UNIVERSITY OF WESTMINSTER

SOCIAL PRESCRIBING UNIT

A GUIDE TO SELECTING PATIENT REPORTED OUTCOME MEASURES (PROMs) FOR SOCIAL PRESCRIBING

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is focused on innovation in the field of social prescribing and growing new ideas. The team has considerable expertise in contract research, consultancy, evaluation and mixed methods research. We are also experts in supporting the implementation of social prescribing within organisations in the VCSE sector, the public sector and the private sector. We have provided advice to policy makers and have led major initiatives in social prescribing nationally and internationally. We founded and Co-Chair the Social Prescribing Network, have produced guidance documents, collaborated to develop the Medical Student Social Prescribing Network and the Social Prescribing Youth Network. We have worked alongside NHS England to shape social prescribing and fully believe that change happens by collaboration not competition.

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Disclaimer

The views expressed in this report are those of the authors and do not necessarily represent those of the Greater London Authority

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Measurement and social prescribing

Over the past few years, the field of social prescribing has grown rapidly and along with it, the need to capture and quantify the impact of social prescribing on individuals.

There are challenges to integrating measurement into practice, especially for social prescribing. This is now a broad term which incorporates a range of conditions and situations that extend well beyond healthcare and into the wider determinants of health. Whilst we now have an agreed architecture in England, of social prescribing connector schemes using link workers, the populations being monitored are different between social prescribing schemes. Furthermore, the connector schemes are designed to address different situations, therefore expect different outcomes and there are differing levels of requirement for data from funders, commissioners and policy makers.

Understandably the most frequent question asked is 'what do I measure'?

This guide is intended to support decision making when selecting appropriate outcome measures for research, evaluation and monitoring of social prescribing. This accompanies an excel spreadsheet of information on PROMS in social prescribing. Note that we are not recommending any specific measure to use and we have taken the most frequently used measures currently and provided key information on them. We expect this to be revised to include more measures in the future.

What are Patient Reported Outcome Measures (PROMs)?

These are questionnaires that capture a persons' opinions on their health or social status. Predominantly PROMs are used in health care settings. As well as routine biomedical diagnostic test and procedures, PROMs enable the patient voice to be included in clinical decision making.

Categories of PROMs

PROMs have been designed with different intentions in mind and there are some broad categories that we can fit them into.

1. General - these capture the overall health, quality of life or wellbeing status. Note that these three terms, whilst used interchangeably, do measure different things. They all have different 'theoretical' routes.

2. Condition focussed - these capture detailed information on one condition or situation. They may be used to screen for a threshold for further investigation or may provide feedback on response to an intervention or to guide the care needs of a person.

3. Person led - these questionnaires avoid having pre-determined items listed and allow a person to nominate their key concerns or symptoms. This always enable the most pressing information to be captured using a person's own words.

Why is it important to use a validated PROM?

As social prescribing has become more active in measurement, there has been a rise in the use of outcome measures that are being taken from one population in which they were validated and tested, into new populations.

There are difficulties with this approach – if the PROM has not been tested in the population you want to use it for, how can you be confident that is will be appropriate or that the score changes will be reliable or useful?

In the research field, for a PROM to be deemed 'valid' a series of studies are undertaken to understand how well a PROM performs. It is important to know that the PROM has had validation studies in the population that you want to use it for. Designing and validating a PROM can take between 5-10 years.

To give you an idea of how to determine if a PROM is reliable, responsive and valid the following questions are researched:

Reliability – can you rely on the PROM to perform consistently when administered by different people and completed by different people? Three areas are routinely checked:

- If you asked a person to score their situation on different days using the same questionnaire, (providing their condition was stable) do they score similar or identical scores.
- How well do items grouped together correlate?
- If the PROM is administered by an interviewer or healthcare professional, are similar or identical scores achieved when tested on the same person?

Validity - How well does the scoring aspect perform?

- How well the questions address all the important aspects of the condition?
- How consistent is the scoring of questions when compared to other PROMs that are validated and used. For instance, you would expect the PROM to be tested against the current gold-standard measure in that field.

Responsiveness - How well can a PROM detect a change within a person over-time?

What does a change in score actually mean?

When you look at some data of score changes of individuals who have been through social prescribing, whilst an improvement in scores is always hoped for and celebrated, ask yourself the question, 'So what does this change actually mean?'.

To be able to know that a certain level of score change has been researched to show that it is associated with tangible changes in a condition, or health behaviour, is very important. This is expressed as either:

- Minimally important difference (MID) e.g. what is the smallest change in score that is associated with tangible change?
- Clinically significant difference (CID) – e.g. what is the smallest change in score that is associated with corresponding clinical symptoms or tests?

