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# The usefulness of healthcare resources for people with mental and physical health concerns: a systematic review using co-design principles

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## ABSTRACT

People living with both mental and physical health concerns are less likely to have their health needs met than people living with just one of these. This systematic review – designed with people living with both mental and physical health concerns – sought to identify and evaluate existing health advocacy resources for this cohort. The research team was comprised of academics and a co-design group of people living with mental and physical health concerns. The co-design group had decision making roles in the conduct of this literature review. Existing health resources were identified through three academic databases. Further resources were identified via hand searching. All resources were screened in Covidence reference systematic review software. Resources included at full text screening were evaluated based on their usefulness and the extent to which lived experience expertise was engaged in their development. Fifty-five resources aimed at addressing the needs of people living with mental and physical health concerns were identified. The co-design group defined and assessed usefulness based on credibility of the resource, and whether it provided practical information for the majority of Australian people with ongoing mental health concerns to manage their physical health in an empowering and accessible manner. Resources that engaged people living with mental health concerns in the conduct of their design were more likely to be considered useful. This suggests that clinical expertise alone is insufficient, and that engaging consumers in research is essential.

## ARTICLE HISTORY

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## KEYWORDS

Mental health; self-advocacy; physical health; public involvement; mental health concerns; health resource; lived experience; mental health consumers


## Introduction

The poor physical health of individuals with mental health concerns<sup>1</sup> is a complex global health problem that leads to significant transdiagnostic morbidity and mortality (Firth et al., 2019; Na & Singh, 2021). Mental and physical health are inter-connected; worsening physical or mental health has reciprocal impacts across both domains (Doan et al., 2023). For example, stress, adverse shock, psychological trauma, illness, and injury can alter body physiology including heightened allostatic load, cortisol levels, long-term blood pressure, sleep disturbance, immune system changes, and chronic endocrinological response (Dorn et al., 2008), creating vulnerability to further stress, illness and disease progression.

Despite being motivated to improve their health and wellbeing, people diagnosed with mental health conditions face significant health inequities that impact physical and mental health outcomes (Peckham et al., 2023). These health inequities lead to significant increases in personal, social, and economic impacts across the lifespan, and reduce life expectancy (Firth et al., 2019).

Increasing healthcare access for individuals with mental and physical health concerns is a priority for Australian healthcare systems (Australian Human Rights Commission, 2016). Identified strategies for improving and adapting services in Australia have included: improving the accessibility of health information, physical accessibility of premises, access to transport, and facilitating better technology for online access (Australian Human Rights Commission, 2016). Other recommendations to enhance access to services include improved collaboration and coordination between sectors, staff training, peer support, facilitating workshops for service-users, and creating accessible and adaptable care plans (Tremblay et al., 2023). Telehealth,

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or virtual counselling, has also been identified as increasing health service access for individuals with disabilities, particularly those in rural and remote areas (Aguillard et al., 2022).

Collaborative care models that recognise the expertise of people accessing treatment have been recommended as the most effective form of healthcare to meet the physical and mental health needs of patients and reduce health disparities (Firth et al., 2019). However, there remains a lack of resources and interventions designed specifically for mental health service consumers to improve their physical health (Rosenberg & Roberts, 2020). Service interventions are often aimed at participation; and are done *for*, *to* and *on* individuals. There remains a critical absence of consumer involvement in the research and design of resources – which we understand to be websites, articles and pamphlets that people can draw on to address their health needs – that concern mental and physical health (Green et al., 2022).

Consumer involvement can be achieved through co-design. This involves consumers as active and equal partners in research design, implementation, communication, and dissemination. Lived experience involvement is critical for understanding complex health conditions and disease prevention, as well as redressing experiences of epistemic injustice in health interventions and services (Hultman & Hultman, 2023; Maylea & Daya, 2019). Co-designed services are key to safeguarding human rights in healthcare and upholding an individual's health sovereignty, meaningful healing and recovery, quality of life and personal goals (Maylea & Daya, 2019). Furthermore, co-design may help to improve culturally safe, inclusive, and affirming services for marginalised populations (Cheng et al., 2021).

*Equally Well* is an initiative that is committed to 'making the physical health of people living with mental illness a priority at all levels' (p. 7; [equallywell.org.au](http://equallywell.org.au)). In 2022, Equally Well was funded to create a resource for people living with mental and physical health concerns. As part of this project, a systematic review was undertaken, involving a team of researchers (including researchers with lived experience of both mental and physical health conditions and service use), and members of a lived experience co-design group.

The aim of the systematic review was to identify resources and tools that people living with mental and physical health concerns could use. Its primary purpose was to inform the development of a health resource by the authorship team – this is reflected in the inclusion criteria.

## Methodology

This literature review was led by two researchers working from a lived experience perspective. The co-design group was engaged to provide feedback for the literature review and oversee other project milestones associated with Equally Well. Members were recruited *via* an open call from Equally Well for people living with a mental and physical health concern on social media. People were appointed to the co-design group after an initial conversation with a member of the research team, on a first come first serve basis. The co-design group was established to be co-directors of the research, and so we have not reported any demographic information from this group or from the researchers. More information on how the co-design group worked with researchers as partners can be found in our companion paper (CITATION TBD).

All members of the co-design group were trained in using Veritas Health Innovation (n.d.), a systematic review screening tool and in the method for extracting data. Training was presented as peer-to-peer skills development, with recognition that the co-design group was bringing expertise to the project and so were not 'trainees' in a traditional sense. All members of the co-design group contributed to decision making and most did abstract and full text screening. All assisted with data extraction and synthesis of the results of this review. Our companion paper (CITATION TBD) reflects on the engagement of the co-design group in more detail.

This systematic review was not registered.

## Eligibility criteria

Resources could report on any methodology and were not limited by country or year of publication.

Records were excluded if they met any of the following criteria: not in English, the primary population did not have a mental illness; palliative care population; terminal illness; paediatric population; mental illness prevention study; drug trials (drug adherence were considered for inclusion); systematic or literature reviews; study protocols. Records were also excluded if they pertained to resources that required long-term maintenance (e.g. if they were reliant on employing staff), because these would not be replicable in the larger project, which aimed to produce a health resource for people with mental and physical health concerns but did not have ongoing funding.

