



EXPLANATORY STATEMENT

Project ID: 42679

Project title: Let's Talk About Follow up Action: examining if Human Rights have improved within Mental Health Service delivery since 1992

Chief Investigator's name:

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Super CRO

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You are invited to take part in this study. Please read this Explanatory Statement in full before deciding whether or not to participate. If you would like further information regarding any aspect of this project, you are encouraged to contact the researchers via the phone numbers or email addresses listed above.

What does the research involve?

The aim of this study is to replicate the Plant & Hardy report, facilitated by the National Community Advisory Group on Mental Health. This report examined how recommendations from the Report of The Inquiry into the Human Rights of People with Mental Illness undertaken by HREOC in 1992 were implemented (Allison, 2006). Consequently, the study will use mixed-methods, an approach researchers Williams et al. (2020) reported the use of both Action Research and Grounded Theory using quantitative and qualitative data "in a health research study has the potential to harness unique strengths and mitigate limitations of each approach". The increase of mixed-method research in healthcare has occurred at a time of international complexity in mental health care delivery.

The aim of this study is to bring a group of stakeholders together to codesign an approach to see whether Human Rights have improved within Mental Health Service delivery and policy development across Australia since 1992. This research will examine that many issues identified in the Let's Talk About Action report (Plant & Hardy, 1994), despite the Australian Commonwealth Government launching the National Mental Health Strategy in 1992 (Whiteford et al., 2002), are still needing to be addressed today. The motivation for this study comes as a result of the external partner investigator receiving a mental health diagnosis in 1992 and then gaining work as an advocate within the Mental Health System since 1996. Finally, the Let's Talk About Action report identified issues including accommodation, education, work and income, leisure and sport, stigma, discrimination, family, and other relationships.

- 1. Scoping workshop:** Members of the newly formed National Mental Health Consumer Alliance and Mental Health Carers Australia will be invited to each nominate up to 5 members to participate in a scoping workshop to engage in the codesign process prior to running focus groups. This process will use the Let's Talk About Action report as a guide, and will take approximately 4 hours. In this study you will be invited to attend either online or face to face, depending upon if logistically possible and your preference. The scoping workshop will be recorded

to assist with analysis. If you choose to participate you will receive the appropriate payment in recognition of your time and expertise as per the National Mental Health Commission Paid Participation Policy:

2. <https://www.mentalhealthcommission.gov.au/sites/default/files/2024-03/paid-participation-policy-2020.pdf>

Why were you invited for this research?

You have been invited to participate because you are currently registered with the National Mental Health Consumer Alliance or Mental Health Carers Australia.

Source of funding

The study has been funded by Super CRO.

Consenting to participate in the project and withdrawing from the research

Participation in this research is voluntary. We encourage you to read the information in this explanatory statement, and if you have any questions, ask the researchers nominated at the top of the statement. Involvement in the scoping workshop will indicate your consent to participate (implied consent). You are free to withdraw at any time. If you are participating, you are free to leave at any time, without question. The information gained will be pooled data and it will not be possible to remove data up until the point of you leaving the workshop.

Possible benefits and risks to participants

You may not directly experience benefits from participating in this project. The anticipated benefits are for people formerly treated for and now in recovery/recovered from mental distress to inform system redesign, thereby increasing their sense of being heard, empowerment, that their opinions and experiences matter, and that they can improve the experiences for others through their insider perspective and knowledge. This has been requested by the Royal Commission into Victoria's Mental Health System (2019-2020, report 2021) and the Productivity Commission report from the same period. Consumer voice, views and expertise will benefit the community by enabling better designed services.

A benefit may be meeting with consumers, carers and service providers from not-for-profit agencies to share the historic experiences and previous advocacy, which is often found to be beneficial for individuals. Further, participants have the opportunity for gaining a greater understanding of the experiences of individuals and families, which may provide benefits through current and future advocacy and raising awareness of policy changes required.

Participating in this research is unlikely to cause you any discomfort but if you become distressed as a result of participation please contact one of the freely available services outlined at the end of this form. There will be – through prior information and arrangement – an agreement with the local community mental health service to respond should it be required on the day.

Confidentiality

No information that you give to us will be revealed to another person in any form which identifies you. The pooled data from the scoping workshop will not include your name, so it will not be possible for the data to be linked to you. No information that you give to us will be revealed to another person in any form which identifies you. Participants within focus groups will be asked to maintain confidentiality and to not repeat information that is revealed within

the group unless given permission. Any identifying information, such as names spoken within the group, will be removed from the transcriptions.

A report of the study may be submitted for publication, used in a thesis, and/or used in conference presentations, but individual participants will not be identifiable in such methods of dissemination.

Storage of data

All data collected in this study will be stored on secured devices/data storage at Monash University and will be destroyed after 7 years. Only the researchers listed on top of this statement will have access to the raw data. Care will be taken to protect your anonymity in any publication of this data. This will involve making sure that any data or excerpts from transcripts do not contain any identifying details.

Use of data for other purposes

We would like to assure participants that only aggregate de-identified data may be used for reporting in advocacy and that ethics approval has been granted for this purpose.

Results

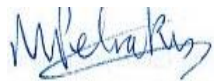
If you would like to receive a summary of the results of this study please contact the researchers at the top of this document.

Complaints

Should you have any concerns or complaints about the conduct of the project, you are welcome to contact the Executive Officer, Monash University Human Research Ethics Committee (MUHREC):

Executive Officer
Monash University Human Research Ethics Committee (MUHREC)
Room 111, Chancellery Building D,
26 Sports Walk, Clayton Campus
Research Office
Monash University VIC 3800
Tel: +61 3 9905 2052 Fax: +61 3 9905 3831
Email: muhrec@monash.edu

Thank you,



Associate Professor Melissa Petrakis

Supports

If you have found topics raised within this research distressing and would like further support, please refer to the following list of supports – If you are in an emergency, in danger or you or someone close to you requires immediate help, call triple zero (000) for emergency services

Lifeline 13 11 14

Anyone can call Lifeline. The 13 11 14 service offers a counselling service that respects everyone's right to be heard, understood and cared for. Lifeline also provides information about other support services that are available in communities around Australia.

SANE Helpline 1800 18 7263

SANE runs a national, out-of-hours helpline offering specialist emotional support and information to anyone affected by mental illness, including family, friends and carers. They are open every day of the year from 6pm to 11pm. The SANE helpline can also provide practical information about services in your local area through their information database.

Grow 1800 558 268

GROW is Australia's only national peer support organisation. GROW has operated for over 50 years and was established and developed by people living with a mental illness. People come to GROW because they have experienced mental illness; depression, anxiety, panic attacks, and mental and emotional distress. GROW participants can join in weekly GROW meetings, attend social activities, and education and information sessions which are structured to assist participants with their personal growth and development.

Suicide Helpline Call-Back Service 1300 659 467

The Suicide Call Back Service provides crisis counselling to people at risk of suicide, carers for someone who is suicidal and those bereaved by suicide, 24 hours per day 7 days a week across Australia. People who are not linked in with current professional support can also access up to six sessions of ongoing counselling with the same counsellor at times scheduled to suit you.

Beyond Blue Info Line 1300 22 4636

The beyondblue info line provides access to information and referrals to relevant services for depression and anxiety related matters. You can call the info line for the cost of a local call or send an email.