



MEASURING RECOVERY

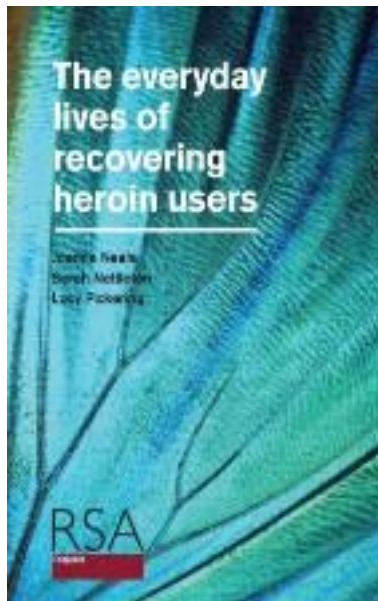
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What is recovery?

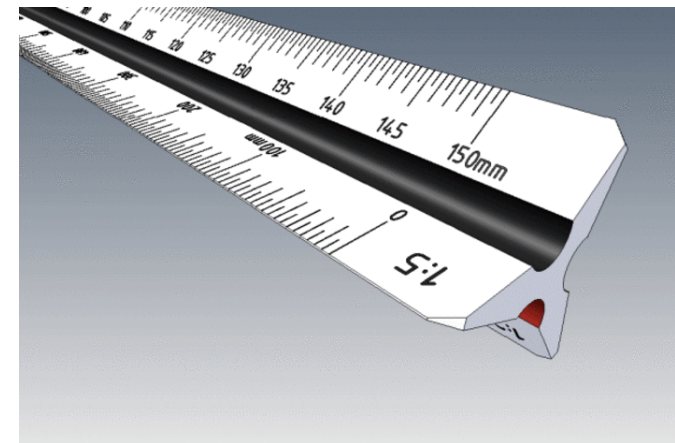
- A contested concept
- A divisive concept
- A concept that cannot be ignored
- More than abstinence



<http://www.kcl.ac.uk/ioppn/depts/addictions/people/profiles/DrJoNeale-RSARecovery-Everydaylivesofrecoveryusers.PDF>

Why do we need a recovery measure?

- To enable individuals to measure their own progress in recovery
- To use in treatment settings
- To use in research studies
- To guide commissioners & policy makers



What sort of measure do we need?

- Quick & easy to complete & score
- Acceptable to a range of stakeholders
- Scientifically robust (i.e. validated by psychometric testing)



11-ITEM Kutcher Adolescent Depression Scale: KADS-11

NAME: _____ CHART NUMBER: _____

DATE: _____ ASSESSMENT COMPLETED BY: _____

OVER THE LAST WEEK, HOW HAVE YOU BEEN "ON AVERAGE" OR "USUALLY" REGARDING THE FOLLOWING ITEMS:

1. Low mood, sadness, feeling blah or down, depressed, just can't be bothered.

0 - Hardly Ever 1 - Much of The Time 2 - Most of The Time 3 - All of The Time

2. Irritable, loosing your temper easily, feeling pissed off, loosing it.

0 - Hardly Ever 1 - Much of The Time 2 - Most of The Time 3 - All of The Time

3. Sleep Difficulties - different from your usual (over the years before you got sick): trouble falling asleep, lying awake in bed.

0 - Hardly Ever 1 - Much of The Time 2 - Most of The Time 3 - All of The Time

4. Feeling Decreased Interest In: hanging out with friends; being with your best friend; being with your partner / boyfriend / girlfriend; going out of the house; doing school work or work; doing hobbies or sports or recreation.

0 - Hardly Ever 1 - Much of The Time 2 - Most of The Time 3 - All of The Time

5. Feelings of worthlessness, hopelessness, letting people down, not being a good person.

0 - Hardly Ever 1 - Much of The Time 2 - Most of The Time 3 - All of The Time



NO
FATIGUE

0



MILD

1 2 3



MODERATE

4 5 6



EXTREME

7 8 9



THE WORST
FATIGUE

10

Patient Reported Outcome Measure (PROM)?

