BMJ Open Mapping mental health recovery tools developed by mental health service users and ex-users: protocol for a scoping review

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ABSTRACT

Introduction Since the emergence in 1997 of the Wellness Recovery Action Plan, a number of other tools developed by users and/or ex-users of mental health services have been published and implemented. All these tools aim to promote self-determination in mental health recovery processes. A scoping review will be carried out in order to (1) identify existing tools, (2) describe their distinctive characteristics and (3) examine how they have been implemented and evaluated.

Methods and analysis The scoping review will be guided by the methodological framework proposed by Arksey and O'Malley and expanded by Levac *et al.* It will involve, primarily, a literature search of the following electronic databases: Cochrane database, Cumulative Index to Nursing and Allied Health Literature, PsycInfo, PsycArticles, Scopus, PubMed and Web of Science. In addition, the search process will consider grey literature databases. Users, ex-users and survivors organisations and networks will be contacted in order to identify any relevant material. The reference lists of the articles identified through the literature search will be inspected. Finally, hand searches of journals will be conducted in order to increase the confidence in the search. Two main approaches will be used to present the charted data: a descriptive analysis and a thematic analysis. The study will be performed between April and December 2020. The results will be reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews.

Ethics and dissemination This study does not require ethical approval because the data used are from publicly available materials. The study results will be disseminated through an article submitted for publication to a scientific journal and presented at relevant conferences. The results will also be shared in future workshops and seminars as part of continuing education programmes for mental health professionals.

INTRODUCTION

The recovery model emerged in the 1990s as a result of and response to critiques of psychiatry (notably from the antipsychiatry, survivors and civil rights movements) that ultimately led to deinstitutionalisation.^{1 2} A milestone

Strengths and limitations of this study

- All publications that meet the inclusion criteria will be included, regardless of the language in which they are written.
- The review will also consider the manuals and guides that have been developed for each of the recovery plans, not only the publications that evaluate the implementation of these plans.
- The scoping review will include published articles and grey literature. User and ex-user networks will be consulted to obtain any potentially relevant material for inclusion.

in the development of this new model was the publication in 1993 of a paper by William Anthony entitled *Recovery from mental illness: the guiding vision of the mental health service system in the 1990s*.³ After summarising pre-existing ideas in the field, Anthony went on to define recovery as: ‘... a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and roles. It is a way of living a satisfying, hopeful and contributing life, even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness (p. 527)’.³

During the 1990s, both the USA and New Zealand introduced the recovery model into their policies and practices, and they were followed by the UK and Australia during the early 2000s^{4 5} and by Canada at the end of the same decade.⁶ The same path was followed by several countries in northern Europe, including Germany, Austria, Switzerland, Norway, Sweden and the Netherlands,⁷ as well as by some regional governments in Spain.^{8 9} This constituted a paradigm shift inspired by international policy on mental health^{10 11} and based on the social model of

disability and the Convention on the Rights of Persons with Disabilities.¹²

In the recovery model the fundamental goal is not the control of symptoms, as in the biomedical model,^{13 14} or the functional adaptation of the person to society, as in the psychiatric/psychosocial rehabilitation model.¹⁵ Rather, the goal is to enable the person to achieve a meaningful and satisfactory life in accordance with his or her own preferences and values, regardless of the presence of symptoms.^{3 16} Accordingly, the US Substance Abuse and Mental Health Services Administration defines recovery as a journey of healing and transformation which allows a person to live a satisfying and meaningful life, contributing in a community of her or his choice.¹⁷ In this model, self-determination and self-management are fundamental factors in the recovery process as they are necessary prerequisites of personal empowerment, of the possibility of regaining control over one's own life.¹⁸

It was precisely with the aim of promoting self-determination in the recovery process of mental health service users that Mary Ellen Copeland developed and published in 1997 the Wellness Recovery Action Plan (WRAP).¹⁹ The WRAP is a practical tool that helps to identify internal and external resources which may facilitate the recovery of mental health, leading to the creation of an individualised plan for living a satisfying life and achieving well-being.^{19 20} This tool has been extensively investigated, with studies examining its effects on attitudes and knowledge related to recovery²¹ and its contribution in terms of decreased psychiatric symptoms,²² increased hope and quality of life,²³ a reduced need to use mental health services²⁴ and improved propensity for patient self-advocacy.²⁵ There is also a systematic review and meta-analysis of the WRAP²⁶ which concludes that its effectiveness lies in its ability to promote self-perceived recovery, rather than to reduce symptoms. All these studies support the use of the WRAP as a tool to promote self-determination in mental health recovery processes.

