Royal Commission into Victoria's Mental Health System

WITNESS STATEMENT OF DR CHRIS GROOT

I, Dr Chris Groot, Academic, of Grattan Street Parkville Victoria 3010, say as follows:

1 I make this statement on the basis of my own knowledge, save where otherwise stated. Where I make statements based on information provided by others, I believe that information to be true.

Background and qualifications

2 I am a Lecturer at the Melbourne School of Psychological Sciences, at the University of Melbourne. I currently coordinate the first-year undergraduate psychology program and lecture in areas of clinical psychology and psychological research methods.

3 I also direct the Mental Illness Stigma Research Lab at the Melbourne School of Psychological Sciences and conduct research in areas of mental illness stigma, psychosis, suicide and mental health service delivery.

4 I am currently the lead researcher on the following mental illness stigma projects:

(a) The National Stigma Report Card (in collaboration with SANE Australia and its Anne Deveson Research Centre);

This project seeks to survey 7000 Australians living with complex mental illness about their experiences of stigma and discrimination in 14 life domains. The survey will commence in September 2019 and will be the largest survey of its kind conducted in Australia to date.

(b) The Hearing Voices Project (In collaboration with SANE Australia and The Dax Centre);

A teaching, learning, and research initiative aiming to embed the voice of lived experience of mental illness in the undergraduate psychology curriculum at The University of Melbourne.

(c) Stigma about Psychotic Symptoms;

A program of experimental research mapping stigmatised cognitive, emotional, and behavioural responses to symptoms of psychosis.[1]

[1] In collaboration with PhD Candidate Kelton Hardingham, and Honours students Beth Hobern and Ellen Rankin.

(d) Does 'Schizophrenia' Matter?

A program of experimental research examining the utility of diagnostic label change in reducing public stigma about schizophrenia.[2]

(e) Media Reporting and Stigma About Schizophrenia; and

A program of experimental research investigating the role of media reporting as a determinant of public stigma about schizophrenia.[3]

(f) Working with Challenging Crisis Presentations.

A program of experimental research examining telephone and online counsellors' stigmatised cognitive, emotional, and behavioural responses to challenging client presentations.[4]

5 I have worked in inpatient, outpatient, community-based, and telephone and online mental health service delivery and research settings. Of note, I have a background in large-scale mental health service delivery. I have governed the clinical and research aspects of national services including but not limited to:

(a) the Suicide Call Back Service;

(b) SuicideLine Victoria;

(c) ATAPS All Hours Suicide Support Service;

(d) Beyond Blue Infoline;

(e) MensLine Australia;

(f) the Australian Defence Force All-Hours Triage Service; and

(g) the Vietnam Veterans After-Hours Counselling Service.

6 The research aspect of these telephone and online mental health services included but was not limited to:

(a) regular analysis and reporting of data pertaining to service use, client sociodemographics, presenting clinical problems, outgoing referral pathways and outcomes;

(b) evaluation of service effectiveness;

(c) trial of new service paradigms and their clinical effectiveness; and

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[2] In collaboration with PhD Candidate Kelton Hardingham.

[3] In collaboration with PhD Candidate Kelton Hardingham and Professor Nicholas Haslam.

[4] In collaboration with SANE Australia, Lifeline, On the Line, Wellways, Dr Michelle Blanchard, Dr Anna Brooks, Clinical Masters student Jessica Westfold, and Honours student Emma Waldron.

(d) reporting and dissemination of national data predominantly on suicide-related issues to the scientific community, mental health sector and government.

7 I completed my PhD with specialisation in the cognitive neuropsychiatry of auditory verbal hallucinations in schizophrenia. I also hold Bachelor and Honours degrees in psychology. The award dates and details of each of these academic qualifications is as follows:

(a) **PhD (Cognitive Neuropsychiatry)**. Melbourne School of Psychological Sciences, The University of Melbourne. March 2016. Supervisors: Prof. Henry Jackson; Prof. Susan Rossell. Thesis: Are auditory verbal hallucinations related to auditory processing deficits and prosodic impairment in schizophrenia?;

(b) **B.A. (Honours) (Psychology)**. Melbourne School of Psychological Sciences, The University of Melbourne. 2007. Supervisor: A/Prof. Christopher Davis. Thesis: Auditory-visual speech recognition: do amplitude and frequency modulations interact with visible speech?;

(c) **B.A. (Psychology)**. School of Psychology, The University of New England, 2006.

8 Attached to this statement and marked "**CG-1**" is a copy of my curriculum vitae.

Mental illness stigma and lived experience

How is mental illness stigma defined for the purposes of your evidence?

What does it encompass?