## Information sources

All peer-reviewed resources were identified through OVID, PubMed, and CINAHL by RE and TZ. A further 51 resources were identified in grey literature, *via* hand searching, Google, Google Scholar, and word of mouth. Figure 1 (PRISMA) outlines the flow of sources through the study. Only the published output was assessed – authors did not locate any other study documentation to learn about individual resources.

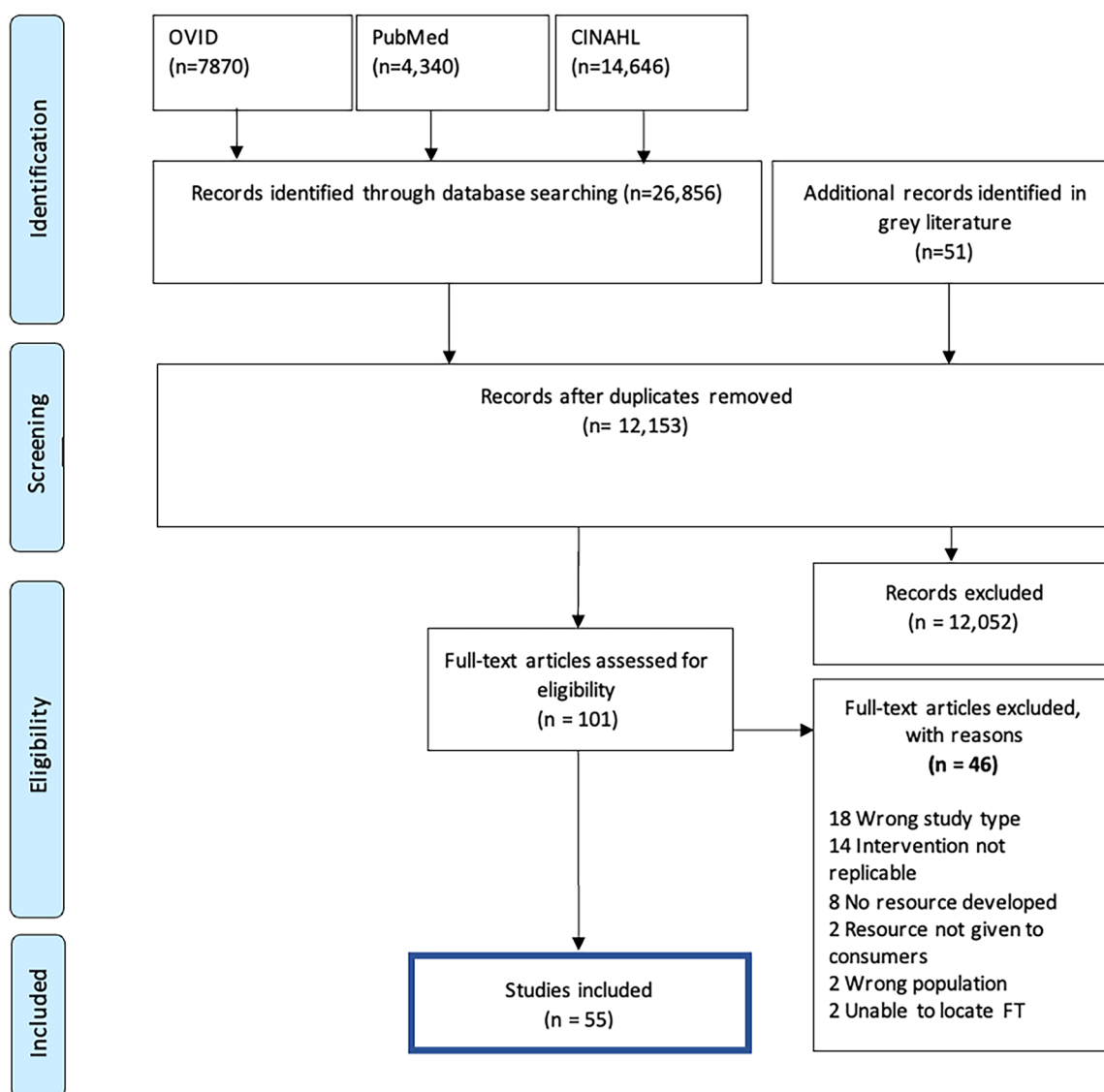


Figure 1. PRISMA diagram of flow of papers through screening process.

## Search strategy

An initial limited preliminary search was undertaken by TZ using OVID (September 2022), followed by an analysis of the search results, text words contained in the title and abstract, and of the index terms used to describe articles.

With the support of an information scientist, RE and TZ agreed on a search strategy that comprised three terms (Table 1). The aim was to identify sources that were about mental illness, physical health, and lived experience advocacy. We included search terms that related to common physical health concerns in this population, to help find resources that focus on a particular diagnosis (e.g. diabetes). All words in the search team were included with the intention that they would ensure resources for people with mental and physical health concerns to get their healthcare needs met. Term 1 focussed on capturing mental-health specific sources. Term 2 focused on physical health (including some common diagnoses) and term 3 included words that were identified as related to instructional or supportive resources in our test searches. For example, some resources might frame a conversation guide as 'advocacy', while others might use 'communication' to describe a similar resource. Terms were linked with the relevant Boolean operator for 'within 5 words of', which varies across databases, to ensure a manageable and relevant selection of resources was accessed.

The result was the search string in Figure 2 but with small alternations based on the syntax of OVID, PubMed, and CINAHL.

## Data collection process

Once resources were identified, they were exported into EndNote. The authors used the automated 'find duplicates' feature to identify multiples. Covidence Systematic Review Software (Veritas Health Innovation, n.d.), a systematic record management tool (Kellermeyer et al., 2018), was used to conduct screening and article selection. 12,152 remaining records were each screened at the title and abstract stage by two members of a team of ten reviewers. The team of reviewers consisted of two

**Table 1.** Search terms.

Term 1	Term 2	Term 3
Mental illness*	Physical health	Advocacy
SMI [note: severe/serious mental illness – full term not used because these papers would be captured in 'mental illness*']	General practitioner*	Communication
Depress*	GP	Consult*
Anxiety	Cancer	Self-advoca*
Schizophreni*	Diabetes	Resource
Bipolar	COPD	
Borderline personality disorder	Chronic obstructive pulmonary disease	
BPD	Smoking	
Eating disorder*		
Anorexi*		
Bulimi*		
Mania		
Obsessive Compulsive disorder*		
OCD		
Panic disorder		
PTSD		
Post-traumatic stress disorder		
Post-traumatic stress disorder		
Phobia		
Personality disorder		
Suicid*		
Smoking		