However, the WRAP is not the only tool that has been designed for this purpose. Two years after the WRAP was first reported, Laurie Ahern and Daniel Fisher published the *Personal Assistance in Community Existence (PACE): A Recovery Guide*.²⁷ The PACE is a training programme aimed at promoting the recovery of people at their own pace.^{28 29} According to its authors it is based on the principles of the empowerment model of recovery, that is, self-determination, a belief in full recovery, being believed in, trust, respect and non-coercion.²⁸

More recently, members of The Icarus Project published another tool: Transformative Mutual Aid Practices (T-MAPs). This was defined as a set of tools that provide space in which to build a personal map of wellness strategies, as well as resilience practices, unique stories and community resources.³⁰

What these tools have in common, and which justifies their inclusion in this scoping review, is that they are guides, manuals or practical materials designed to promote self-determination and the active participation

of people in their own recovery process. Moreover, because they are based on the experiences of mental health service users and ex-users themselves, they synthesise what these people have learnt during their recovery process.³¹ In addition, although these tools are aimed primarily at people who are experiencing or have experienced a mental disorder, their use is not limited to a specific type of diagnosis or to individuals who have been formally diagnosed.³²

Study rationale

Given that the WRAP was published more than 20 years ago and that at least two other tools with a similar purpose have since been created, a scoping review will provide useful information about:

- ▶ The existence of tools designed to promote self-determination in mental health recovery processes, in addition to the three referred to above.
- ▶ Tools of this kind that have been developed beyond the English-speaking world, and/or the adaptation of existing tools to other cultural contexts.
- ▶ The distinctive characteristics of available tools, including their similarities and differences.
- ▶ The ways in which these tools have been applied, and with what objectives, and how they have been evaluated.

A scoping review is an appropriate way of examining a large set of studies with a wide range of designs,³³ and it will enable us to gain an overview of the object of study, namely tools developed by mental health service users and ex-users with the aim of promoting recovery, empowerment and well-being. A thematic analysis will be included in the scoping review as a means of interpreting, synthesising and reporting the results. This is an added advantage of the approach that will allow us to better understand how these tools seek to achieve their stated objectives.

Study objectives

The primary aim is to map the different manuals, guides and similar materials produced by mental health service users and/or ex-users with the aim of promoting recovery, empowerment and well-being in mental health. That is, tools that literally explain that they were created by movements of users and survivors of psychiatry or people with their own experiences in mental health problems and recovery processes. They are based on the knowledge that these experiences provide and not by academic knowledge. The secondary objectives are to explore how these materials have been created, implemented and evaluated, and which are their distinctive features.

METHODS AND ANALYSIS

Protocol design: We will conduct a scoping review in accordance with the framework described by Arksey and O'Malley,³⁴ while also taking into account the recommendations of Levac *et al.*³³ This approach will enable

us to describe the extent, range and nature of evidence in the field. Accordingly, the scoping review will involve five stages: (1) identifying the research question; (2) identifying relevant studies; (3) selecting studies; (4) charting the data; and (5) collating, summarising and reporting the results. The study will be carried out between April and December 2020. The results obtained will be reported following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews.³⁵

Stage 1: identifying the research question

Following Arksey and O'Malley's approach,³⁴ we will begin by formulating our research question, which will guide the whole of the subsequent literature search and study process. The initial research question will be defined through an iterative process involving all members of the research team. As recommended by Arksey and O'Malley, the question will be formulated in broad terms, focusing on any available tools for promoting the self determination of people in the process of recovering their mental health. In order to clarify this step and to answer the research question, we will define the main concepts, the target population and outcomes of interest for the scoping review.³³ Therefore, the initial research question that will guide our scoping study will be: which tools, created by people with direct experiences of mental health problems and personal recovery and/or movements of users, ex-users and survivors of psychiatry, exist to develop personal recovery plans and to promote self-management of well-being? This question will allow us to identify and explore the specific characteristics of the tools, including how they have been created and implemented.

