La Trobe Law School

FINAL REPORT
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Physical Health Experiences of People who have Accessed Mental Health Services: A qualitative research and online resource development project

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[1] National Mental Health Commission, *Equally Well Consensus Statement: Improving the physical health and wellbeing of people living with mental illness in Australia* (Sydney, NSW: National Mental health Commission, 2016), https://www.equallywell.org.au/wp-content/uploads/2018/12/Equally-Well-National-Consensus-Booklet-47537.pdf.

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1. Introduction

This report presents an overview of the qualitative research and online resource development project Physical Health Experiences of People who have Accessed Mental Health Services. The project was conducted by researchers at La Trobe University, RMIT, Charles Sturt University and University of Melbourne with Healthtalk Australia and Equally Well, and supported by funding from the National Mental Health Commission, NSW Mental Health Commission and Victorian Government.

The project team created an online resource that enables users to explore how people navigate the complex relationship between their physical and mental health through video clips, audio recordings and written statements of their experiences. Our researchers spoke to 32 people around Victoria and New South Wales with lived experience of a wide variety of concurrent physical and mental health concerns, 28 of whom agreed to their stories being included on the online resource. These people came from a range of backgrounds and were at different stages of their health journeys. People talked about how they understood their physical and mental health to be connected, how the healthcare system and individual practitioners could get in the way of their pursuit of health, how to manage their health within the context of their day-to-day lives, what interactions with health providers made a difference, and thoughts on how to gain more agency and control over their health, among other topics.

All project funds were expended.

2. Project Team

2.1 RESEARCH TEAM

The research project was co-led by Associate Professor Christopher Maylea (now La Trobe University, formerly RMIT University) and Professor Renata Kokanović (RMIT University) with Grace McLoughlan, Rosiel Elwyn (University of the Sunshine Coast), Dr Nicholas Hill (University of Melbourne; Visiting Fellow RMIT University), Dr Kate Johnston-Ataata (Visiting Fellow RMIT University), Professor Stuart Thomas (RMIT University) and Professor Russell Roberts (Charles Sturt University). All researchers assisted in the recruitment and interviewing of participants, contributed to data analysis, supervised the project team during the process of writing talking points, and reviewed talking points and participant profiles. Project Research Associate and qualitative researcher Dr Chloe Green conducted interviews and data analysis, wrote participant profiles and talking points, oversaw the preparation of all materials for web publication, and coordinated the development of the website. Esther Le Couteur provided administrative support, liaised with participants, and assisted with the coordination of the development of the website during the data analysis and writing stage.

2.2 CONSUMER LEADERSHIP ADVISORY GROUP (CLEAV)

The Consumer Leadership Advisory Group (CLEAV) included a range of people with experiences of accessing services for physical and mental health. They met across the course of the project and provided feedback on all aspects of the project plan, production, delivery and implementation. Wherever possible, project decisions were taken to the CLEAV for discussion and feedback.

2.3 PROJECT ADVISORY GROUP (PAG)

The Project Advisory Group (PAG) met regularly to provide feedback and oversight on every stage of the project. It included representatives from across Victoria and New South Wales, including from each funder.

3. Project Timeline

3.1 LIVED EXPERIENCE FRAMEWORK PRINCIPLES

In line with best practice mental health research methodology, the project team committed to reporting progress against the NSW Mental Health Commission's Lived Experience Framework Principles throughout the project. These principles are informed by lived experience to be flexible and agile, transparent and accountable, sustainable, and foster continual learning. The project team employed lived experience researchers throughout every stage of the project and assembled a lived experience advisory group of senior lived experience experts in the field. Input from research team members with lived experience led to interviews being co-conducted with lived experience researchers, additional support and input from people with lived experience in producing the online resource, and the inclusion of additional lived experience perspectives in the lived experience advisory group.

3.2 PLANNING AND RECRUITMENT

Planning and staff recruitment began between July and October 2020. Research assistants and lived experience experts were recruited by December 2020, with inter-institution agreements finalised by early 2021. Human Research Ethics Approval was granted by the RMIT University Human Research Ethics Committee (Project #23687) on 10 December 2020. The overarching timeline for the project is provided in Appendix 1.

In early 2021, the research staff completed training in both Stage 1 and Stage 2 Healthtalk Australia methodology, focusing respectively on maximum variation sampling (recruiting a diverse group of participants with respect to both lived experience of mental and physical health concerns and demographic characteristics), data collection and processing (Stage 1) and preparing the online resource for publication, including thematic analysis, writing thematic summaries and selecting interview extracts for the resource, and other website content, and the user checking process (Stage 2). The training was provided by Dr Kate Johnston-Ataata, who has extensive experience in Healthtalk projects and is currently the Co-Director of Healthtalk Australia. Dr Johnston-Ataata has previously worked on multiple Healthtalk Australia research projects ranging from depression and mental health to infertility and early menopause.