- Short self-completed questionnaire
- Widely used & accepted across a range of health fields
- Assesses health status or health-related quality of life, focusing on the patient/ service user/ client perspective
- Can be used to monitor individual progress, gauge treatment needs & evaluate outcomes following interventions
- Development includes significant consultation with patients/ service users/ clients
- After initial development, PROMs are subject to rigorous psychometric testing
- PROM development is constantly evolving, with valuable examples of innovative participatory methodology from the mental health field

The PROM-AR study

- **Title:** Development of a patient reported outcome measure for addiction recovery (PROM-AR)
- **Researchers:** Neale, J., Finch, E., Marsden, J., Mitcheson, L., Rose, D., Strang, J., Wykes, T.
- **Partners:** Addiction Service User Research Group (SURG)
- **Funders:** Biomedical Research Centre for Mental Health, Institute of Psychiatry, Psychology & Neuroscience, King's College London
- **Aim:** To produce and undertake psychometric testing of a new PROM for addiction recovery (PROM-AR)

Stage 1: Delphi groups

- **Aim:** To identify service providers' views on defining and measuring recovery
- **Methods:** Online Delphi groups with addiction psychiatrists, senior residential rehabilitation staff & senior inpatient detoxification staff
- **Findings:**
 - 76 indicators of recovery that comprised 15 broad domains
 - Domains were very consistent across the 3 service provider groups
 - Considerable disagreement on the relative importance of specific indicators

Reference:

- Neale, J., Finch, E., Marsden, J., Mitcheson, L., Rose, D., Strang, J. Tompkins, C., Wheeler, C. and Wykes, T. (2014) 'How should we measure addiction recovery? Analysis of service provider perspectives using online Delphi groups', *Drugs: education, prevention and policy* 21, 310-323.

Stage 2: Focus groups

- **Aim:** To explore whether & how current and ex service users' views of measuring recovery differed from those of service providers
- **Methods:** 5 focus groups with service users
- **Findings:**
 - Service users identified multiple problems with the 76 indicators generated from the service provider Delphi groups
 - Difficulties included:
 - Expecting the impossible of service users
 - The dangers of progress
 - The hidden benefits of negative outcomes
 - Outcomes that negate the agency in recovery
 - Contradictory measures
 - Failure to recognize individual differences
 - Entrenched vulnerabilities
 - The misattribution of feelings and behaviours
 - Inappropriate language

Reference: Neale, J., Tompkins, C., Wheeler, C., Finch, E., Marsden, J., Mitcheson, L., Rose, D., Wykes, T., and Strang, J. (2015) "You're all going to hate the word 'recovery' by the end of this: service users' views of measuring addiction recovery", *Drugs: education, prevention and policy* 22, 26-34.

Stage 3: Expert panels

- The research team combined the findings from the Delphi groups & focus groups
- Many of the 76 Delphi group indicators had to be rejected & others were reworded
- A revised list of 33 possible recovery indicators resulted
- Two expert panels of current & ex users were asked to debate & rank the list of 33 recovery indicators in terms of wording, acceptability & importance
- 30/33 indicators seemed largely acceptable & important to service users



Stages 4 & 5: Cognitive interviews & feasibility study

- Face-to-face cognitive interviews with 8 service users
- 40 service users participated in a small feasibility study to:
 - rate themselves on the proposed recovery indicators
 - comment on the appropriateness & usefulness of the proposed recovery indicators
- Several indicators were again reworded or modified
- One indicator was eliminated & one indicator was added



Stage 6: Field-testing

- 50 current & ex service users completed the draft PROM twice within 2-7 days
 - To test the reliability of each individual indicator
- 111 individuals completed the draft PROM, plus 3 other validated measures once
 - To test for concurrent validity
 - Analyses found that two indicators were unreliable & so they were removed