9 Mental illness stigma is a complex and multidimensional construct. Numerous taxonomies of stigma have been provided since Erving Goffman's seminal structured work '*Stigma: Notes on the Management of Spoiled Identity*'[5], most of which are largely variations on a theme. A recent concise and clear model is provided by Pryor and Reeder.[6,7]

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[5] Goffman, I. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall.

[6] Pryor, J. B., & Reeder, G. D. (2011). HIV-related stigma. In J. C. Hall, B. J. Hall & C. J. Cockerell (Eds.), *HIV/AIDS in the Post-HAART Era: manifestations, treatment, and Epidemiology* (pp. 790–806). Shelton, CT: PMPH-USA.

[7] Bos, A., Pryor J., Reeder, G., & Stutterheim, S. (2013): Stigma: Advances in Theory and Research, Basic and Applied Social Psychology, 35:1, 1-9

10 The Pryor and Reeder model asserts that stigma has four primary factors or domains.

11 **Public stigma** – refers to stereotyped attitudinal, prejudicial emotional, and discriminatory behavioural responses by members of the public towards those living with mental illness.

12 For example, a commonly held stereotype is that people living with schizophrenia are dangerous. If one holds this attitude, then a prejudicial fear response is likely to be experienced. These experiences in turn are thought to influence discriminatory behaviour, such as distancing oneself socially from people with schizophrenia.

13 In Pryor and Reeder's model, public stigma is considered to be the factor that drives the other elements of stigma outlined below.

14 **Structural stigma** – this aspect of stigma can be observed at an institutional level and is therefore also commonly referred to as institutional stigma. Structural stigma manifests in discriminatory policies, laws and institutional practices that marginalise and block opportunity for people living with mental health problems.[8]

15 Structural stigma is said to manifest both intentionally and unintentionally.[9] A classic example of intentional structural mental illness stigma from the private sector is repeated representations in news media of people with schizophrenia in a negative light.[9] Arguably, another example would be top-tier mental health insurance products that carry a cost that is unlikely to be afforded by many who need them most.[10]

16 In contrast, an example of unintentional structural stigma would be the distribution of government funding across the Australian and Victorian mental health system. Professor Pat McGorry (University of Melbourne) recently coined the term "missing middle" to describe this problem – Professor McGorry contends that the current funding spread is geared towards addressing mild to moderate high prevalence disorders such has anxiety and depression in particular, and that in comparison, people living with more severe and complex mental illnesses do not receive adequate resources.[11]

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[8] Corrigan, P., & Lam, C. (2007). Challenging the structural discrimination of psychiatric disabilities: Lessons learned from the American disability community. Rehabilitation Education, 21, 53–58.

[9] Corrigan, P. W., Markvwitz, F. E., & Watson, A. C. (n.d.). Structural Levels of Mental Illness, 481–492.

[10] Katinka Day, CHOICE Campaigns and policy team lead, retrieved from https://www.choice.com.au/money/insurance/health/articles/mental-health-and-health-insurance

[11] Pat McGorry, Mental illness is more ubiquitous than cancer. How can we help the 'missing middle'? Retrieved from https://www.theguardian.com/commentisfree/2019/apr/26/mental-illness-is-more-ubiquitous-than-cancer-how-can-we-help-the-missing-middle

17 The concept of structural stigma can also be extended to agents of the mental health system, for example, psychiatric nurses, psychiatrists and psychologists. It is well established that certain patient groups are stigmatised within mental health systems, and Borderline Personality Disorder (**BPD**) is the classic example.[12] Evidence indicates that stigmatised attitudinal, emotional and behavioural responses in mental health system staff to clients with BPD are driven in part by inadequate system resourcing.[13]

18 **Self-Stigma** – self-stigma has multiple components. It refers to the experiences and internal psychological processes of people with lived experience of mental illness.

(a) First, self-stigma manifests in terms of the direct negative effects of experienced structural or public stigma. For example, one may have the experience of being denied employment (an outcome of structural discrimination) or being socially excluded (an outcome of public stigma).

(b) Second, self-stigma can refer to the awareness of structural or public stigma and anxious anticipation of similar future experiences.

(c) Third, the concept of self-stigma also encapsulates the internalisation of public stigma and arguably structural stigma, which can in turn have devastating implications for individuals in terms of exacerbation of existing mental health issues. This process hinges upon point (b) above – awareness, and manifests via a process of *agreement*, *application* to the self and resultant *impact* on self-esteem.[14]

For example, if one is aware of a public stigmatised stereotype that people living with mental illness are to blame for their problems, and in turn agrees with this attitude and applies it to the self (*I have a mental illness, therefore I am to blame for my problems*), then it follows that self-esteem would be detrimentally affected (*I currently respect myself less because I have a mental illness)*.