\*is used as a wildcard character that represents one or more possible characters, to expand the search.

```
(Mental-illness* or SMI or Depressi* or Anxiety or Schizophreni* or Bipolar or Borderline-
personality disorder or BPD or Eating disorder* or Anorexi* or Bulimi* or Mania or Obsessive-
compulsive disorder* or OCD or Panic disorder or PTSD or Post-traumatic stress disorder or
Post-traumatic stress disorder or Phobia or Personality disorder or Suicid* or Smoking) adj5-
<within 5 words of> (Physical health or General practitioner* or GP or Cancer or Diabetes or
COPD or Chronic obstructive pulmonary disease or Smoking) and (Advocacy or
Communication or Consult* or Self-advoca* or Resource)¶
```

**Figure 2.** Search string.

members of the research team (RE screened 95%; TZ screened 50%), and seven members of the Lived Experience co-design group (each having screened as follows: MS, 32.9%; MB, 5.8%; AD, 5.6%; JD, 4.5%; DJ, 4%; HLPR, 3.6%; AR 0.9%). All records that proceeded to full text review were assessed against eligibility criteria by at least two reviewers, with TZ screening 100% of these records, and three other reviewers splitting the reviews among them (MS, 78%; RE, 26%; CM, 8%). At both stages, conflicts were resolved by group consensus.

Once full text screening had been completed and a final sample of 55 resources had been finalised, the team commenced extraction. The co-design group met with the lived experience researchers to determine the questions that would be addressed in extraction. One member of the research team showed the co-design group the GRIPP2 framework for reporting of patient and public involvement in research (Staniszewska et al., 2017) as an example. This framework identifies key concepts that should be used to report to describe consumer involvement in research. The guideline addresses five topics: (1) the aim of PPIE in the study, (2) methods used for PPIE, (3) results of PPIE in the study, (4) extent to which PPIE influenced the study overall, and (5) reflections. The co-design group used this as a reference point to develop their own questions to evaluate consumer engagement. These became: (1) Did the research team include consumers? (2) Was there evidence of critical reflection as to what specific consumer expertise and experience was relevant? (3) Was there evidence the research team sought out a range of different perspectives and included consumers representing a range of experiences and backgrounds? and (4) Is the resources useful? Do you think a mental health consumer could/would use this? Members of the co-design group provided short responses of roughly 1–2 sentences for each question. Responses were then compiled by two lived experience researchers and reported in the results section of this paper.

As this is a systematic review, we categorised resources into the following categories: completely useful, somewhat useful, and not useful. One of the limitations of this methodology is that usefulness is assessed as a gradient rather than as a static category. Regardless, we attempted to sort studies into these three categories using consensus in order to produce the findings.

### Study risk of bias assessment

No formal risk of bias assessment was performed because of the diverse nature of the resources included in this review. However, all resources were assessed by a member of the co-design team and one of the researchers, working independently. Consensus was used to determine whether resources were considered completely useful, somewhat useful or not useful.

## Results

Overall, 26,856 resources were identified. Of these, we included 55 resources aimed at improving healthcare of people with mental and physical health concerns that met the inclusion criteria. The flow of resources through the screening process can be viewed in [Figure 1](#). [Tables 3](#) and [4](#) outline the characteristics of each resource, but in summation, they focussed on a wide variety of health needs, including, age, mental health, overall health, increasing increase capacity to self-advocate in medical contexts and promoting access to healthcare. The resources varied in form and function. For example, a resource by Health Direct Australia (2023) focussed on suggesting questions that could help the user get more out of appointments with health professionals. Other resources, like the one by the Mental Health Coordinating Council (2020a) focussed on providing information for the person to use public health and disability support services. Others, like one developed by Porter and Aggar (2021), focussed on health planning. All were directed at people living with mental health concerns.

### Characteristics of interest

The co-design group assessed resources based on two things that they felt were important: usefulness and lived experience engagement in design.

#### Usefulness, empowerment, and accessibility

For the purpose of this research, usefulness was defined as ‘a resource that is credible and provides practical information for the majority of Australian people with ongoing mental health concerns to manage their physical health concerns in an empowering and accessible manner’. We understood empowerment in the resources as features that supported capacity building, self-advocacy, and person-directed care. We understood accessibility of the resources as plain language, glitch-free (for online resources), and easy to open (for example, clicking a single link, rather than having to create an account).

Whether the resource met this understanding of useful was assessed by the co-design group members. As the target of such resources, this group was well positioned to make this assessment. Members also considered the potential of the resources to enhance self-advocacy as a feature of their usefulness. Of the 55 resources examined, the group concluded that 19 completely met their definition of usefulness. A further 10 somewhat met this definition; they were useful but only for a researcher, activist, carer, clinician, or someone with specific concerns. With that, 26 resources were evaluated to be not useful at all. The rate of usefulness determined by the co-design group was then analysed in tandem with the following variable of lived experience engagement to understand if there was a correlation between usefulness and lived experience involvement in resource design.

#### Lived experience engagement in resource design

We found that most resources, tools and interventions were developed and led by health researchers and/or designed for use by health practitioners to assess physical health (e.g. Fernandez Fernández Guijarro et al., 2019; Usher et al., 2013), and focused on clinical/technical aspects of improving physical health in service-users. However, many included the voices of lived experience experts outside of leadership roles on the individual resources. In this section, we outline the rates of lived experience expert involvement and the correlation this had with usefulness.

Usefulness of the resource seemed to be linked to whether the resource research team included lived experience experts in any capacity (e.g. co-design or consultation). A full outline of how consumer experts were engaged in each resource is available in [Table 4](#).

Of the 19 resources which were found to be completely useful, 14 (74%) indicated that lived experience experts were included on their research team. When including the 10 resources which were found to be somewhat useful, seven indicated the inclusion of lived experience experts on their research team, which maintains the usefulness at three times more likely (73%). Of the 26 resources which were found to be not useful at all, seven (27%) indicated that lived experience experts were included on their research team. In all, this variable made the resource two and three quarters more likely to be classified as useful than not useful.

