A practical Guide to Measuring, Monitoring and Improving MENTAL HEALTH OUTCOMES – 22ND October 2013

Measuring Recovery Outcomes

Professor Geoff Shepherd
Recovery Programme Programme Director
Measuring Recovery Outcomes - Why?

- To determine if services are ‘doing their job’ and that money is being spent wisely.

- An analysis of how outcomes are produced should be based on an understanding of the relationship between aspect of quality (‘process variables’) and specific outcomes. Commissioners and providers need to be interested in both.

- Nevertheless, I will concentrate on outcomes.

- Hence, I will not consider instruments like WRAP or the Recovery STAR which are undoubtedly useful tools for engaging people and monitoring individual progress, but are not suitable as outcome indicators.

- A separate paper is being prepared by the ImROC team which covers both quality and outcomes (Shepherd & Boardman, *in press*).
So, what are relevant outcome domains for individuals being supported in their recovery?

The ‘CHIME’ framework

Connectedness

Identity

Empowerment

Meaning and purpose

Hope and optimism

Personal Recovery
Recovery outcome domains
(consensus of DoH expert group)

**Definite**

1. **Improved experience of recovery-oriented care**

2. **Achievement of personally valued individual goals** – ‘I want to live independently and get a job which uses my computer skills’

3. **Improvements regarding subjective aspects of personal recovery** – increased control, hope, identity, meaning and empowerment.

4. **Achievement of socially valued life goals** - housing, meaningful occupation, community integration, social support

**Possible**

5. **Improved quality of life/well-being**

6. **Reduced service use**, e.g. inpatient admissions, community contacts. [N.B. Beware!]
Domain 1. – Experience of care

- Not really an outcome measure, but actually a measure of process
- But, recognised as an outcome in both NHS and Adult Social Care Outcomes framework
- Could use relevant items from National Patient Survey data
- Often attempts to measure using local quality of care initiatives

Recommended measure: INSPIRE
Evaluating experience of care – the INSPIRE tool
[http://www.markslide.com/refocusstudies#inspire]

- 21 item questionnaire filled in by the service user on the basis of her/his contact with the staff member whom they judge to be most important in supporting their recovery.
- Each item is rated on a 5 point scale, with an option to indicate that a specific area of support is not relevant to the individual. Contains 2 sub-scales; (a) ‘Support’ and (b) ‘Relationships’
- Good face validity. Relatively quick and easy to use (generally takes about 10 mins. to complete)

Newman-Taylor et al. (2012) administered to 58 service users as a structured interview, conducted by trained user researchers. Recommended as suitable for routine auditing of recovery-related service quality.
INSPIRE (Version 3)

People talk about recovery in different ways but one way to think about it is ‘living a satisfying and hopeful life’.

This questionnaire asks about how your worker supports your recovery. Section One (Support) asks about important parts of your recovery and how your worker supports you with them. Section Two (Relationships) asks about your experience of working with this person.

<table>
<thead>
<tr>
<th>An important part of my recovery is...</th>
<th>I feel supported by my worker with this...</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling hopeful about my future</td>
<td>No</td>
</tr>
<tr>
<td>Believing that I can recover</td>
<td>No</td>
</tr>
<tr>
<td>Feeling motivated to make changes</td>
<td>No</td>
</tr>
<tr>
<td>Having hopes and dreams for the future</td>
<td>No</td>
</tr>
<tr>
<td>Feeling I can deal with stigma</td>
<td>No</td>
</tr>
<tr>
<td>Feeling good about myself</td>
<td>No</td>
</tr>
</tbody>
</table>
INSPIRE – a short version

Slade (personal communication) suggests that INSPIRE could be shortened to 5 items using the CHIME framework

<table>
<thead>
<tr>
<th></th>
<th>A brief version of INSPIRE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>My worker helps me to feel supported by other people [C]</td>
</tr>
<tr>
<td>2</td>
<td>My worker helps me to have hopes and dreams for the future [H]</td>
</tr>
<tr>
<td>3</td>
<td>My worker helps me to feel good about myself [I]</td>
</tr>
<tr>
<td>4</td>
<td>My worker helps me to do things that mean something to me [M]</td>
</tr>
<tr>
<td>5</td>
<td>My worker helps me to feel in control of my life [E]</td>
</tr>
</tbody>
</table>
Domain 2. – Individual recovery goals

- Requires a very flexible method to cope with the range of individual goals (‘Getting a job in Next’ > ‘Swimming with dolphins’)

- Individualised measures capture individuality, but are often difficult to aggregate and compare across groups (e.g. care plans)

- Standardised measures can be applied to groups, but they may conceal important individual variations.

