and are sometimes travelling a distressing pathway themselves while in a voluntary role supporting others. Our role at the GSNV is to support these organisations and also provide opportunities for them to support each other. We also provide a peer support training program for the sector. The voluntary nature of the work makes it difficult to attract a professional workforce, most support groups in the genetic, undiagnosed and rare communities are voluntary ? it's only the larger, more well-known and with greater populations diagnosed that attract funding. Remember, if you put all the rare conditions together and treated them as one, there are more people in Australia with a rare disease than with diabetes. How do we better support the mental health workforce for the genetic, undiagnosed and rare conditions? Recommendation Create a small pool of mental health professionals that can act as mentors to the genetic and rare health support sector Recommendation Upskill the peer support

professionals through the provision of the Mental Health First Aid program "

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?

"It is important to recognise that a change in community attitudes and greater understanding and acceptance are key factors in the capacity of individuals and families to participate economically and socially. We cannot have the same environment and expect a different result. It is not generally mental illness that is a barrier to social and economic participation for people with genetic, undiagnosed or rare conditions except where the condition can be genetically linked. We can expect increasing linkages between mental illness and genetics over the next few years as resources are directed into depression, alzheimer's disease, anxiety disorders, neurological disorders causing developmental delays etc. Conditions such as schizophrenia, bipolar and autism have extremely high genetic probability. Improved participation could be developed using the USA model that seeks to develop job roles around prevalent conditions and disabilities. Roles developed in conjunction with key stakeholders are more likely to be a successful experience for the employer and the person with the mental illness. Creating a round hole to put a round peg into. Social enterprises could also be funded to encourage the development of small businesses. There are successful models for this that could be utilised to build inclusive and supportive environments. As identified, many people with genetic, undiagnosed or rare conditions are not advised about or referred to support networks, thus increasing their feelings of isolation. Participation in support networks with peers and expertise is highly valued by these who have accessed and has a significant impact in mental wellness. Recommendation Instigate a communication campaign to change community attitudes and to all the support sector to make itself much more widely known and accessible. Recommendation Develop job roles based upon specific conditions in liaison with key stakeholders and support these roles in appropriate industries and sectors Recommendation Develop and support opportunities for the development of social enterprises with key stakeholders which would support roles of varying conditions Recommendation Patients and carers should be routinely signposted to sources of support by healthcare professionals. "

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?

"There is a high level of need but mental health care is rarely coordinated with other genetic, undiagnosed and rare disease care. The most effective pathway to improving mental health care and outcomes is to ensure that it becomes an integral part of health care. It must be recognised to be as important as physical health and identified as a significant unmet need for person-centred coordinated care. Coordinated health services must include assessment of mental health needs and access to mental health services. This should be extended to carers. These recommendations are specifically targeted to achieve these aims and while all are important, they have been placed in a loose' priority order to assist the Royal Commission decision making: 1.Recommendation Integrate mental health and health at a policy level ? focussing on health and social needs for wellbeing and integrated care and focussed on the outcome of the best possible life' for patients and carers. Developed in liaison with people with genetic, undiagnosed and rare conditions and relevant stakeholders ? mental health experts, schools, local communities, grief counselling experts etc 2.Recommendation Healthcare professionals should be provided with the skills, knowledge and capacity to: -demonstrate awareness of the emotional challenges of living with a genetic, undiagnosed or rare disease; -handle discussions about mental health