**Relationship between lived experience involvement and evaluations of usefulness.** Of the 19 resources which were found completely useful, 10 (53%) indicated that they considered lived experience expertise as relevant. This shows that this consideration does not impact whether the resource is classified as completely useful. When including the 10 resources which were found to be somewhat useful (increasing the total to 29), 45% considered lived experience expertise, which maintains a similar correlation to usefulness. Of the 26 resources which were found to be not useful at all, three (12%) had this consideration. In all, this variable made the resource three and three quarters more likely to be classified as useful than not useful. [Table 2](#) provides an outline of this intersection, with a more detailed version of this data presented in [Table 4](#).

**Table 2.** Usefulness and lived experience involvement of included studies.

Usefulness	#	Had lived experience involvement	Did not have lived experience involvement
		n (%)	n (%)
Completely	19	10 (53)	9 (47)
Somewhat	10	3 (30)	7 (70)
Not	26	3 (12)	23 (88)
Total	55		

**Table 3.** Characteristics of included resources.

Author	Population	Number of participants	Purpose of the resource	How the resource was delivered	Description of the resource
Aged and Disability Advocacy Australia (n.d)	Older people in Queensland	N/A	To guide older people in Queensland through various services and pathways where they may need to self-advocate; for example, when leaving hospital, when dealing with Centrelink or the NDIS, and when dealing with essential services such as telecommunications, banking, or electricity	Website	Short guides on different aspects in word document form
American Academy of Family Physicians (2023)	Mental health consumers	N/A	Provides basic information about getting a mental health diagnosis and what this means	Webpage	A short article
Being–Mental health Consumers (2020)	Health consumers in NSW	N/A	To provide training for lived experience activists	Website	Basic information on being an advocate, mostly with links to relevant courses
Better Health Channel (2021)	The general Australian population	N/A	Provides basic information about talking to your GP about mental health	Webpage	An online article
Black Dog Institute (2022)	Anyone looking to talk to their GP about mental health	N/A	Basic information about getting a GP	Webpage	A three-page PDF document
Canberra Health Literacy Hub (2023)	The general Australian population	N/A	To help people to self-advocate	Website	A website with various information
Carer Gateway (n.d)	Carers of people with physical and psychosocial disabilities	N/A	To support carers of people with disabilities to effectively work with and communicate with health and medical services to support the well-being of the person receiving care	Website	A website to support carers of people with disabilities to effectively work with and communicate with health and medical services to support the well-being of the person receiving care. A phone number is also provided for real-time advice
Centre for Primary Health Care and Equity, UNSW Social Policy Research Centre (2022)	Anyone who is interested in both their physical and mental health	N/A	Support for people experiencing mental and physical health concerns, doctors, and other support workers to assist conversations about physical health	Online and digital	A plain language guide with prompting questions that can be completed on paper or a device. It can then be provided to GPs, carers, clinical teams, and social workers
Consumers of Mental Health WA (2018)	WA consumers	N/A	Information on health records	Webpage	A 5-page PDF document on health records and reasons you may want/not want one
Consumers of Mental Health WA (2020)	Mental health consumers in WA	N/A	To provide tips to people on how to self-advocate; not only in healthcare settings but also generally	Website	A three-page PDF document with series of strategies to increase an individual's capacity to advocate for themselves
Deena Ashoorian (2014)	People taking medication	N/A	To provide information regarding the side effects from mental health medications based on a series of questions related to the past 4 weeks	A word document that can be printed	An eight-page questionnaire with specific questions about medications and observed side effects from the viewpoint of the patient
Equally Well Australia (2022)	Health consumers in Australia	53 Researchers	To share academic research on physical and mental health	Website	A website with links to research presentations from the Equally Well 2022 Symposium

(Continued)

Table 3. Continued.

Author	Population	Number of participants	Purpose of the resource	How the resource was delivered	Description of the resource
Flourish (2019)	Mental health consumers with a psychosocial disability	N/A	To support people with mental health problems and psychosocial disability to talk about their physical health and well-being	Webpage	A resource that can be used as a 'to do' list that aims to support mental health consumers to talk about their physical health
Fountain of Health (2014)	Older people	N/A	A handbook to help older Australians stay active	A PDF handbook	A PDF handbook to help older Australians stay active. It contains FAQs and five key suggested activities.
Headspace (2022)	Headspace consumers	N/A	This is an end-product to inform consumers	A two-page A4 'Fact Sheet'.	A two-page A4 'Fact Sheet' for wide distribution and information sharing
Health Consumers NSW (2010)	General health consumers with a focus on NSW	N/A	To provide basic information to health consumers about their rights and how to engage with their doctor	Three webpages.	Webpages on: how to be involved in your own care, how to make the most out of your doctor's visit, and a copy of the Australian Charter of Healthcare Rights.
Health Direct Australia (2017)	The general population, WA focused	N/A	To create a checklist for seeing a GP or health specialist	Webpage	An online form builder
Health Direct Australia (2023)	General health consumers	N/A	To assist people to prepare for a doctor's appointment by suggesting questions to ask	Webpage	A page suggesting questions to ask your doctor surrounding health problems, treatments, medicines, and tests
HealthTalk (2019)	General population	29 people.	This is an end-product to inform consumers	A webpage	An information and empowerment website
Hennessy et al. (2020)	Mental health nurses working with people with severe mental illness	20 nurses.	Development and implementation of a physical health passport, known as My Physical Achievement Log (My PAL), which aims to improve physical health monitoring in people with severe mental illness	A questionnaire designed to be printed as a paper-based face to face prompt	A booklet of plain language questions and prompts to note physical health check-ups and status
Choosing Wisely Australia An Initiative of NPS MedicineWise (2022)	The general population	N/A	Sources for information on understanding and selecting medicine	Digital.	Information sheets
Lived Experience Australia (2019)	Anyone looking to talk to their GP about mental health and self-advocacy	N/A	Information on being your own advocate in your health care and mental health care	Webpage	A six-page PDF document
Lived Experience Australia, General Practice Mental Health Standards Collaboration (2021)	Anyone looking to talk to their GP about mental health	N/A	Basic information about accessing a GP and what questions to ask	Webpage	A one-page tip sheet
MacDonald-Wilson et al. (2013)	People with mental ill health in recovery	5584 Consumers	Common Ground is a web-based app. Common Ground offers three primary ways for individuals to exercise self-care: identification and communication of personal medicine, development of a power statement, and generation of a summary health report	Online via website with assistance from peer supports	A tool for consumers to be able to describe their personal health objectives/goals and to give them tools to work with clinicians regarding medicine
Mental Health Australia (2019)	Mental health consumers and carers	N/A	Checklists of questions to ask mental health practitioners	Webpage.	PDF checklists.