**Recommended measure:** Goal Attainment Scale (GAS)
Achievement of personally valued goals
e.g. Goal Attainment Scaling, GAS (Kirusek & Sherman, 1968)

Where I am now
Beginning
Half-way there
Good
Perfect

Define: …………….. …………….. …………….. …………….. …………….. ……………..

✓ Goals are agreed with service user. Need clear definitions.
✓ Problems with ‘scaling’
✓ Goals can be weighted
✓ Good inter-rater reliability, construct validity and sensitivity to change (Hurn et al., 2006)
✓ May be particularly valuable for helping the individual record and monitor their own progress.
Domain 3. – Subjective measures

- Lots to choose from! Burgess et al. (2011) reviewed 22 and recommended 4: RAS, IMR, STORI & RPI.

- All were developed in the US (and Australia). Would require further testing before using in England.

- Simple, ‘home grown’ measures can be useful, e.g. ‘I feel more hopeful about the future since attending the Recovery College’, rated on a 5pt. Likert scale, but no psychometrics.

**Recommended measure: Questionnaire about the Process of Recovery (QPR)**
To cite this Article Neil, Sandra T., Kilbride, Martina, Pitt, Liz, Nothard, Sarah, Welford, Mary, Sellwood, William and Morrison, Anthony P. (2009) 'The questionnaire about the process of recovery (QPR): A measurement tool developed in collaboration with service users', Psychosis, 1: 2, 145 – 155

Aims: To develop and validate a short recovery questionnaire in collaboration with service users.

Method: 126 people with experience of psychosis were recruited via the National Health Service (NHS) Trust and self-help organisations nationwide. Items were generated from in-depth interviews into recovery and developed into a 25-item self-report questionnaire. Data were factor analysed, and a final 22-item measure (the QPR) was tested for reliability and validity. To assess validity the QPR was administered together with measures of: psychological distress (the General Health Questionnaire – GHQ); empowerment (the Making Decisions and Empowerment Scale – MDES), and quality of life (the Schizophrenia Quality of Life Scale – SQLS). The QPR was administered again at two weeks to assess reliability.

Results: The QPR is comprised of two subscales (intrapersonal and interpersonal). Internal consistency and reliability of the scale was satisfactory. There was a high level of association with MDES, GHQ and SQLS scores, and between QPR scores at time one and time two.

Conclusions: The QPR possesses internal consistency, construct validity and reliability, and promises to be a useful tool for assisting clients to set goals, evaluation of these goals and promoting recovery from psychosis in routine service evaluation and research trials.
QPR – ‘Please take a moment to consider and sum up how things stand for you at the present time, in particular over the last 7 days, with regards to your mental health and recovery. Please respond to the following statements by putting a tick in the box which best describes your experience’ (5 point scale, Disagree strongly > Agree strongly)

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>I feel better about myself</td>
</tr>
<tr>
<td>2.</td>
<td>I feel able to take chances in life</td>
</tr>
<tr>
<td>3.</td>
<td>I am able to develop positive relationships with other people</td>
</tr>
<tr>
<td>4.</td>
<td>I feel part of society rather than isolated</td>
</tr>
<tr>
<td>5.</td>
<td>I am able to assert myself</td>
</tr>
<tr>
<td>6.</td>
<td>I feel that my life has a purpose</td>
</tr>
<tr>
<td>7.</td>
<td>My experiences have changed me for the better</td>
</tr>
<tr>
<td>8.</td>
<td>I have been able to come to terms with things that have happened to me in the past and move on with my life</td>
</tr>
<tr>
<td>9.</td>
<td>I am basically strongly motivated to get better</td>
</tr>
<tr>
<td>10.</td>
<td>I can recognise the positive things I have done</td>
</tr>
</tbody>
</table>
Domain 4. – Achievement of socially valued goals

- ‘Objective’ changes in social functioning/social inclusion – housing, employment, social integration.