These are important terms to look out for and I can explain why. You can statistically analyse score changes in a group of individuals and come up with positive findings. The larger the group of individuals you analyse, the more likelihood that even a small change in score with be statistically significant.

This change, however, could still fall below the minimally important difference or clinically significant difference threshold. Therefore, whilst there is small change occurring, the level of change is not yet at the threshold to make a tangible different to a person's behaviour or symptoms.

What else affects the quality of data collected?

There are other challenges that have been identified with using PROMs in social prescribing

- Who collects the data?
- What training is required?
- Is it part of the persons' job description?
- How is the data going to be analysed?
- Who has the expertise to analyse the data?
- What will the organisation use the data from once it has been analysed?

Once you have answered those questions, it is worth reflecting on whether you have collected the right type of data to enable decisions to be made, or whether you need to collect different data? And what PROMs do you choose?

The excel sheet that accompanies this guidance document has reviewed a range of PROMS and provided data on a range of categories that researchers have determined as important to know when selecting PROMs. Some of the categories relate to validity but we also provided practical information on the domains covered the time it takes to complete and other pertinent information which is summarised on the following pages.

Theme	Measurement tools
General health, well-being or quality of life	Measure Yourself Concerns and Wellbeing (MYCaW) [person led]
	36-Item Short Form Health Survey (SF-36)
	Office for National Statistics personal wellbeing scale (ONS4)
	The Quality of Life Scale (QOLS)
	R-Outcomes - Health Status (howRU)
	EQ-5D (EQ-53-3L)
Psychological	Warwick-Edinburgh Mental Wellbeing Scale (WEMWS)
	Hospital Anxiety and Depression Scale (HADS)
	General Anxiety Disorder assessment (GAD-7)
	Patient Health Questionnaire (PHQ-9)
	Museum General Wellbeing questionnaire (MWM)
	Perceived Stress Scale (PSS)
	Clinical Outcomes in Routine Evaluation measure (CORE-10)
	R-Outcomes - Personal Well-being (PWS)
	General Health Questionnaire 12 (GHQ-12)
	Work and Social Adjustment Scale (WSAS)
Social	UCLA Loneliness Scale (revised version 3)
	Campaign to End Loneliness Measurement Tool (CELMT)
	De Jong Gierveld Loneliness Scale (DJGLS)
	Duke Social Support Index (DSSI)
	Lubben Social Network Scale – Revised (LSNS-R)
	Hawthorne Friendship Scale (HFS)
	Duke-UNC Functional Social Support Questionnaire (FSSQ)
Physical	International Physical Activity questionnaire (IPAQ)
	Health Assessment Questionnaire Disability Index (HAQ-DI)
	General Practice Physical Activity Questionnaire (GPPAQ)
	Clinical Frailty scale (CFS)
	Edmonton Frail Scale (EFS)
Self-management/recovery	The Recovery Star
	The Wellbeing Star
	R-Outcomes - Health Confidence Score (HCS)
	Patient Activation Measure (PAM)

A description of the type of information contained in each column of the table is outlined below:

Category

The outcome measures have been categorised into six themes, including 1) Overall health, well-being, or quality of life, 2) psychological, 3) social, 4) physical, and 5) self-management/recovery. Measures were categorised based on the theme of the outcome they measure. Categorising the measures in this way makes it easy to see what types of measures have been used previously in social prescribing schemes in your area of interest.

Outcome measure and abbreviation

These columns detail the official name of the measure and it's commonly used abbreviation.

What is it measuring?

This column details the phenomenon that the tool seeks to measure.

Validity

Validity is the ability of an instrument to measure what it is intended to measure. This column indicates whether there have been studies to test whether the measures in question are valid.

Description of tool

A brief description of the tool is included in this column, including some details of the types of concepts measured by the tool and exemplar items.

Response scale

This column provides information on the type of response options used by the tool, including the scoring system used, in order for participants to indicate their answers.

Other versions

Details of different versions of the tools, such as shorter, longer or population-specific versions, are included here.

Population

All tools included are for adult populations. This column provides further information on the type of population the tool is suitable for, such as generic (e.g. the general public population) or specific (e.g. specific conditions).

Completion time

This column details approximately how long it takes to complete the measure according to its licencing body or academic studies, or in relation to other similar measures.

County of origin

The country in which the tool was originally developed in indicated here.

Licensing

This column provides information on whether a license or permission is required to use the measure, including details of the licensing body.

Cost

Information on whether there is a cost associated with use of the tool is included here.

Translations

Translated versions of the tool are indicated in this column.

Reference

A reference to the original development of the tool, where possible, is provided here.