(Continued)

Table 3. Continued.

Author	Population	Number of participants	Purpose of the resource	How the resource was delivered	Description of the resource
Mental Health Coordinating Council (2020a)	People with mental illness and psychosocial disability who are applying for NDIS	N/A	To inform people with mental health conditions about how to apply for the NDIS if they have a psychosocial disability. Additionally, to offer support and advice	An interactive website with videos and a downloadable workbook	Website with comprehensive information about psychosocial disability, NDIS, whether you can apply and how to apply. Includes 'hubs' for diverse consumers as well as a downloadable workbook
Mental Health Coordinating Council (2020b)	Potential NDIS participants with a psychosocial disability	N/A	To assist consumers who are applying for NDIS, specifically when asking their doctor for supporting evidence	Online checklist that can be printed	A checklist to take to medical appointments
Mental Health Families and Friends (2022)	The general population, Tasmania focused	N/A	To provide assistance on self-advocacy for mental health consumers	Webpage	A PDF workbook
Mental Health Literacy (n.d)	Canadians	N/A	To deliver health and mental health information	Website	A collection of PDF documents and webpages
Mental Illness Fellowship Australia (2021)	The general Australian population	N/A	Information for mental health support people or carers	Website	Website information and chat functions
Mental Illness Fellowship Australia (n.d)	The general Australian population	N/A	A forum for getting advice regarding mental health	Webpage	A moderated forum
Mind Australia (2023a)	General population	N/A	An information page that is text based	Webpage.	Basic text-based webpage
Mind Australia (2023b)	People going to hospital	N/A	Information about having an inpatient stay	Information sheet	PDF Information sheet
Mind Australia (2023c)	Mental health consumers	N/A	A guide to support mental health consumers to set and achieve goals	Website	A support model aimed at supporting mental health consumers to set and achieve goals
National Domestic Family and Sexual Violence Counselling Service (2018)	People experiencing family violence or sexual violence	N/A	To tell your story and receive information about support	Phone app	A place to access information and tell your story
National Institute on Aging (n.d)	Americans	N/A	Delivers information to Americans on aging and health	Website	Information from the government on aging and health
National Mental Health Commission (2018)	Mental health consumers and carers	N/A	To provide a framework and set of principles for best practice in consumer and carer engagement and participation in the mental health system	Online PDF handbook	A 30-page PDF handbook which assists in identifying ways to engage with the mental health system, how to implement best practice, how to plan your activities, and how to implement and evaluate your activities
National Mental Health Commission (2020)	Mental health consumers and carers	N/A	A handbook to empower and support mental health consumers and carers to engage with improving safety and quality in mental health services	Online PDF handbook	A 60-page PDF handbook that supports mental health consumers and carers to advocate for improvement in the mental health sector, including advocating for the amplification of lived experience voices. The guide provides practical guidance and information to help you contribute to, and partner with, services to promote positive change
NPS MedicineWise (2019)	General population	N/A	Information on medications	Digital	An app with information on medications
NPS MedicineWise (2022a)	Young people and their support people	N/A	Information on medications	Digital	Videos and information sheets

(Continued)

Table 3. Continued.

Author	Population	Number of participants	Purpose of the resource	How the resource was delivered	Description of the resource
NPS MedicineWise (2022b)	Anyone prescribed an anti-depressant	N/A	Information on medications	Digital	Information via a questionnaire for people who have been prescribed anti-depressants
NSW Ministry of Health (2021)	Health consumers, NSW focused	N/A	This details the role of NSW Health Services to meet the physical health needs of people with mental health problems	Webpage	A PDF policy document regarding the NSW Health Services
Oregon Office on Disability and Health (2021)	People with physical health concerns	N/A	To assist people to self-advocate for their physical health and mental health	Digital	A set of videos, presentations, guides, and checklists to assist people in advocating and managing physical health (and some mental health) matters
Patients Rising USA (2015)	Individuals interacting with the health-care system in the USA	N/A	To suggest to both patient and doctor how to approach a medical appointment to ensure both are on the same page	Webpage	A short article identifying that often language and communication can be a barrier to health literacy and empowering patients
Pelletier et al. (2015)	Nursing staff	Nurses across three wards	To assess the efficacy of the Lester Tool app in improving care plan outcomes for patients. The project aimed to: improve knowledge of the Lester Tool among nursing staff, improve the physical health of patients with mental health problems, evaluate the experience of using the app, and improve the quality of physical healthcare plans.	Use of app was piloted in three wards after nurses were educated about the Lester Tool and how to use the app to write and update care plans. The project was evaluated by comparing care plans before and after the use of the app using a survey of the nursing staff	An article describing the use of a Lester Tool app to improve nurses' understanding of the Lester Tool methodology and improve patients' care plans. The target group was the nursing staff
Phull and Naoui (2018)	Mental health patients aged 18–65, and nursing staff in mental health facilities	33 Staff, 37 patients	An app based on the Lester Tool, aimed at supporting nursing staff to work with mental health patients to improve physical healthcare plans	The app was piloted in three mental health rehabilitation facilities	A physical health app based on the Lester Tool, a summary poster to guide healthcare workers to assess the cardiometabolic health of people experiencing psychosis and schizophrenia, and to enable them to deliver safe and effective care to improve the physical health of people with mental health problems
Porter and Aggar (2021)	Looking at metabolic syndrome in people with severe mental illness	39 Clinicians employed in a regional inpatient unit, and 80 patient file audits	To evaluate a locally developed practical toolkit, called 'Let's Get Physical: Improved Physical Health in Mental Health Services', to support mental health clinicians to manage Metabolic Syndrome. The study explored clinician's knowledge and attitudes towards managing Metabolic Syndrome, confidence to intervene, and improvement in documentation	To clinicians working with people with severe mental illness and metabolic disorder. Face-to-face and video education aimed at raising awareness of the toolkit	The Let's Get Physical Toolkit was developed due to the need for a practical how-to guide to improve clinicians' knowledge and confidence in Metabolic Syndrome screening and intervening
Queenslanders with Disability Network (2018)	NDIS participants and carers	N/A	To provide information for people accessing NDIS	Webpage	A print-friendly booklet on NDIS patient information.