In early February 2021, the Consumer Leadership Advisory Group (CLEAV) and Project Advisory Group (PAG) convened to assist with planning and participant recruitment. Both advisory groups met throughout the project to review the interview guide design, initial data analysis, research findings, website content and provide guidance.

3.2.1 Participant recruitment

Information about the project was advertised on the Equally Well and Healthtalk Australia websites and social media from March 2021, and used to contact health organisations for letters of support. These letters then informed an expression of interest form for participants, who were recruited following a maximum variation sampling approach from across regional and metropolitan Victoria and New South Wales. Participants reported finding out about the project through social media, particularly Twitter, and services Independent Mental Health Advocacy (IMHA), SANE Australia and Neami National.

Recruitment initially occurred at a slower pace than the team anticipated, due to uncertainties around interstate travel and the impact of COVID-19 on burdened service providers. However, the project team were able to progress recruitment through relationships with supportive service providers.

3.3 RESEARCH AND ANALYSIS

3.3.1 Literature review

The project team completed a literature review in August 2021, which has been accepted for open-access publication in *Frontiers in Public Health*[2] . The team used systematic methods to source literature examining mental health consumer perspectives on their physical and mental health published between 2005 and 2021. Initial searches with key terms related to mental health, physical health and consumer perspectives were conducted in Web of Science, Informit, Sciencedirect, Pubmed, CINAHL, Psyinfo and Scopus. Papers were uploaded to covidence and selected based on the inclusion and exclusion criteria developed by the CLEAV. These searches identified 1,865 papers, 116 of which met the inclusion criteria and were reviewed and analysed for their level of consumer perspective and their discussion of physical and mental health experiences. The initial analysis was cross-checked for scholarly rigour by additional team members.

Included studies predominantly focused on consumers' individual experiences of their physical and mental health, including but not limited to their understandings and experiences of medication and associated risk factors. They also captured some social aspects of mental health consumers' physical health, including factors that impacted individual agency, stigma, and social and interpersonal factors. Structural factors affecting physical and mental health, such as accessibility of services and financial constraints, were also identified. The review revealed that in comparison to clinician perspectives, direct representation of consumer perspectives was lacking in many studies. Clinician and carer perspectives on structural factors were also investigated, with consumer perspectives again limited in this area. The review also found few genuine codesigned or coproduced research studies. The findings of the reviews and subsequent article are described further below at 3.7.1.

3.3.2 Interviews

Interviews commenced on 31 March 2021, conducted by research staff, including members of the research team with lived experience. The interviews were video or audio recorded, according to each participant's preference, with some interviews retained solely as a written transcript.

The project team spoke to 32 people around Victoria and New South Wales with lived experience of a wide variety of physical and mental health concerns, 28 of whom chose to have their story featured in the online resource. Thirteen participants were from metropolitan NSW, 10 metropolitan from Victoria, 5 from regional NSW and 4 from regional Victoria. These people came from a range of backgrounds, were at different stages of their health journeys, and recounted diverse experiences of mental health and physical healthcare. Participants were aged between 21 and 66 years old at the time of their interviews. We spoke to 12 men and 20 women; none of our participants identified as non-binary or transgender. Participants grew up and/or had lived in Australia, New Zealand, the United Kingdom, Lebanon, Oman, Egypt, Malaysia, the Philippines, and one participant is a member of the Gamilaroi nation. Eleven people had children. Participants' education backgrounds varied, with five people leaving secondary school before Year 12, three people completing secondary school, five people completing diplomas or certificates, nine people attaining Bachelor's degrees and five people completing Master's degrees. Ten people were currently working, 12 were actively volunteering, and seven were studying at the time of their interview.

3.3.3 Data analysis

In consultation with the CLEAV, the research team used NVivo to develop a data coding framework to identify common themes among interviews and assist in the production of research outputs. The research team, including lived experience researchers, completed coding of interview transcripts by mid-2022.