Stage 2: identifying relevant studies

This stage will involve the identification of different sources for answering our research question, as well as the creation of search strategies for identifying studies. The search strategies will be updated and refined based on abstracts retrieved from the initial searches.³³ We will use three main strategies to ensure the inclusion of all relevant studies. First, we will carry out searches in the following databases: Cochrane database, Cumulative Index to Nursing and Allied Health Literature, PsycInfo, PsycArticles, Scopus, PubMed and Web of Science without date and language restrictions. These databases have been chosen for their broad coverage of the discipline and of topics such as wellness, recovery, mental health and mental disorder. The search terms from the following keywords: action plan, crisis plan, crisis program, empowerment, making choice, mapping madness, Mapping Our Madness, own pace, Personal Assistance in Community Existence, taking action, Transformative mutual aid practices, self-determination, self-management, recovery program, wellness, wellness recovery action plan, wellness recovery action planning will be useful to capture any potential resources from the databases. Boolean operators (AND, OR, NOT) will be used to

combine them. The initial search strategy already used in the Scopus database is as follows: ("Wellness Recovery Action Plan*" OR "Personal Assistance in Community Existence" OR "Mapping Our Madness" OR "Transformative mutual aid practices") in topic OR ("empower*" OR "self-determination" OR "wellness" OR "self manag*" OR "self-manag*" OR "get better" OR "mak* choice*" OR "tak* action") in title AND ("crisis plan*" OR "action plan*" OR "action program*" OR "crisis program*" OR "recovery plan*" OR "recovery program*" OR "mapping mad*" OR "own pace") in topic. Grey literature databases such as EThOS and the System for Information on Grey Literature in Europe will also be considered in the search process. Because of the specific features of grey literature databases, each of the following keywords will be entered separately without language or year of publication restriction: Wellness Recovery Action Plan, Personal Assistance in Community Existence, Mapping Our Madness, Transformative mutual aid Practices, T-MAPS, Madness and Oppression. Only the most relevant titles will be extracted and assessed for possible inclusion.

Second, mental health experts by experience and organisations and networks working in this area will be contacted in order to locate any relevant study or material. The worldwide network of users, ex-users and survivors of psychiatry is interconnected and maintains fluid communication. Moreover, the authors (HMS and VRC) are also members of a users' association, *ActivaMent Catalunya Associació*, which is part of several networks such as: (1) The Latin American and Caribbean Network of Human Rights and Mental Health; (2) Absolute Prohibition—Campaign to support the Convention on the Rights of Persons with Disabilities absolute prohibition of commitment and forced treatment. The association also maintains close connections with entities such as: (3) World Network of Users and Survivors of Psychiatry; (4) European Network of Users and Survivors of Psychiatry. These previous established connections will facilitate and make possible to identify any material of interest.

Third, we will screen the reference lists of articles identified through the literature search and conduct hand searches of journals in order to identify any additional relevant studies and to achieve the level of comprehensiveness required. Finally, an additional search with no date restriction will be also conducted in Google Scholar (only the first 100 outcomes will be inspected). The search strategy in this case will be the same as the one used with grey literature databases.

All records obtained from the search process will be evaluated for possible inclusion regardless of the language in which they have been published. And if necessary, expert translators for Chinese, Korean, Dutch, Arab and Japanese will be available.

Stage 3: study selection

The results obtained from each search will be downloaded into a citation management database, where duplicate records will be removed. We will use a two-stage

study selection process comprising (1) screening of titles and abstracts, and (2) a full-text review.

Following the recommendations made by Levac *et al*³³ two reviewers will independently inspect titles, abstracts and full-texts to identify potentially relevant studies. All articles considered relevant by either reviewer will be included for full-text evaluation. Any disagreements in the selection process will be resolved by discussion with a third reviewer. The inclusion and exclusion criteria will be drawn up by consensus among the research team and tested on a sample of abstracts to determine whether they capture studies with the potential to answer the research question. Research papers, conference abstracts, dissertations, books and book chapters, manuals, guides and research reports will be considered for inclusion if:

- a. They concern materials or practical tools for promoting self-determination and empowerment of people in their mental health recovery process.
- b. They report tools based on the recovery model.
- c. They are comprehensive tools for improving well-being and recovery (more than just a crisis plan or a wellness toolbox).
- d. They are tools developed by people who are experiencing or have experienced a mental health issue and/or by users, ex-users and survivors' movements.
- e. They are tools developed for use by people who experience psychiatric symptoms, although they can be used by any person who wishes to achieve health and well-being.
- f. They are studies involving participants aged 18+.
- g. They are publications reporting the main applications of tools in people with any mental health problem.

Exclusion criteria will mainly concern the study design, and hence opinion articles, reviews, protocols and meta-analyses will not be considered for inclusion.