(Continued)

Table 3. Continued.

Author	Population	Number of participants	Purpose of the resource	How the resource was delivered	Description of the resource
Safer Care Victoria (2021)	The general population, VIC focused	N/A	To help people understand what health professionals are telling them	Website	A set of self-directed learning modules to help people better understand and have confidence in asking questions about what their health professional meant
South Western Sydney Primary Health Networks (2022)	Older people	N/A	To provide older people with information on all health matters	Website.	A set of resources such as PDF documents and links on aging and health.
University of WA, Government of WA (2011)	General population	N/A	A booklet to give information and track results on physical health	A PDF document	A PDF document with sections on different physical health matters
University of WA, Government of WA (2019)	General population	N/A	An app to track physical health and related information	An app for Google	A standard tracking app
Victorian Mental Illness Awareness Council, Victorian Legal Aid (n.d)	Voluntary consumers of in-patient psychiatric hospitals	N/A	To inform consumers who are an inpatient of a mental health facility, but not being treated as a compulsory patient under the MH Act, of their rights	Online and downloadable 16-page brochure, also 10 postcards and a 'slap band' memory stick for consumers with internet access. The resources are intended to be made available in wards	A 16-page booklet comprised mainly of 16 questions voluntary inpatient consumers may have about their rights, that are then answered
Government of Western Australia Mental Health Commission (2020a)	Consumers, carers, and clinicians	N/A	An information and empowerment website to inform consumers	A website	A questionnaire and output for consumers
Government of Western Australia Commission (2020b)	WA people worried about mental health for themselves or someone they care about	N/A	Information about how to access help and what questions to ask	Website	An interactive website

This shows that having lived experience engagement made the resource three times more likely to be classified as completely useful than those that did not.

### ***Were a range of lived experience perspectives sought?***

Of the 19 resources which were found completely useful as per the definition above, eight (42%) indicated that they sought a range of lived experience perspectives. This shows that this variable does not impact how likely a resource will be classified as useful. When including the 10 resources which were found to be somewhat useful, three indicated lived experience engagement in this regard, which maintains a similar correlation to usefulness (38%). Of the 26 resources which were found to be not useful at all, only one (4%) had lived experience involvement. In all, seeking a range of lived experience perspectives made the resource ten times more likely to be classified as useful than not useful.

## **Discussion**

Despite the significant physical health disparities for individuals diagnosed with mental health conditions (Australian Human Rights Commission, 2016), this review found that there are a limited number of resources, tools, and interventions developed to support these individuals to advocate for their physical health. In comparison, there was a dearth of resources and interventions that have been co-created, co-designed, led by, and/or developed for the primary use of people diagnosed with mental health conditions to actively manage and advocate for their physical health.

Mental health consumer involvement in the development of resources aimed at improving physical health in this population was found to increase the likelihood of these resources being *completely useful* or *somewhat useful*, according to the definitions used in this project. Resources that indicated having had consumer engagement in their development were just over two times more likely to be rated as useful by our co-design group. Future research could investigate if clinicians similarly ranked resources with lived experience engagement as useful.

These results underscore the importance of consumer co-creation, co-design, and consultation in the development of resources to improve the physical health of individuals with mental illness. Consumer involvement in resource development may enhance credibility, relevance, and uptake, potentially translating to beneficial outcomes for physical health and well-being for individuals diagnosed with mental illness.

**Table 4.** Usefulness and consumer engagement in resources.

Author	1. Did the research team include consumers?	2. Was there evidence that researchers considered what specific consumer expertise and experience was relevant?	3. Was there evidence the research team sought out a range of different perspectives in designing or evaluating their resource?	4. Is the resources useful? Do you think a MH consumer could/would use this?
Aged and Disability Advocacy Australia (n.d)	No	No	No	The resource is useful by providing information and a guide for how to navigate systems, targeting older Queenslanders. A consumer could use this, but it is targeted to older people and/or those with disabilities.
American Academy of Family Physicians (2023)	No	No	No	No. Stigma inducing and patronising.
Being– Mental health Consumers (2020)	No	No	No	No.
Better Health Channel (2021)	No	No	No	Yes. The website has good and reliable information. It is trustworthy.
Black Dog Institute (2022)	Unclear	No	No	Yes. Good basic information
Canberra Health Literacy Hub (2023)	Yes	Yes	Yes	Yes. It has good tips about how to self-advocate.
Carer Gateway (n.d)	The website states that ‘a four-year consultation process with carers and the sector was undertaken.’ However, it is not clear how this consultation was done	No	No	No, but a carer might.
Centre for Primary Health Care and Equity, UNSW Social Policy Research Centre(2022)	Says it was co-produced. No evidence.	No	No	Yes. It provides a good list of resources and also points people to advice for GPs and carers.
Consumers of Mental Health WA (2018)	No	No	No	No. It is out-dated.
Consumers of Mental Health WA (2020)	Yes. The organisation itself is a consumer-based organisation	Unclear	Unclear	Yes, the resource is useful although a little simplistic. While it provides useful tips about self-advocacy it does not specifically relate to a healthcare/medical context or acknowledge the power imbalance between a consumer and a medical practitioner which can make self-advocacy difficult.
Deena Ashoorian (2014)	Unclear	Unclear	Unclear	The resource is useful in that it invites the responder to consider the specific side effects of possible medications by asking a series of questions about various physical side-effects. It then asks the responder to identify how often these side-effects have been experienced and whether this impacts on the person’s motivation to take the medication. A consumer could use this, but it seems that it is more for the purposes of the medical practitioner.
Equally Well Australia (2022)	Yes	Yes	Yes	The research is useful to researchers and some consumers.
Flourish (2019)	Yes. The specific process of involvement is unclear	Yes	No	Yes. Consumers might use the ‘to do list’.
Fountain of Health(2014)	Unclear	N.	No	No.
Headspace (2022)	Unclear	No	No	No, except for the ‘box barcode’ that consumers could scan and get a link to information.

(Continued)

Table 4. Continued.