19 **Stigma by Association** – this refers to the experiences of a person who is associated with a person living with mental illness, such as a carer, partner or relative. The experiences are similar to those of the person living with mental illness: the direct negative

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[12] Aviram, R. B., Brodsky, B. S., & Stanley, B. (2006). Borderline personality disorder, stigma, and treatment implications. *Harvard Review of Psychiatry, 14*(5), 249-256. doi:10.1080/10673220600975121.

[13] Dickens, G. L., Lamont, E., & Gray, S. (2016). Mental health nurses' attitudes, behaviour, experience and knowledge regarding adults with a diagnosis of borderline personality disorder: systematic, integrative literature review. *Journal of Clinical Nursing, 25*(13- 14), 1848-1875. doi:10.1111/jocn.13202.

[14] Corrigan, P. W., Watson, A. C., & Barr, L. (2006). The self-stigma of mental illness: Implications for self-esteem and self-efficacy. *Journal of Social and Clinical Psychology, 25,* 875-884.

effects of structural or public stigma, and awareness and anxious anticipation of such future experiences.

20 The core domains of stigma presented by Pryor and Reeder (and others – see Fox et al (2017) for a corresponding more nuanced model[15]) while discreet, are interrelated, with public stigma sharing the greatest intersectionality with other domains. For example, public stigma is the touchstone that drives much of structural stigma – the stereotypes and prejudices that members of societal institutions may hold as members of the public are inevitably brought to the table when discussing and drafting legislature and so forth as regards people living with mental illness.

Current knowledge on stigma and discrimination

21 The makeup of public stigma is complex. A fundamental tenet of modern psychological practice is notion that thoughts often drive emotion and behaviour.[16] This fundamental concept can be extended to public stigma in order to understand the direction of relationship between its constituent elements of stereotyped attributions (thought – cognition), prejudicial emotional responses and discriminatory behaviour.

22 For example, a core stereotype regarding people living with schizophrenia is that they are unpredictable and dangerous. If ones held that misinformed attitude, then an expected emotional response would be one of fear and trepidation. In turn, one may have numerous behavioural responses, including but not limited to *social distancing*. Social distancing here refers to avoidance – limiting the amount to which a person with schizophrenia could be present in your life as a housemate, friend, romantic partner or so forth.

23 This misled and stigmatised stereotype of people living with schizophrenia as being characteristically dangerous, and its ensuing emotional and behavioural responses, have been observed to endure throughout the history of mental illness stigma research. However, in actuality, evidence suggests that people living with schizophrenia in the community are 14 times more likely to become victims of violence than perpetrators.[17]

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[15] Fox, A. B., Earnshaw, V. A., Taverna, E. C., & Vogt, D. (2017). Conceptualizing and Measuring Mental Illness Stigma: The Mental Illness Stigma Framework and Critical Review of Measures. *Stigma and Health*.

[16] Beck, A. T. (1964). Thinking and depression: Theory and therapy. *Archives of General Psychiatry*, **10**, 561–571.

[17] Wehring, H. J., & Carpenter, W. T. (2011). Violence and schizophrenia. *Schizophrenia bulletin*, *37*(5), 877–878. doi:10.1093/schbul/sbr094

24 There is empirical literature dating from the 1950s speaking the link between perceived dangerousness and social distancing around schizophrenia.[18] Unfortunately, it is easy to maintain that erroneous and stigmatised link (I discuss this further below). This is just one example highlighting that experiences of stigma and discrimination are characteristically different regarding severe and complex mental illness such as schizophrenia, when compared with other experiences such as mild to moderate anxiety and depression.[19] One does not commonly observe public attributions of dangerousness about people living with depression, for example.

Role of diagnostic labels

25 As I mentioned above, I direct the Mental Illness Stigma Research Lab at the Melbourne School of Psychological Sciences. The Lab is young but evolving rapidly. Our niche area of research is experimental interrogation of core hypotheses regarding stigma about severe mental illness. The origin of our work was in examining the role of psychiatric labels and precisely how they elicit public stigma in terms of cognition, emotion and behaviour.

26 It has been suggested that changing the label of mental disorders, and in particular, schizophrenia, would result in a decrease in public stigma about them. There are numerous theoretical and opinion pieces, descriptive or correlational studies of this topic, and reviews thereof,[20] but very little experimental evidence. Such evidence derived from projects with randomised experimental designs is critical in order to legitimately make inferences as regards cause and effect as regards label change and stigma.

27 To this end, our preliminary research in the lab investigated the efficacy of relabelling schizophrenia in reducing cognitive, emotional and behavioural aspects of public stigma about the disorder.[21] Our results suggested that label change is not an effective means of stigma reduction and that any alternative label will likely be equally stigmatic if applied

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[18] Starr, S. "The Public's Ideas about Mental Illness." Paper presented at the annual meeting of the National Association for Mental Health, Indianapolis, IN, November 1955.