Since quality assessment does not take part of the scoping study methodology because it is not addressed to assess the evidence for a particular intervention,³⁴ we will not consider the quality of studies as a criterion for inclusion/exclusion. However, the integration of multiple documents and research designs requires the use of a set of criteria to choose the best evidence. In our study, this set has the following criteria: (1) when there are multiple documents reporting the same target with the same participants, only the published articles will be considered for inclusion. (2) In cases of reports describing the implementation or assessment of a tool, only the documents with some basic information regarding study (year of publication, authors, country, sample size, design, evaluated tool, main results) and participants' characteristics (gender, age, profile: users, professionals, family or relatives) will be considered for inclusion. (3) Regarding specific tools localised through the network of users, ex-users and survivors of psychiatry, the quality criteria will be their application and recognition as useful tools for people integrating these networks.

Stage 4: charting the data

A preliminary scoping phase has already allowed us to develop a data extraction framework comprising 39 categories (see table 1). This framework represents an initial consensus about what is relevant to record, and it will be used to review every retrieved text that fulfils the criteria for inclusion.

Two team members will pilot the data extraction framework using a sample comprising 10% of the included documents, the aim being to demonstrate that the framework is being applied consistently. Any disagreements will be discussed and resolved by consensus among all team members. If necessary, the framework will be revised, any ambiguous categories changed and categories that come up during the data extraction process will be discussed and added to the data extraction form. The data from each included document will likewise be charted by two team members working independently. Any discrepancies in the extracted data will be resolved by arbitration in a consensus meeting.

Stage 5: collating, summarising and reporting the results

Following recommendations by Arksey and O'Malley,³⁴ two main approaches will be used to present the charted data: a descriptive analysis and a thematic analysis. Descriptive analysis will involve numerical calculations of frequency in order to display the extent, nature and distribution of studies included in the scoping review. Specifically, we will carry out a descriptive analysis focused on country, type of study, design, data analysis and synthesis, the demographics characteristics of the sample and the characteristics of the tools identified. These initial descriptive analyses will identify the predominant research methods and the geographical locations in the literature. Thematic analysis will be performed; that is, the articles included will be organised and analysed by recurring themes, points of agreement and points of disagreement.^{34 36 37} That is to identify, examine and record the relevant patterns or themes in order to answer our research question.

ETHICS AND DISSEMINATION

This scoping review will be the first study to compare different tools for developing personal recovery and wellness plans in mental health, specifically those based on the recovery model and created by mental health service users and ex-users themselves. The results obtained will be useful in terms of adapting existing tools and developing new tools for different cultural contexts.

This protocol is based on a comprehensive, rigorous and transparent methodology. It does not require ethical approval because the scoping review methodology involves collecting and categorising publicly available materials.

The results of the scoping review will be disseminated through an article submitted for publication to a scientific journal and presented at relevant conferences. They

Table 1 Data extraction framework

N	Category	Description
Descriptive characteristics of the document		
1	Type of document	The categories are: (a) paper, (b) guide, (c) manual, (d) book chapter (e) book and (f) other.
2	DOI	Digital Object Identifier
3	Database	Database from which the document was extracted. If the document is identified by consulting reference lists, record the first author and the year of publication (eg, Copeland, 1997). If the document is retrieved through a manual search, record the name of the journal inspected and the search date (eg, BMJ Open 20200818).
4	Year	Year of publication
5	Authors	Authorship of the document
6	Title	Title of the document
7	Tool	Name of the tool which the document refers to
8	Aim of the tool	What is the purpose of the tool described in the document? *This category is only applicable for original documents or manuals in which the creation of the tool is explained.
9	Publication (Journal/Book)	Record where the document has been published (eg, record name of journal for a paper, name of book for a book chapter). In the case of an unpublished document, record as 'unpublished'.
10	Country	Name of the country or countries participating in the publication. If there are two or more authors from the same country, record as a single contribution from that country.
11	Institution	The name of the authors' institution and/or intellectual property of the document.
12	Language	Language in which the documents have been written.
Study methodology		
13	Aim	Aim or purpose of the study
14	Type of objective	Record the purpose of the study. The categories are: (a) construction of the tool, (b) exploration, (c) evaluation, (d) other (eg, reporting/description, argumentation in favour).
15	Study design	Code the design of the study. The categories are: (a) RCT, (b) non-randomised controlled trial, (c) pretest/post-test design, (d) qualitative design, (e) mixed methods, (f) other.
16	Outcomes measured	Specify what was investigated in the study (eg, satisfaction, stage of the recovery process, empowerment, symptoms, etc.).
17	Data collection technique	Specify the data collection technique. The categories are: (a) survey, (b) Delphi study, (c) interview, (d) questionnaire, (e) focus group, (f) other.
18	Data analysis	Record the techniques and/or theories used to gather and interpret the data.
19	Instrument(s) for assessment	If interventions have been evaluated, specify which evaluation instruments were used in the study.
20	Control group	If the study includes a comparison/control group, specify its composition (sample characteristics).
21	Who evaluates	Record who evaluates what is measured or collected as data. The categories are: (a) professional evaluation (by academic or service professionals), (b) first-person evaluation (ie, by the persons evaluated themselves and/or by other users of mental health services), (c) mixed, that is, both (a) and (b).
22	Participative development	Record whether or not the tool has been developed through a participative process. If collective knowledge was gathered, record in detail how this was done: through expert committees, open days of reflection, surveys, interviews, focus groups, etc. *This category is only applicable for original documents or manuals in which the creation of the tool is explained.
Characteristics of participants		
23	Type of participants	Record who the study participants are (eg, users, family, etc.). If they are users, specify the type of service whenever possible (eg, community rehabilitation service).
24	Sample size	Number of people participating in the study (either in the process of constructing the tool or the sample size in studies that evaluate a programme). Specify the number of users, professionals and/or family members whenever possible.
25	Diagnosis	Record whether or not the document specifies a diagnosis for the people participating in the study (eg, yes, no). Code diagnoses if they are stated in the document.
26	Age	Age of participants. Indicate mean and SD in brackets(eg, 24 years (6.5)).
27	Education	Number of years of education. Report mean and SD(eg, 10 (2.3)).
28	Gender	Number and percentage of participants of each gender. The categories are: (a) female, (b) male, (c) other.
29	Ethnicity	Number and percentage of participants of each ethnic origin if this is reported.