Author	1. Did the research team include consumers?	2. Was there evidence that researchers considered what specific consumer expertise and experience was relevant?	3. Was there evidence the research team sought out a range of different perspectives in designing or evaluating their resource?	4. Is the resources useful? Do you think a MH consumer could/would use this?
Health Consumers NSW (2010)	Whist Health Consumers NSW is a consumer organisation, it is not clear who has put together this webpage	Beyond Health Consumers NSW being an organisation that represents consumer interests, no.	No	No, it is very basic and too generic.
Health Direct Australia (2017)	No	No	No	No. It is basic.
Health Direct Australia (2023)	No	Yes. Health Direct works with 200 'information partners' which includes some consumer-led groups such as ACON and Cancer Council.	Likely. Two sources were cited for this resource – the 'Conversation Starter Kit' produced by Choosing Wisely which was co-designed with NPS Medicine, Consumers Health Forum of Australia and consumer advocates, health professionals and representatives of Primary Health Networks as part of a Choosing Wisely Australia Consumer Expert Working Group	Yes, this resource is easy to read and is broken up into sections: suggested questions about health problems, about treatments, about medications, about tests.
HealthTalk (2019)	Yes. In the 'overview' it shows the extent to which the resource was designed with Lived Experience included	Yes, in the 'overview' and 'advisory panel' links it explained the involvement of consumers and carers. The 'advisory panel' provides legitimacy to this project. We should do the same.	Yes, 'from all around Victoria'	Yes. It has colourful YouTube clips and real-life consumer stories.
Hennessy et al. (2020)	No	No. Design team included nurses	No	No.
Choosing Wisely Australia An Initiative of NPS Medicine Wise (2022)	It states so, however it is unclear on depth of consumer involvement and feels very clinical	No	No	No. Very clinical and talks down to consumers.
Lived Experience Australia (2019)	Yes, the organisation is consumer run	Yes	Yes	Yes. Good information on what things to think about when self-advocating. A supportive document.
Lived Experience Australia, General Practice Mental Health Standards Collaboration (2021)	Yes, the organisation is consumer run	Unclear	Unclear	No. It is too basic.
MacDonald-Wilson et al. (2013)	Software development includes consumers. Article is about assessment of effectiveness of the software. It does not discuss consumer involvement in this assessment	Software development includes consumers. Article is about assessment of effectiveness of the software. It does not discuss consumer involvement in this assessment	Software development includes consumers. Article is about assessment of effectiveness of the software. It does not discuss consumer involvement in this assessment	No.
Mental Health Australia (2019)	Unclear	Unclear	Unclear	No. This resource is not user-friendly. It lacks readability, easy navigation, and visual engagement. There are too many questions lumped together which feels quite overwhelming. It is also formatted as a checklist (with tick boxes) yet asks questions that need longer answers, and there is inadequate space to write down answers. The document is too clinical.

(Continued)

Table 4. Continued.

Author	1. Did the research team include consumers?	2. Was there evidence that researchers considered what specific consumer expertise and experience was relevant?	3. Was there evidence the research team sought out a range of different perspectives in designing or evaluating their resource?	4. Is the resources useful? Do you think a MH consumer could/would use this?
Mental Health Coordinating Council (2020a)	Yes, however; it is not clear if they were in leadership positions or not	Yes	Yes.	Yes. It has been updated to be easier to navigate, and the different 'Hubs' add a lot of value. The website is quite well done, with the options to print a workbook, watch short videos, and covert to different languages adding to its utility.
Mental Health Coordinating Council (2020b)	Yes. The checklist was co-designed with 'people living with mental health concerns and their supports' in Ceduna, SA along with the Mental Health Coalition of South Australia. It is not clear how much influence those with lived experience had	Unclear	Unclear	Yes, however is unlikely sufficient on its own. It does suggest using it in conjunction with a brochure they have also produced ('6 Steps to the NDIS'). It does have an engaging format.
Mental Health Families and Friends (2022)	Yes	Yes	Yes	Yes. It is a good set of information that could help carers and supporters.
Mental Health Literacy (n.d)	Yes	Unclear	Unclear	Yes. Really good information that could be used in Australia.
Mental Illness Fellowship Australia (2021)	Yes. Not always clear as to the level of consumer engagement	Yes	Yes. For example, veterans and LGBTQI included	Possibly. Especially if one wanted to understand how to develop peer networks. It is more for activists than consumers.
Mental Illness Fellowship Australia (n.d)	Yes	No	No	It is a forum for support and information. It could be helpful depending on what issue you have or whether you want to chat to people
Mind Australia (2023a)	No	No	No	No. It is very limited.
Mind Australia (2023b)	Yes	Yes	No	Yes. There is not much information available on this. It is helpful.
Mind Australia (2023c)	Yes	Yes	No	No.
National Domestic Family and Sexual Violence Counselling Service (2018)	Yes	No	No	Yes. For some people this would provide support and good links.
National Institute on Aging(n.d)	No	No	No	No. It is USA based and by the government.
National Mental Health Commission (2018)	Yes, however; not in leadership	Somewhat	No.	No. It is not on topic, but rather about engaging carers and consumers in projects like ours.
National Mental Health Commission (2020)	Yes	Yes	Yes	No, it is quite lengthy, text heavy and complex. Many consumers might be put off by this.
NPS Medicine Wise (2022a)	No	No	No.	No. It comes from a pharmaceutical perspective.
NPS Medicine Wise (2022b)	No	No	No	No.
NPS MedicineWise (2019)	No	No	No	No. It comes come from a purely 'medication and your GP know best'.
NSW Ministry of Health(2021)	No	No	No	Yes, as good background information.

(Continued)

Table 4. Continued.