[19] Corrigan, P., Rowan, D., Green, A., Lundin, R., River, P., Uphoff-Wasowski, K., White, K., & Kubiak, M. Challenging Two Mental Illness Stigmas: Personal Responsibility and Dangerousness, *Schizophrenia Bulletin*, Volume 28, Issue 2, 2002, Pages 293–309, https://doi.org/10.1093/oxfordjournals.schbul.a006939

[20] Lasalvia A, Penta E, Sartorius N, Henderson S (2015). Should the label 'schizophrenia' be abandoned? Schizophrenia Research 162, 276–284.

[21] Groot, C. J., & Hardingham, K. (2018) 6th Schizophrenia International Research Society Conference, Florence, April, 2018. *Stigma about Schizophrenia: The effects of diagnostic labels, symptoms, and illness phase*

diagnostically to the experience of schizophrenia. This is in line with previous suggestions that diagnostic labels provide equivalent signals of otherness, thereby contributing to public stigma about schizophrenia.[22] It is important to note, however, that public stigma elicitation is just one of the numerous considerations as regards the utility of relabelling schizophrenia and that others, such as consumer perspectives, hold independent importance.

28 It is generally accepted that diagnostic labels are useful from a clinical perspective, including because they can inform decisions around whether and how to treat certain conditions. However, the use of these labels has a number of unintended effects including by perpetuating and increasing the prevalence of stigma through a mark of differentiation.[22]

29 An association created by pairing a diagnostic label with certain conduct will tend to become compounded and more entrenched the more it is repeated, which in turn makes it more difficult to displace.

30 Furthermore, the effects of stigma perpetuated by the use of diagnostic labels can be broad reaching within the mental health system itself. BPD is one such label that is well-established to elicit stigma from some agents of the mental health system.[23]

31 Stigma about the label of BPD and people living with the disorder manifests in various ways. For example, there is a common perception in mental health workers that people labelled with BPD are manipulative and may not actually be at risk of suicide when they present as such to crisis services; however, they are 45 times more likely to die by suicide than people in the general population.[24]

32 Frontline emergency department workers, psychologists, psychiatrists, psychiatric nurses and others may tend to distance themselves from people with BPD due to the false stigmatisation and this can be manifested in a number of ways such as longer than average waiting periods in emergency departments. Often, the customer can tell that the service providers are putting up these boundaries and this can trigger a fear of abandonment which in turn escalates their presentation which increases the service providers' desire to distance themselves, and so it becomes a cycle.[12, 13, 23]

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[22] Corrigan, P. (2014). Erasing Stigma Is Much More Than Changing Words. Psychiatric Services, 65(10), 1263-1264.

[23] Sansone, R. A., & Sansone, L. A. (2013). Responses of Mental Health Clinicians to Patients with Borderline Personality Disorder. Innovations in Clinical Neuroscience, 10(5-6), 39-43.

33 Along with colleagues in the Mental Illness Stigma Lab and in collaboration with an alliance of leading national telephone counselling organisations and staff including but not limited to SANE Australia and Dr Michelle Blanchard, I am currently conducting research into this issue in a telephone counselling setting. This research involves understanding again, through randomised experimental designs, how various features of BPD differentially elicit responses from mental health workers and, in turn, we will build sector capacity to deliver services to this population, if funding is obtained.

Features of disorders

34 While our work in the Mental Illness Stigma Research Lab has observed that different hypothetical diagnostic labels appear to have equivalent effects on public stigma about schizophrenia, our findings suggest that different features of severe mental illnesses like schizophrenia elicit public stigma in differential ways.

35 At the symptom profile level, we have demonstrated that positive and negative symptoms of schizophrenia differentially elicit stigmatised cognitive, emotional and behavioural responses in the general public.[21] For example, positive symptom profiles (like hallucinations, for example) tend to elicit stereotypes of dangerousness and fearful emotional responses. In contrast, negative symptom profiles (like low motivation, for example) appear to elicit attributions of laziness and emotional responses of irritation and anger. Each of these observations ultimately result in greater desire for social distance; however, the causal route for each instance of this outcome is unique. We also observed active illness phases to elicit far greater stigmatised responses across all of our measures than symptomatically remitted phases.

36 Building upon this preliminary work examining differential responses to features of disorders, we are currently completing a program of research that is examining responses to individual symptoms of schizophrenia and their subtypes. In doing so, we aim to develop a systematic understanding of how each specific element of schizophrenia elicits public stigma about the disorder. Findings from this program have been recently peer-reviewed and accepted for oral presentation at the 9th International Together Against Stigma Conference, to be held in Singapore in October 2019. In brief, our findings highlight that public stigma about schizophrenia is affected by processes at the levels of symptoms and symptoms subtypes. The findings also suggest that the sex of both members of the public and persons living with schizophrenia influence stigmatised responses to symptoms. Together, these results highlight the importance of considering responses to clinical features and other characteristics of individuals in order to

comprehensively understand stigma about schizophrenia, and certainly when planning interventions for such stigma.[25]

National Stigma Report Card

What is the National Stigma Report Card?