- But need to measure subjective satisfaction as well ‘objective’ status (then becomes very like ‘quality of life’ measures, e.g. MANSA)

- Inevitably based on self-report, so important to clarify definitions, time period, etc.

- Data from Adult Social Care Outcome framework can be used but these only refer to those currently in receipt of LA services.

**Recommended measure: Questionnaire about the Process of Recovery (QPR)**
Suggested socially valued outcomes

- Living in settled accommodation of their choice where they feel safe and secure
- Engaged in full or part-time employment of their choice
- In full or part-time education or training
- Volunteering
- Regularly (e.g. 2-4/month) participating in local community activities
- Reporting increased social network (number and type)
- Availability of confidant
http://www.ndti.org.uk/what-we-do/community-inclusion/the-inclusion-web/

The Inclusion Web resource pack

A practical resource pack for organisations and groups to support people to increase their community inclusion and help demonstrate service effectiveness

The Inclusion Web is an easy way to help people, and the organisations who support them, to look at the people and places in their life and how things may be changing over time. Developed by NDTi and refined over a number of years, the Inclusion Web has been used by many organisations to:

- Help people who need support to think about their life in the community and make plans for the future
- Evaluate change in people’s lives over time
- Measure outcomes of the support provided

The Inclusion Web has now been redesigned – illustrated in an attractive and colourful graphic style in an easy to use leaflet with step by step instructions.
Domain 5. – Quality of life, Well-Being

- **MANSA** short. Developed for use in a British context. Sensitive to change.
- Measures ‘objective’ and ‘subjective’ quality of life
- Relates subjective satisfaction to specific areas of life (including leisure, safety, physical and mental health)

- **WEMWBS**, 14 items. Refers to person’s feeling over last 2 weeks
- Good test-retest reliability and sensitivity to change.
- High internal consistency, low social desirability response bias
- Correlates highly with GHQ-12

N.B. Well-being **not** the same as ‘quality of life’ (Connell et al., 2012)

Reviewed qualitative research on quality of life for people with mental health identified 6 key dimensions:

1. well-being and ill-being;
2. control, autonomy and choice;
3. self-perception;
4. belonging;
5. activity;
6. hope and hopelessness.

Given the very strong similarities between these dimensions and basic recovery principles (hope, control, opportunity) it would be good if there were a quality of life/recovery measure based on them. In the absence of this one is drawn back towards a single measure like the QPR.
Domain 6. – Service use

- Recovery is about building a meaningful and satisfactory life, this is difficult if the person is frequently in hospital for long periods.

- But, reduced use of services should be a consequence of recovery; service reductions cannot be justified by saying that they facilitate recovery.

- Least controversial service indicators are probably reduced length and frequency of inpatient admissions and reduced number of admissions under MHA.

- Reduced use of community services might be considered as a recovery outcome - but might not.
Service use indicators, e.g. Mental Health Minimum Data Set (MHMDS)

? 
- Number of inpatient admissions
- Average length of stay
- Detained under MHA?
- Subject to Supervised Community Treatment Order (CTO)

?? 
- Number of face-to-face contacts with psychiatrists
- Number of face-to-face contacts with CPN or care co-ordinator
- Number of face-to-face contacts with other healthcare professionals
Conclusions

- Recovery is a complex construct and measuring outcomes is therefore a complex process. It cannot be reduced to a single measure just because this is convenient.

- It is important to distinguish between process (quality) indicators and outcomes.

- At the heart of recovery outcomes must be the experience of the person and their unique hopes and dreams for the future. In terms of measurement, this is probably the weakest area.

- But, considerable progress has been made. The notion that, ‘Recovery sounds alright, but it’s too vague and it’s not possible to define outcomes” is therefore not sustainable.

- As usual, the main problems lie much more in meeting the demands for this kind of information on a routine basis. Simple measures of the kind described here may help with this objective to build relevant, local information systems.
Thank you

For further information contact

geoff.shepherd@centreformentalhealth.org.uk

OR

www.imroc.org