sensitively -recognise developing mental health challenges. 3.Recommendation Patients and carers should be routinely signposted to sources of support by healthcare professionals. 4.Recommendation Support the genetic, undiagnosed and rare condition support organisations to be sustainable and to ensure the safety net of networks and support are firmly in place and well known by all. 5.Recommendation Coordinated genetic, undiagnosed and rare disease services should include assessment of mental health needs and access to mental health services. This should be extended to families, carers and support organisations 6.Recommendation Develop a patient participant panel that informs research projects, health professional practice and the support sector on the real and everyday' mental health impacts arising from living with a genetic, undiagnosed or rare condition. 7.Recommendation Mandate that all research projects involving patient or carers in the health sector must include an exit strategy that ensures minimisation of mental health risks through the transition out of the project and into the next phase ? which may be treatment or nothing. 8.Recommendation GP surgeries and clinics should have mental health specialists as part of the team of doctors. Medication should not be prescribed without clear evidence that other avenues have been sought (unless there is a diagnosis of mental illness, psychosis etc where evidence informs that this is the best' course of action). 9.Recommendation Greater access to free Mental Health First Aid for not for profit organisations and a mandate that health service organisations must have staff trained in this specific area ? mirroring general first aid mandating in high risk sectors. 10.Recommendation Support the education of NDIS planners and area coordinators through support organisations in the development of mental health impact information around clusters of genetic, undiagnosed and rare conditions such as neurological, mobility, blood, cardiac, cancers etc 11.Recommendation GP surgeries and clinics should have mental health specialists as part of the team of doctors. Medication should not be prescribed without clear evidence that other avenues have been sought (unless there is a diagnosis of mental illness, psychosis where evidence informs that this is the best' course of action). 12.Recommendation Greater access to free Mental Health First Aid training for not for profit organisations and a mandate that health service organisations must have staff trained in this specific area ? mirroring general first aid mandating in high risk sectors. 13.Recommendation Undertake a similar study in Australia to the UK based study and develop a better understanding and evidence base for the Australian environment and the systemic issues we face. 14.Recommendation Create a small pool of mental health professionals that can act as mentors to the genetic and rare health support sector 15.Recommendation Upskill the peer support professionals through the provision of the Mental Health First Aid program 16.Recommendation Develop job roles based upon specific conditions in liaison with key stakeholders and support these roles in appropriate industries and sectors 17.Recommendation Develop and support opportunities for the development of social enterprises with key stakeholders which would support roles of varying conditions 18.Recommendation Create a communication strategy focussing on high profile diverse people talking about: i) How they focus on and maintain their mental health ii) How they have managed and been impacted by mental illness' iii) How they continue to manage mental Illness' iv) The existing support network and how to access services and support If effectively implemented, these changes could do much to address some of the mental health issues patients, families and carers currently face; ensuring that mental health is considered as important as genetic, undiagnosed and rare disease patients' and carers' physical health. "

What can be done now to prepare for changes to Victorias mental health system and support improvements to last?

"This is a systemic problem requiring a systemic solution. There are clear facts and we know that the current system and practice does not work. Change must happen in approach, delivery and

culture and it is acknowledged that sustainable change will take time. Recognition in policy and practice that mental and physical health are synergistic, and cannot and should not be viewed separately is critical to long term sustainability. This recognition would change health professional practice from GP to specialist, focus health spending and have significant impact on our population. We need to focus on the society we want, not the one we don't want and target our resources to these areas. I think this is the first step because change can then flow through to education of health professionals, delivering of health services etc. The strengthening of the existing support network to ensure that first tier' access to mental health support is available while systemic changes are made would provide a stronger safety net. Developing a patient participant panel to advise, recommend and focus health professionals in research projects and clinical trials and research to provide for mental health support would also assist in upskilling our health system and practice at a low investment and risk. There is a model for this in Genomics England and the 100,000 genomes project. This would also lead into mandating this focus in research projects of the future. "