37 The National Stigma Report Card (**NSRC**) is a national project that aims to understand the experience of stigma and discrimination for Australians living with severe and complex mental illnesses, and to in turn effect system change.

38 The NSRC project is delivered by SANE Australia and its Anne Deveson Research Centre in partnership with the Melbourne School of Psychological Sciences at the University of Melbourne and with the support of the Paul Ramsay Foundation.

39 I am leading the project along with Dr Michelle Blanchard. We are fortunate to have recruited a stellar staffing cohort for the project, including our two post-doctoral research fellows; Dr Cal Andrews and Dr Imogen Rehm. The project is further staffed by members of the Anne Deveson Research Centre, Mental Illness Stigma Lab, and Melbourne School of Psychological Sciences.

40 We aim to survey 7000 Australians living with severe and complex mental illness on their experiences of stigma and discrimination across 14 life domains, commencing in September 2019. I hesitate to divulge more about the details of the survey at this point in time so as not to pollute data collection.

41 For the purposes of the NSRC, severe and complex mental illness is defined by experiences of mental illness that are considered to be severe and episodic, severe and persistent, or require complex multiagency support. Some of the specific diagnostic groups we seek to include are: psychotic illness (eg. schizophrenia, schizoaffective disorders, mania with psychotic symptoms, bipolar affective disorder with psychotic symptoms, depression with psychotic symptoms, persistent delusional disorders, acute and transient psychotic disorders and other and unspecified non-organic psychotic disorder) personality disorders (eg. paranoid, schizoid and schizotypal personality disorders; antisocial, borderline, histrionic and narcissistic personality disorders; avoidant, dependent and obsessive-compulsive personality disorders), bipolar and related disorders, severe and persistent depression and anxiety, and eating disorders.

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[25] Groot, C., Hobern, B., Hardingham, K., & Rankin, E. (2019) Symptoms Matter: How Diverse Features of Schizophrenia Differentially Affect Public Stigma. 9th International 'Together Against Stigma' Conference, Singapore, October, 2019.

42 Latter stages of the project will use the evidence gathered from the national survey to inform policy and advocacy to effect positive change for Australians living with severe and complex mental illness.

43 A comparable initiative has been undertaken overseas in the U.K. and the 'Time to Change' program. This program is ongoing and includes stigma-reduction, awareness raising, and research and evaluation aspects. Experts from this project including Prof. Graham Thornicroft have kindly supported the NSRC project through sharing of stigma measures, and provision of feedback on the draft NSRC survey under development as part of a consensus-based quality assurance process.

44 The inquiry will cover experiences of stigma and discrimination within the mental health system and will extend to other areas such as housing, employment education and training, the welfare system, relationships, mass media and social media.

What is the purpose of the NSRC?

45 The results will provide a baseline by which changes in stigma and discrimination experienced by people living with severe and complex mental illnesses can be assessed over time at national, state and regional levels.

46 This knowledge can be used to drive systemic changes through the development of improved policies, better support and directed actions.

47 There have been other large surveys that have investigated the experience of mental illness stigma in Australia and internationally. Prominent example include the evaluation of the Time to Change stigma-reduction campaign in the U.K.,[26] Survey of High Impact Psychosis (**SHIP**) study [27] and the 2014 study of discrimination and positive treatment.[28] Critically, the NSRC differs from the first and last of these studies in that their samples covered a broad range of mental illnesses and had relatively low representation of people with severe and complex mental illness. Moreover, while the NSRC is similar to the SHIP study in terms of a focus on severe mental illness, it differs in that the sample to be

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[26] Evans-Lacko S, Corker E, Williams P, Henderson C, Thornicroft G. Effect of the Time to Change anti-stigma campaign on trends in mental-illness-related public stigma among the English population in 2003—13: an analysis of survey data. Lancet Psychiatry. 2014;1(2):121–8.

[27] Morgan, V. A., Waterreus, A., Jablensky, A., Mackinnon, A., McGrath, J. J., Carr, V., Saw, S. (2012). People living with psychotic illness in 2010: The second Australian national survey of psychosis. *Australian & New Zealand Journal of Psychiatry*, *46*(8), 735–752. https://doi.org/10.1177/0004867412449877

[28] Reavley, N. J., & Jorm, A. F. (2015). Experiences of discrimination and positive treatment in people with mental health problems: Findings from an Australian national survey. Australian & New Zealand Journal of Psychiatry, 49(10), 906–913. https://doi.org/10.1177/0004867415602068

recruited includes severe mental illnesses other than psychosis and also topically focusses on the lived experience of stigma and discrimination.