Continued

Table 1 Continued

N	Category	Description
30	Other	Other descriptive variables regarding participants. Code any other variable of potential interest for the analysis (eg, marital status, employment status, etc).
Implementation		
31	Access	Record whether or not the tool is open access (eg, yes, no).
32	Type of application	Indicate how the tool is applied: (a) individual, (b) group. If it is applied individually, record in brackets if the tool can be self-applied, with or without external support (eg, individual (self-applied)). In the case of group application, specify in brackets if this was through a course, workshop or both(eg, group (course)).
33	Duration	Whenever possible, specify the duration of the programme or number of sessions.
34	Setting	Location in which the programme has been implemented or the study carried out.
35	Activities	Record the activities performed in the workshops or sessions used for implementation of the tool (eg, life stories, participatory dynamics, MAG, etc.).
36	Trainers	In the case of workshops/training, indicate who the trainers are. Specify if the training is given: (a) Through peer support alone, (b) Through peer support plus one or more non-peer professionals, (c) By one or more non-peer professionals, (d) Not specified.
37	Support material for implementation of recovery plan	Indicate whether or not the tool serves as support material to implementation of a recovery plan or recovery strategy (eg, yes, no). It can be an independent workbook or a section of the material with questions to answer. Specify in brackets the type of support material (eg, yes (workbook)). *This category is only applicable for original documents or manuals in which the creation of the tool is explained.
38	Support material for implementation of workshops/ training	Indicate whether or not the tool serves as support material to the implementation of workshops or training (eg, yes, no). It can be a guide, a manual and/or teaching material showing the content and structure of the sessions. Specify in brackets the type of support material(eg, yes (guide)). *This category is only applicable for original documents or manuals in which the creation of the tool is explained.
39	Follow-up support material	Indicate whether or not the tool serves as support material to the follow-up and assessment of the implementation of, compliance with and/or usefulness of the recovery plan in question (eg, yes, no). It can be independent material and/or a section included in the materials. Specify in brackets the type of support material (eg, yes (workbook)). *This category is only applicable for original documents or manuals in which the creation of the tool is explained

MAG, mutual aid group; RCT, randomised controlled trial.

will also be shared in workshops and seminars offered by the authors as part of their ongoing contribution to the training of future professionals in nursing, clinical psychology and psychiatry, as well as in continuing education programmes for mental health professionals.

Patient and public involvement

The manuscript has been designed and developed by users of mental health services. The fact that the research team includes them is an added advantage when it comes to identifying tools, and it will also help to contextualise the findings. The knowledge produced by the scoping review will be useful for various key stakeholders within health systems.

Contributors HMS and VRC designed the study and the initial search strategy. HMS developed the conceptual framework and wrote the first draft of the manuscript. VRC developed the methodological framework and reviewed the draft of the manuscript. JG-B and JER provided regular feedback on each of these steps and contributed to revision of the final manuscript.

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Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

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