Draft indicators

1. Not drinking too much
2. Not using street drugs
3. Not experiencing cravings
4. Taking care of mental health
5. Coping with problems without turning to drugs or alcohol
6. Feeling emotionally stable & secure
7. Feeling like a worthwhile person
8. Taking care of physical health
9. Managing pains & ill-health without misusing drugs or alcohol
10. Taking care of appearance
11. Eating a good diet
12. Sleeping well
13. Getting on well with people
14. Feeling supported by people
15. Having stable housing
16. Having a regular income (from benefits, work, or other legal sources)
17. Managing money well
18. Having a good daily routine
19. Going to appointments
20. Spending free time on hobbies & interests that do not involve drinking or drug use
21. Participation in education, training or work (paid or voluntary)
22. Feeling happy with overall quality of life
23. Feeling positive
24. Having realistic hopes & goals for oneself
25. Being treated with respect & consideration by other people
26. Treating others with respect & consideration
27. Being honest & law-abiding
28. Trying to help & support other people

Draft domains

1. Abstinence/ reduced drinking and drug use
2. Good mental health
3. Good physical health
4. Good relationships
5. Material resources
6. Having a meaningful daily routine
7. Feeling positive about life
8. Having rights & responsibilities

In progress

- **Stage 7: Validity testing**
 - 400-500 current & ex service users are completing the PROM (paper & online versions)
 - All participants will be asked to complete the PROM again after 3 months
 - Analyses will include factor analyses & tests for sensitivity
- **Stage 8: National consultation exercise**
 - Involves stakeholders working in the field
 - To explore the extent to which stakeholders agree with the measures included in the draft PROM
 - Stakeholders score each of the 28 indicators on a scale of 1-10 for importance
 - This is repeated 3 times

Stage 8 Consultation exercise

	N (%)
N	146
Gender	
Male	79 (54.1)
Female	67 (45.9)
Personally in recovery	
Yes	38 (26.0)
No	102 (69.9)
Do not wish to answer	6 (4.1)
Current job/ role	
Non-clinical practitioner, worker or volunteer	41 (28.1)
Commissioning/ policy/ strategy	28 (19.2)
Clinical/ medical practitioner	26 (17.8)
Non-clinical administration/ management	19 (13.0)
Clinical administration/ management	14 (9.6)
Campaigning/ activism/ advocacy	9 (6.2)
Research	9 (6.2)

Indicator	Mean
1. Coping with problems without turning to drugs/alcohol	9.29
2. Not using street drugs	9.08
3. Not drinking too much	8.94
4. Taking care of mental health	8.89
5. Having stable housing	8.85
6. Managing pains and ill-health without misusing drugs/alcohol	8.81
7. Spending free time on hobbies/ interest that do not involve alcohol/drugs	8.69
8. Feeling like a worthwhile person	8.58
9. Having a regular income (benefits, work, other legal sources)	8.57
10. Having a good daily routine	8.39
11. Treating others with respect and consideration	8.27
12. Having realistic hopes and goals for oneself	8.25
13. Being honest and law-abiding	8.21
14. Feeling emotionally stable and secure	8.18
15. Participation in education, training or work (paid or voluntary)	8.13
16. Taking care of physical health	8.00
17. Feeling happy with overall quality of life	7.98
18. Going to appointments	7.96
19. Feeling supported by people	7.94
20. Managing money well	7.92
21. Feeling positive	7.91
22. Being treated with respect and consideration by other people	7.85
23. Sleeping well	7.81
24. Eating a good diet	7.64
25. Trying to help and support other people	7.32
26. Taking care of appearance	7.24
27. Getting on well with people	7.04
28. Not experiencing cravings	6.23

Endpoint: 2016

- Complete the final validation testing (Stage 7)
- Produce a robust, easy to complete measure that has been validated by psychometric testing & published in a high quality peer-reviewed journal
- Developed with significant service user input
- Acceptable to service users, service providers, commissioners & researchers
- Suitable for self-monitoring, therapeutic use in treatment settings, research, service audit

Thank You