Will the NSRC be representative?

48 There are a few questions here. One is the question of how representative the survey items are in relation to real-world experiences of stigma and discrimination. Concepts of construct and face validity tie in here. Said differently, and for example, consider housing. How precisely does discrimination in the housing sector manifest in the real world and how does that differ from the experience of discrimination in any of the other 13 life domains of interest for our study?

49 Generating items that are representative of real-world experiences are one of the core challenges of the project. The NSRC survey will use a mixture of previously validated items, adapted items, and bespoke items. Many of the adapted and bespoke items have been created with a focus on construct validity. Again, this aspect of the survey is currently being scrutinised in the Delphi consensus quality assurance process by an expert reference group and findings from the first round of our consensus process have been very favourable in this respect.

50 Another consideration relates to the sample recruited for the study. The priority is to ensure that the sample captures the range of diagnoses and experiences that are encapsulated under the banner of 'severe and complex mental illness'. As mentioned earlier, it has been determined that our inquiry will extend to schizophrenia spectrum disorders, bipolar and related disorders, personality disorders, PTSD, severe depression and anxiety, eating disorders, hoarding disorders. Therefore, we will recruit participants from these various diagnostic groups. It is important to note, however, that we seek to recruit people with these experiences, whether they have been diagnosed or have accessed sort support or treatment, or not, given that stigma is a known barrier to help-seeking.

51 It is important to acknowledge the observation that stigma is a core concern for people living with a range of mental illnesses, and commonly delays or prevents help-seeking.[29,30] This is a central assumption of the NSRC project.

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[29] Corrigan, P., Thompson, V., Lambert, D., Sangster, Y., Noel, J. G. and Campbell, J. (2003) 'Perceptions of Discrimination Among Persons With Serious Mental Illness', Psychiatric Services, 54(8), pp. 1105–1110. doi: 10.1176/appi.ps.54.8.1105.

[30] McNair, B. G., Highet, N. J., Hickie, I. B. and Davenport, T. A. (2002) 'Exploring the perspectives of people whose lives have been affected by depression', *Medical Journal of Australia*, 176(SUPPL.). doi: mcn10080_fm [pii].

52 Given that stigma affects help-seeking, a strictly epidemiological, probability-based sampling approach that hinges upon national and state-based service usage data is insufficient for the NSRC project. The NSRC survey recruitment strategy will certainly leverage the reach of SANE Australia and its partners across Victoria and the nation more broadly, but will also involve community-facing communications targeting people with lived experience who are not currently or have never sort help for severe and complex mental health issues. These communications will speak about the survey in terms of indexing experiences in the 14 life domains of interest for NSRC rather than explicitly outlining that the survey focuses on discrimination. This approach is standard in stigma research in order to render a less-biased and more representative sample.

53 The NSRC is both a research and an advocacy project. Therefore, the sample of 7000 people is not only determined by statistical considerations, but by the need to obtain a sample with gravitas that is likely to motivate positive change for Australians living with severe and complex mental health issues. To this end, the sample will also be as representative of its accessible population as possible, and careful attention will be paid to sociodemographic quotas while, of course, balancing the pragmatic goal of recruiting this ambitious target.

How reliable do you expect the NSRC to be?

54 We are very confident about the survey we are creating. The draft survey was developed through a recent judicious systematic literature review of previous measures of stigma and discrimination. Again, the draft survey and methodology is being subjected to a quality assurance process prior to implementation. A group of international stigma experts have been drawn together to scrutinise and provide feedback on the proposed survey and methodology via a consensus quality assurance process.

55 Following this quality assurance process, the survey will be subjected to a statistical validation study. This study will trial the survey delivery in a sample of people with complex mental illness and determine and refine the psychometric properties of the measure and its constituent subscales.

56 The final NSRC measure will therefore be scrutinised in terms of reliability and validity prior to its launch in September.

What are the potential limitations of the NSRC?

57 The survey seeks to strike a balance between breadth and depth of inquiry. In doing so, it is limited in its ability to achieve either of these levels of inquiry as well as would be possible with multiple focussed studies. We are philosophical about this, and consider the survey to be the first iteration in an ongoing program of research. Future research in this program will likely become specialised in each of these respects.

Trends in stigma

What are the trends in mental health stigma? Has Victoria (or Australia, if there is no Victorian-specific data) progressed in reducing stigma and what are the changes over time?