3.4 QUALITATIVE RESEARCH FINDINGS

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[2] Chloe R. Green, Rosiel Elwyn, Nicholas Hill, Kate Johnston-Ataata, Renata Kokanovic, Chris Maylea, Grace McLoughlan, Russell Roberts and Stuart D. M. Thomas, "A critical review of research into mental health consumers' perspectives on their physical health: Is there an absence of consumers in the design, conduct, analysis and reporting of this research?" *Frontiers in Public Health* 10:982339. doi: 10.3389/fpubh.2022.982339

> *Your story is valid and* [you should] *push for the right care. Don't just back down because someone tells you, like that someone is de-validating that you're important and that their story is important and it deserves to be listened to and just because people can't see it doesn't mean that it's not there. (Elise)*[3]

Thematic analysis of the interview data resulted in a range of findings regarding the health challenges people face, how the healthcare system impacts service users, how people manage their health, what can make a difference in people's experiences of physical and mental health systems, and how service users regain agency over their health. While the project built on established knowledge about how some physical health challenges, such as cardiovascular conditions and diabetes, are interlinked with mental health conditions, project participants identified a much wider range of experiences of physical and mental health conditions.

Many participants had experienced some services that had played a key supporting, validating and encouraging role. In particular, people appreciated services that collaborated with them on their healthcare and provided enough time to talk through their concerns and support to make informed choices. On the other hand, problems with communication were common, particularly in talking about mental health concerns with physical health professionals or in having physical health needs overlooked or ignored within mental health services. For many people, health challenges were made worse by difficulties with service accessibility, including unreasonably long wait lists, limited access in regional areas, or experiences of being excluded from services based on one's health history. Many participants shared experiences of health professionals dismissing their physical health symptoms because of their history of mental distress rather than taking their symptoms seriously and providing care. People also described feeling discriminated against and invalidated and provided advice and suggestions for others about navigating these challenges when accessing physical health and mental health services. People with many different services and health providers involved in their care described 'falling through the cracks' when providers failed to communicate or work together.

In managing their day-to-day health, many people we spoke to described the impact of taking medication for mental health concerns, such as antipsychotics, antidepressants, sleep medication and mood stabilisers. Many said they wanted to use these treatments, but most described unexpected and challenging side effects that negatively impacted their physical health and emotional wellbeing, such as sleep problems, weight changes and sexual dysfunction. Of particular concern to many people were experiences of being pressured and forced to take medication, not being properly informed about potential side effects of medication or interactions with other medications, not listened to when they raised concerns and not being supported in their choices.

In terms of other strategies to support and manage day-to-day physical and mental health, the people we spoke to had a range of experiences and opinions. Some people found it difficult to find the right support or method for physical activity, while others faced challenges due to injury, ability, mental health challenges, effects of medication, lack of support people, gym membership cost, low self-esteem and/or weight-related stigma. Some people were frustrated by health professionals encouraging them to do more exercise without considering these challenges, whereas others identified exercise as an important part of their recovery. Similarly, while food and eating habits were an important part of supporting day-to-day health, many people described barriers to eating and accessing food the way they wanted to, including the impact of a lack of money or being on medications that changed their appetite, which in turn affected their health. For many people, supportive and nurturing relationships were crucial to their everyday wellbeing.

Participants described how they regained some agency and control when navigating their health challenges. They shared advice and personal experiences, including around advance statements, wellness plans, and reaching out for support. Advocacy and self-advocacy made a difference for many people we spoke to in getting the right healthcare, including through peer support networks and making connections to people with similar experiences. People also shared their suggestions for what needs to change on a systemic level for people to access better services. When asked if they had any advice they wanted to pass onto others facing similar challenges, many people shared their insights which included, including trusting your own expertise, knowing what works for your own health and wellbeing, making connections, and pushing back against stigma and discrimination. As one participant reflected:

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[3] Participants could choose a pseudonym if they preferred.

> *Are you ready to advocate for yourself a lot? It's going to be tough, which is sad to all say, but it's true. You have to advocate yourself a lot. And if you can't do that, you need to have people around you who can. (Jessica)*

3.5 ONLINE RESOURCE CONTENT PRODUCTION

The research team commenced producing content for the online resource in April 2022. In consultation with the CLEAV and PAG advisory groups, reviewed and selected interview clips, organised these thematically into talking points, and prepared descriptions for each section of the website. Once selections of clips from interviews were made, members of the research team reviewed these with participants, providing each person with an opportunity to review, make edits or provide feedback on the final website content.

The final website clips, animations and overall resource were produced with assistance from Chad O'Brien, Crosswalk Media. Opportunities to review and provide feedback on web design, content, initial clips, credits and descriptions were provided to the CLEAV and PAG. The initial website content was prepared and reviewed by team members to ensure all edits were incorporated by 29 November 2022, with the complete content published by January 2023.