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

"The Genetic Support Network of Victoria Formal Submission to the Royal Commission into Victoria's Mental Health System The Genetic Support Network of Victoria (GSNV) is Victoria's peak body supporting people with genetic and rare conditions and those who support them. We are funded by the Victorian State Government. The GSNV was established in 1997 in response to a changing complex environment; in recognition of the importance of a broad consumer voice in genetic and rare disease health; acknowledgement of a gap in existing support for many rare, undiagnosed and genetic conditions and to increase awareness of the challenges faced by people with genetic conditions and those who support them. We are a state-wide service and we serve all genetic conditions ? taking an inclusive approach to what is common across all conditions; for people with conditions and those who support them. Our work is underpinned by clarity of strategic direction, values and principles and is developed with a focus on empowerment through Education, Advocacy and Support. Our vision is for a Victoria where everyone can flourish. We adopt our definition of health from the World Health Organisation (WHO) ""a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity and in accordance with the Ottawa Framework for Health Promotion, we seek to enable people with genetic, undiagnosed and rare conditions to increase control over and improve their health and health decisions. Health is seen as a resource for everyday life, not the objective of living. In our sector we have established a trust between GSNV and the support sector where the GSNV will represent, listen, engage and seek to understand and advocate. We all recognise that as a collective, our community voice is clearer and focussed and together we are stronger. We are also part of the Genetic, Undiagnosed and Rare Disease (GUARD) Collaboration, a national collaboration between 5 peak bodies coming together to provide a united patient and community voice. Our collaboration seeks to advocate for better access to testing and support services. Genetic Support Network Victoria Genetic Alliance Australia ? NSW The Genetic and Rare Disease Network - WA Rare Voices Australia ? National Syndromes Without A Name (SWAN) - National In Australia, it is estimated that 60% of the population will be affected by a condition which has some genetic contribution. Current conservative estimates indicate that approximately 6-8% of Australians are affected by a rare disease, 80% of which are genetic in origin. This equates to more than 2,000,000 people and this does not included families and carers. The number of rare diseases identified is increasing every day, with the tally so far at more than 10,000. It is expected that all these statistics will continue to grow! It is critical to note that if you put all the rare conditions together and treated them as one, there are more people in Australia

with a rare disease than with diabetes. We live in an age where we are unlocking some of the secrets of our genetic code, beginning to understand that we have coded sequences that are sometimes optimal, sometimes not ? because of the pre-programmed pattern we follow or because of an unexplained mutation or change which occurred inexplicably, just for us. We are also beginning to explore the relationship between our environment and our genes in an already complex space. Discovery can bring hope and possibility; understanding and knowledge; fear and despair. Lack of diagnosis can bring frustration and isolation. Increased focus and funding in the genetic health area over the past 5 years have highlighted the impact on individuals, families and support structures. Funding is targeted at the health system and focussed on physical health. Increased choices and access to testing, geographic inequities, diagnosis or non-diagnosis, access to treatment and services, navigating NDIS, health and service pathways, potential impact on extended family and future family planning, insurance are some of the elements that individual and families are increasingly seeking assistance with and increasingly impacting their mental health and wellbeing. It is in this context that the GSNV is making a formal submission to the Mental Health Royal Commission. Increased access to testing is increasing the number of people and families impacted and this is leading to a downstream impact on the existing support structures (often formed due to a personal link to a condition or disease). More support organisations are reporting to the GSNV pressures on themselves and concerns about the impact of increasing pressures on their own mental health. There is no existing research detailing the impact of increasing diagnosis on mental health in Australia. We do have research from the UK that highlights what impacts on people living with genetic and rare disease and those who support them. This work evolved out of an inquiry conducted by the All Party Parliamentary Group on Rare, Genetic and Undiagnosed Conditions, which identified mental health as a key issue facing rare disease patients and carers. The GSNV also conducted a pilot research study in 2018 exploring the role and perspectives of genetic and community support services in supporting mental health. Australia is committed to patient centred care (PCC), which focusses on the whole person', through the Australian Charter of Health Care Rights (2007) and the Australian Safety and Quality Framework for Health Service Standards (2011). Engagement with the genetic health system through preparing for testing, testing, diagnosis, communication, treatment and management can cause higher levels of anxiety as evidenced by many existing and recent studies. www.raredisease.org.uk/our-work/living-with-a-rare-condition-the-effect-on-mental-health-2018/ The GSNV welcomes this Royal Commission and we look forward to positive outcomes for people living with genetic, undiagnosed and rare conditions. We have noticed over the past two years that mental health is increasingly expressed as a priority area by our support groups. Other priority areas are being addressed such as access to testing and pre-conception options etc however there has been no traction at all in the area of mental health. We would also like recognise the outstanding work of many of our health professionals and the personal commitment many show to going above and beyond to support a patient. A patient experience however cannot be luck', all patients, families and carers deserve and have a right to excellent health care which is inclusive of mental health. We would welcome the opportunity to discuss our submission. [redacted]"