58 There is no significant longitudinal Australian data on trends in mental health stigma, and particularly regarding severe mental illness. The NSRC aims to fill this gap by providing a comprehensive baseline that can be referenced over time. Other useful data that will provide a useful baseline for the future comes from the SHIP study[31] and 2014 study of discrimination and positive treatment.[32] For example, the SHIP study found that 37.9% of respondents had experienced stigma or discrimination because of their experience of psychotic disorder in the past year, and that experienced discrimination (20.3%) or fearful anticipation thereof (22.7%) had prevented them from pursuing opportunities. We look forward to adding to such valuable baseline data with the NSRC project.

59 Internationally, recent evaluative evidence as regards the effectiveness of the Time to Change stigma-reduction campaign in the U.K. was mixed[33]. Improvements in prejudice towards and exclusion of people with mental illness were observed. Some regional improvements were also observed in attitudes. However, no improvements in terms of intended behaviour were observed.

60 Internationally, Bruce Link and colleagues have done some substantive work on this topic in relation to the USA by comparing public attitudes towards mental illnesses including schizophrenia, depression and alcohol dependence based on national data collected in 1996 and 2006. The main themes that have emerged from that work are:

(a) Core beliefs about the aetiology (the causes) of mental illness have changed. Public attitudes were focussed on psychosocial causation in 1996 but had shifted towards biological/medical conceptualisations in 2006. This shift away from psychosocial causation is generally associated with less blame attribution directed at the person with lived experience. However, there is also a downside,

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[31] Morgan, V. A., Waterreus, A., Jablensky, A., Mackinnon, A., McGrath, J. J., Carr, V., Saw, S. (2012). People living with psychotic illness in 2010: The second Australian national survey of psychosis. *Australian & New Zealand Journal of Psychiatry*, *46*(8), 735–752. https://doi.org/10.1177/0004867412449877

[32] Reavley, N. J., & Jorm, A. F. (2015). Experiences of discrimination and positive treatment in people with mental health problems: Findings from an Australian national survey. Australian & New Zealand Journal of Psychiatry, 49(10), 906–913. https://doi.org/10.1177/0004867415602068

[33] Evans-Lacko S, Corker E, Williams P, Henderson C, Thornicroft G. Effect of the Time to Change anti-stigma campaign on trends in mental-illness-related public stigma among the English population in 2003—13: an analysis of survey data. Lancet Psychiatry. 2014;1(2):121–8.

in that medical attributions in the general public are often married with greater expectation of poor prognosis;

(b) Core stereotypes have not changed. For example, schizophrenia is still thought to make people violent and unpredictable; and

(c) Public and structural stigma endures.

61 Even without formal data focused on trends as regards stigma overtime, we can see anecdotal evidence of progress in Australia. Organisations like Beyond Blue have made good progress in terms of opening up regular national discussion about high prevalence conditions like anxiety and depression. One needs only to attend to the twitter-sphere or mass media to see regular evidence of this. However, there is still a very long way to go for other more severe and complex experiences, relatively speaking. We certainly do not see schizophrenia regularly featuring in positive mass media stories about hope and help seeking, for instance.

Have these changes been different for different people and communities? For example, across different mental illnesses and diverse communities.

62 Even allowing for the limitations noted above, is well established that the experience of stigma and discrimination varies considerably across cultural groups.

63 In smaller communities we see a paradox of social proximity where people might be geographically isolated but socially, members of that community tend to know a lot about what is going on in each other's lives. In smaller communities with this level of interconnectedness, such as rural towns, people may be disinclined to go to the chemist to get a prescription filled for anti-psychotic medication and so forth.

64 Unfortunately, there is very little evidence at this point in time as regards intersection stigma for people with severe mental illness. The second round of the NSRC project survey aims to address this as it drills down into intersectionality with a range of issues for LGBTI+, CALD, Aboriginal and Torres Strait Islander peoples, and other populations.

What do the trends or other research suggest for the future of mental-illness stigma?

65 That it will endure without effective intervention. Particularly where perceived threat to the self is implicated.

Why do certain stigmatising attitudes remain?

66 From an evolutionary perspective, humans are neurobiologically and psychologically predisposed to stereotyping. Social stereotyping theoretically helps us navigate our world safely on a daily basis in an efficient manner without having to think about every fleeting

social interaction we have in an in-depth, contextualised fashion. From an evolutionary perspective, in this respect, stigma is functional and adaptive. It ensured our safety if something poses a threat to the self, because we are able to identify and respond to it more quickly.[34] As such, with any effort to reduce mental illness stigma, we are theoretically waging war against natural psychological mechanisms - an uphill battle.

67 Beyond evolutionary psychology, there are numerous and complex factors that are influential in stigmatizing mental illnesses such as schizophrenia. It is theorised that mass media plays an important role in establishing and maintaining stigmatised stereotypes about schizophrenia in particular.