Author	1. Did the research team include consumers?	2. Was there evidence that researchers considered what specific consumer expertise and experience was relevant?	3. Was there evidence the research team sought out a range of different perspectives in designing or evaluating their resource?	4. Is the resources useful? Do you think a MH consumer could/would use this?
Oregon Office on Disability and Health (2021)	Yes. The resource created in collaboration with the Oregon Self Advocacy Coalition (OSAC) and State Government and a university. It is unclear who held decision-making authority	Yes. The resource appears to have been part of a wider grant program and as the Self Advocacy coalition was involved it appears that consumers were heavily involved in design and who would be impacted	Yes	Yes. These resources and the style of design might look a little 'dated' and are USA based, however the concepts and the forms make for good prompts. It was also good to see information for carers, and the videos make it more accessible.
Patients Rising USA (2015)	This article was written from the perspective of the author, Carley Flumer, a thyroid cancer survivor and data analyst who is passionate about patient advocacy and education, health literacy, oncology research, and patient-provider communication. No other consumers were mentioned or cited.	Unclear	No	No.
Pelletier et al. (2015)	From the methodology outlined, it does not seem as if consumers were involved in the design of the research project. They were only used as subjects in the research	No	No	No.
Phull and Naoui (2018)	Yes, includes the involvement of consumer researchers	No	No	The article provides no indication as to whether consumers found the app useful.
Porter and Aggar (2021)	It appears that only one member of the research team identified as having lived experience	There is no further information provided on the specific expertise or experience of the one individual involved who had lived experience. There is minimal reflection on the need to further involve consumers themselves	There is no evidence that this occurred	This Toolkit is aimed for use by clinicians (in this instance primarily nurses in an inpatient unit). The response by consumers would largely depend upon how motivated clinicians were to employ it, and how well they communicated the need for it with the consumers they were working with.
Queenslanders with Disability Network, (2018)	No	No	No	No.
Safer Care Victoria (2021)	Yes	No	No	Possibly. It felt a bit patronising. However, if used in the right way it could be very useful to people with cognitive decline, or people who struggle with English.
South Western Sydney Primary Health Networks (2022)	Unclear	No	No	No, it is too broad.
University of WA, Government of WA (2011)	No	No	No	This is very outdated. Some sections may be helpful to less IT savvy consumers or carers.
University of WA, Government of WA (2019)	Unclear	No	No	Yes. It is a solid tracking app. It is not commercial based so would have a higher trust factor.

(Continued)

Table 4. Continued.

Author	1. Did the research team include consumers?	2. Was there evidence that researchers considered what specific consumer expertise and experience was relevant?	3. Was there evidence the research team sought out a range of different perspectives in designing or evaluating their resource?	4. Is the resources useful? Do you think a MH consumer could/would use this?
Victorian Mental Illness Awareness Council, Victorian Legal Aid (n.d)	Yes, all VMIAC staff identify as having lived experience	Yes	Likely	A consumer who was a voluntary in-patient in a public hospital (especially if at risk of being placed on a treatment order) would find this resource useful. Having postcards (with links, phone numbers, and QR codes) that can be left in hospitals makes it more accessible. However, the document is a bit too legal-focused and does not include enough on self-advocacy.
Government of Western Australia Mental Health Commission (2020a)	They did not mention consumers and carers in the design	No	No	No. It is not inspiring, it encourages consumers to ask questions, however; it is not empowering.
Government of Western Australia Mental Health Commission (2020b)	Yes, for elements. It is a gathering of work done by WA that brings many parts of the consumer and carer perspective in	Yes. The resource is very broad	Yes	Yes. It contains lots of information and some on how to talk to GPs about medications and physical health concerns.

### Strengths and limitations

There are potentially additional papers that may have been missed in the database searches, including those published after the initial searches. However, this was a large review with many records included in the screening. The main limitation was that only resources published in English were included. Some resources will not have been the subject of peer-reviewed studies or not published online and were not able to be included. There was also potential for bias in that the researchers were aware of lived experience involvement prior to the evaluation of usefulness.

It would also have been useful to address the extent to which consumers had been engaged in the development of the resources to understand if co-design contributed to usefulness more than consultation. However, due to the low sample size of resources that included consumer involvement and the relatively low uptake of consumer involvement in research globally, we made the decision not to demarcate between consultation and co-design so as not to single out authors who were only able to engage in limited consumer involvement. As a team made up mostly of consumer experts, we encourage all researchers to engage with lived experience communities and recognise that consultation is sometimes the most involvement some projects can achieve due to budget and skill constraints.

Strengths of this review included the use of multiple authors in the article evaluation and data extraction. Authors involved in article evaluation and extraction included members of the lived experience co-design group. In keeping with high-level participatory action research principles of lived experience involvement, all members of the co-design group received research training as part of this process. The involvement of consumers in the evaluation of resources exemplifies ethical research practices and research with real-world significance. Lived experience involvement in research evaluation and analysis promotes balanced power dynamics and enhanced translational capacity of research and information exchange. The involvement of consumers in the research process can increase trust in research and creates opportunities for individuals to subvert experiences of marginalisation and flip their status from being the subject of the medical gaze to being included as a valued contributor to medical research.

### Conclusion

Involving consumers in this systematic review increased the rigour and focus of the study. The co-design group encouraged a strong focus on consumer involvement in the included resources and could lead evaluation of if the resources were useful. As the target audience for the resource, the co-design group was uniquely positioned to evaluate them in a way that would not have been accessible to the research team alone. Consequently, we confidently conclude that resources for people living with both mental and physical health concerns were two times more likely to be considered useful if lived experience experts had been engaged in their design. However, the level of engagement of lived experience experts varied significantly across resources. The overall low uptake of lived experience involvement in any form prevented comparison of the level of

engagement, but the results of our analysis indicate that lived experience involvement of any level improved the overall usefulness of the resource.

This finding suggests that the included resources benefitted from lived experience involvement, and that to develop this finding, lived experience expertise was needed in the research team conducting this review. Mental health service users should be included in all research that concerns them.

## Note

1. In this article, we use different terminology to refer to people living with a mental health diagnosis. People living with mental and/or physical health concerns are called 'consumers'. People who had these experiences but were employed as a part of research teams are referred to as 'lived experience experts'.

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## Author contributions

TZ: Conceptualisation, Data curation, Formal analysis, Investigation, Methodology, Project administration, Supervision, Writing – original draft, Writing – review and editing.

RE: Conceptualisation, Data curation, Formal analysis, Investigation, Methodology, Writing – original draft, Writing – review and editing.

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MB: Conceptualisation, Data curation, Formal analysis, Investigation, Writing – review and editing.

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AR: Conceptualisation, Data curation, Formal analysis, Investigation, Writing – review and editing.

HLPR: Conceptualisation, Data curation, Formal analysis, Investigation, Writing – review and editing.

RR: Initial project conceptualisation and funding submission, Methodology, Project administration, Resources, Supervision, Writing – review and editing.

CM: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Resources, Supervision, Writing – review and editing.

All authors approved the final version to be published.

## Disclosure statement

The authors have no competing interests to declare.

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## Data availability statement

All relevant data has been published in this manuscript.

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