3.6 DISSEMINATION

3.6.1 Resource soft launch

A soft launch of the online resource was held via a webinar on 29 November 2022. The event was chaired by Associate Professor Chris Maylea, with the online resource introduced by guest speakers, including representatives from our funders:

- Maggie Toko, Assistant Commissioner, Victorian Mental Health Complaints Commission
- Anna Love, Chief Mental Health Nurse, Safer Care Victoria
- Christine Morgan, Chief Executive Officer, National Mental Health Commission
- Tim Heffernan, Deputy Commissioner, Mental Health Commission of New South Wales

Each speaker described their connection to the project and why it was important to focus on mental and physical health. Attendees were provided with the opportunity to ask questions and give feedback on the website. In particular, speakers highlighted the potential for change led by people with lived experience and what it means for people to be heard, respected and to have choice in accessing services. Over 50 people attended the event, and a recording of the speakers and panel discussion is available on the Equally Well website.[4]

3.6.2 Resource promotion

The website will continue to be promoted by the project partners throughout early 2023 via social media, mailing list distribution and other relevant opportunities. In February 2023, a SurveyMonkey tool will be established to collect feedback on the resource as a strategy to co-implement and refine the resource in collaboration with people who participated in the project and the wider community. The survey will not inform any published research but will enable quality improvement, particularly around functionality and accessibility, given the site's innovative, interactive design. It will be distributed by Healthtalk Australia and Equally Well.

3.6.3 Equally Well Symposium 2023 launch

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[4] Equally Well, "Healthtalk: Physical health & wellbeing resource", *Equally Well Webinars* (Online, 2022), https://www.equallywell.org.au/webinars/.

The full online resource will be formally launched at the 2023 Equally Well Symposium, held in May or June.

3.7 RESEARCH OUTPUTS

3.7.1 Forthcoming literature review

The project's literature review, described above at 3.3.1, will be published in a forthcoming edition of *Frontiers in Public Health*.[5] The review concludes that to better identify and respond to the health needs as prioritised by consumers, it is imperative that future studies prioritise codesigned and coproduced research. It observes that a focus on "services as provided" rather than "services as received" has contributed to a lack of progress in addressing the life expectancy gap for consumers. In response, it recommends that journals, ethics committees and research policy organisations develop guidelines and standards to inform best practice in research on consumer perspectives and experience and to support the implementation of codesigned and/or coproduced approaches in future research.

3.7.2 Future publications

The research team are currently preparing an article on women's gendered experiences of healthcare based on the qualitative data. Researchers, including team members with lived experience, have reviewed data analysis of transcripts of women participants, in particular around themes around invalidation, delayed treatment, access challenges and interrelationships between physical and mental health. They have then also returned to the transcripts to further review the data, conducting thematic analysis around gendered dismissal of health concerns and having their physical health issues perceived to be anxiety or psychosomatic. This data analysis will then inform the drafting of an article on the impact of gender on people's experiences of mental and physical healthcare.

Other publications are currently under development.

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[5] Chloe R. Green, Rosiel Elwyn, Nicholas Hill, Kate Johnston-Ataata, Renata Kokanovic, Chris Maylea, Grace McLoughlan, Russell Roberts and Stuart D. M. Thomas, "A critical review of research into mental health consumers' perspectives on their physical health: Is there an absence of consumers in the design, conduct, analysis and reporting of this research?" *Frontiers in Public Health* 10:982339. doi: 10.3389/fpubh.2022.982339

Appendix 1 Timeline

Stage	Activities	Deliverables (National MHC)	Dates
Planning	Recruit Research Associate and Consumer (Lived Experience) researcher Conclude Inter-Institutional Agreement / finalise project plan Recruit advisory group members, both Consumer Leadership Advisory Group (CLEAV) and Project Advisory Group (PAG)	Progress report 1 and project plan (18 December 2020)	1 July – 18 December 2020
	Complete and receive approval for ethics application	Progress report 2 (2 April 2021)	Granted 10 December 2020
Research & analysis	CLEAV and PAG first convened (February 2021) Information about project advertised online, supporting health organisations sourced Complete literature review and background document, including grey literature (August 2021) Team members trained in Healthtalk Australia methodology	Progress report 3 and copy of literature review (1 September 2021)	1 November 2020 – 1 September 2021
	Recruit and interview 32 participants (13 metropolitan NSW, 10 metropolitan Victoria, 5 regional NSW, 4 regional Victoria) Transcribe interviews and member check transcripts Code and analyse interviews CLEAV and PAG meetings held to review data analysis	Progress report 4 (31 March 2022)	1 March 2021 – 31 May 2022
Online resource development & launch	Develop content for Healthtalk online resource CLEAV and PAG meetings held to review resource development		1 April 2022 – 15 May 2022
	Develop Healthtalk online resource User checking and final corrections Soft launch online resource (29 November 2022) Final additions to website completed (January 2023) Formal launch at Equally Well Symposium 2023	Final report and online resource (16 January 2022)	16 May 2022 – 16 January 2023