68 There is data that shows that there is a bias in TV news reporting around mental illnesses like schizophrenia in particular to reporting violent crime.[35,36,37] It is most often the case that the experience of mental illness was an insignificant factor in relation to the reported crime[38], but often in modern media illness is paired with violence without necessary elaborative context. This reporting style creates a simple yet powerful association in the viewing public between an illness like schizophrenia and violence. Unfortunately, such an association is difficult to break when instances of this pairing are intermittently repeated. Even in the context of a campaign to extinguish stigma and combat misinformation presented in problematic news reporting, after the initial pairing, the pairing will theoretically be reacquired more easily, strongly and rapidly the second time and every subsequent time. This phenomenon is known as 'reacquisition of a conditioned response', which is a fundamental and powerful process in classical conditioning.[39]

69 As I mentioned above, the Mental Illness Stigma Research Lab is now looking at the fine-grained features of disorders and how they play a role in stigmatising attitudes. This is a completely new area of mental illness stigma research and this observation alone highlights that our understanding of mental illness stigma is still evolving, and we don't have all the answers.

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[38] Varshney M, Mahapatra A, Krishnan V, Gupta R, Deb KS (2016) Violence and mental illness: what is the true story? J Epidemiol Community Health 70(3):223–225

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70 Another challenge for combatting stigma is getting support for the cause, when the cause is itself stigmatised. It is a bit circular, in that sense, and it is difficult to break the cycle. For example, I mentioned earlier the inequitable spread of funding across the mental health system that affects the 'missing middle'. Given this arguable instance of unintentional structural discrimination, which may hinge upon, at the very least, a lack of perceived importance or urgency as regards service provision for this population, then it follows that obtaining the necessary funds to support destigmatisation of the experiences comprising that missing middle, and in turn encourage help-seeking, would be equally problematic.

Strategies and recommendations to combat stigma

71 Numerous strategies have been applied in Australia and internationally to address mental illness stigma with mixed effects, including psychoeducation, symptom simulation, protest, coming out, media interventions and contact-based interventions. The findings are highly variable across the literature.

72 The response to stigma should be multifaceted. Stigma is a complex issue and is further complicated in relation to any particular experience of mental illness.

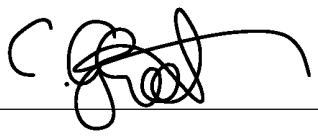
73 The majority of the international evidence points to contact as the most effective way to reduce stigma about mental illness. For example, see Corrigan et al (2001), who experimentally contrasted protest, educational and contact based interventions.[40] Interpersonal contact with somebody with mental illness challenges any stereotypes that are held. When a person sits across a table from somebody with a diagnosis of schizophrenia and realises that the other person is just like them, this tends to trigger empathy and reduce stereotypes of dangerousness and prejudicial emotions like fear. Regular, ongoing contact seems to be the most effective way to combat stigma.

74 It is obviously not be pragmatic to have every person in Victoria sit down with a person living with a highly stigmatised mental illness (like schizophrenia) one on one. So one then needs to think creatively about how to achieve contact. To this end, the Melbourne School of Psychological Sciences at the University of Melbourne, in partnership with SANE Australia and The DAX Centre, have recently received preliminary funding for the development of our 'Hearing Voices' program. This program will embed the voices and perspectives of people with lived experience of mental illness into the undergraduate clinical psychology curriculum through a suite of videos, live-stream Q&A sessions, and

[40] Corrigan, P.W.; River, L.P.; Lundin, R.K.; Penn, D.L.; Wasowski, K.U.; Campion, J.; Mathisen, J.; Gagnon, C; Bergman, M.; Goldstein, H.; and Kubiak, M.A. Three strategies for changing attributions about severe mental illness. Schizophrenia Bulletin, 27(2): 187-196, 2001c.

an art gallery tour. I recently piloted this program with 20 students to take a guided tour of an exhibition of art produced by people with lived experience of mental illness and attend a talk from a lived experience ambassador with schizophrenia. The results of this pilot were very encouraging and provided evidence of a range of de-stigmatising outcomes. Students reported being less fearful of people with schizophrenia, and more willing to seek help themselves if they had an issue in the future. The implementation of this program for the 2019 cohort of roughly 2000 semester 2 first-year psychology students will be formally evaluated and published later in the year.

75 As I've outlined above, the purpose of the NSRC is to establish the nature and extent of stigma and discrimination experienced by people with severe and complex mental illness. In my view, that data is critical to informing the type of action that is needed to reduce stigma through advocacy for policy change. This mechanism of research-informed policy change is effective in other areas of stigma[41] and we expect it will be here also. Again, there is real merit in contact-based interventions in particular, but also education, awareness raising, and increased discourse on stigma, but more is needed. We hope to make a valuable additional layer of contribution through the NSRC's research and advocacy to effect positive change for people living with severe and complex mental illness.

sign here ► 

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