Measuring recovery: moving to agreement

To optimise treatment and recovery, service providers' and users' definitions of addiction recovery must converge more – Dr Joanne Neale and colleagues start the research.

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"You're all going to hate the word 'recovery' by the end of this": Service users' views of measuring addiction recovery is a research paper by myself and colleagues (see left) published in *Drugs Education Prevention Policy (2015; 22(1): 26-34)*. The quote was given by 'Sean' half way through an ex-user focus group. With the other participants, he was debating the importance of good physical health. His throwaway line sits in notable contrast to one of the final remarks made in the same group. On being told that the session was formally over and everyone was free to leave, group members responded: "We don't want to go! We don't want to go!". Therein, perhaps, lies a further valuable insight into service users' views of measuring recovery. It is simultaneously a frustrating but compelling activity and one that can be enjoyable.

The research came about because we wanted to explore how service users' views of measuring addiction recovery differ from those of service providers. Service users have detailed knowledge and understanding of their own health status, psychosocial problems, personal resources, support needs and aspirations. Such information can be crucial to researchers, service providers, service commissioners and policymakers who might not have first-hand experience of addiction and related problems. Involving service users in designing measures of recovery can lessen the likelihood that researchers develop assessment tools that use inappropriate, contradictory or objectionable outcomes, and ambiguous and unclear language. People who have experienced drug or alcohol problems can highlight important weaknesses in dominant recovery discourses.

This work forms part of a broader study in which we are seeking to develop a novel recovery outcome measure that will prioritise the goals of people who are, or who have been, addicted to alcohol or drugs and used treatment services. I plan to share those preliminary findings at Recovery Plus in May.

In recent years, 'recovery' has become a core principle in the drug and alcohol sector, resulting in a significant move towards 'recovery-oriented' drug treatment nationally and internationally *(Duke, Herring, Thickett, & Thom, 2013)*. But recovery definitions range from vague and nebulous ('recovery is what each individual wants it to mean') to the highly prescriptive ('recovery means abstinence from all substance use'). Latterly, there has been emergent stakeholder agreement that recovery can be achieved with appropriately prescribed medications (*Recovery Orientated Drug Treatment Expert Group, 2012*) and is more than just a reduction in substance use (*ACMD, 2013; HM Government, 2010; Scottish Government, 2008*). Instead, it involves people achieving benefits in a wide range of life areas, including their relationships, housing, health, employment, self-care, use of time, community participation and wellbeing (*ACMD, 2013; Burns & MacKeith, 2012; Neale, Pickering, & Nettleton, 2012*).

Definitional ambiguity renders measuring recovery outcomes particularly complex.

About the author

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Influenced by the medical model of addiction and a pervasive culture of monitoring and performance targets, there has been a tendency to focus on very basic quantitative indicators, weighted particularly towards reduced drug consumption and offending. The extent to which measures of recovery used in the addictions field reflects the goals and aspirations of people who experience problems with drugs and/or alcohol has, meanwhile, received little attention.

Patients' views of their own health and treatment are now proactively sought in many areas of medicine, and this has resulted in the development of myriad questionnaires, rating scales and assessment forms – known as patient reported outcome measures, or PROMs (*Dawson, 2009; Epstein, 1990; Garratt, Schmidt, Mackintosh, & Fitzpatrick, 2002*). PROMs focus on the quality rather than just the quantity of patients' lives and give priority to the patient's – rather than the clinician's – perspective.

We are committed to ensuring that the opinions of those who have experienced drug or alcohol dependence and have been users of addiction services are central to our work. To this end, we are working closely with a newly formed service user research group that is advising us as we progress. We are also using *Service users' views of measuring addiction recovery* documenting service users' reactions to 76 recovery measures suggested by 25 senior service providers – the list is over the page – in a preliminary stage of the research. Measures on which service providers and service users largely agreed will be included in the next stage of the PROM.

In this article, we disclose how and why service users disagreed with service providers. This is relevant both to the development of our PROM for addiction recovery, and for drug and alcohol policy, practice and research more generally.

The initial exercise revealed that almost all service users agreed that recovery was a very important concept, with only two people from the ex-user group questioning its utility and arguing that it was a meaningless word that had been hijacked by politicians. Furthermore, there was a high level of consensus that recovery constituted a unique personal journey but one that would last a lifetime, as the risk of relapse was ever-present. Service users in all groups emphasised that recovery was not only about their substance taking; rather, it involved them making changes in their lifestyles, behaviours, relationships, physical and mental health, and social circumstances. Whether someone could be in recovery while receiving opioid substitution treatment was a more divisive issue with no consensus in any group.

Our analyses found nine main types of problem with service providers' views of recovery, as below.

1. Expecting the impossible of service users
2. The dangers of progress
3. The hidden benefits of negative outcomes
4. Outcomes that negate the agency in recovery
5. Contradictory measures
6. Failure to recognise individual differences
7. Entrenched vulnerabilities
8. The misattribution of feelings and behaviours
9. Inappropriate language.

Delegates at Professor Neale's presentation at Recovery Plus will leave with the ability to:

1. Explain why we need to think critically about the word 'recovery'
2. Discuss how research can help us define and measure recovery
3. List service providers' definitions of recovery
4. List service users' views of what recovery is, in order to be able to respond to service providers
5. List measures that most people (service users, service providers, and commissioners) believe show recovery
6. Identify the types of treatment and support needed to nourish recovery.

Expecting the impossible of service users.

Many service provider-suggested measures of recovery expect service users to behave better and achieve more than 'normal' people – who can also break the law, get into debt, have bad relationships, become dependent on other people, lack self-awareness. Everyone feels anxiety, depression, loneliness, shame and guilt at some point – these are natural emotions, and feeling them can be progress. Also, measures such as good physical or mental health, can be impossible for some people with health problems.

The dangers of perceived progress.

Suggested outcomes such as having confidence/feeling in control/experiencing self-belief were important to a point, but beyond that could result in people being complacent and relapsing.

The hidden benefits of negative outcomes.

If people in recovery did not experience tiredness or feel anxious, shame or guilt, they were probably not 'working at their recovery' and 'did not care'. Tiredness, some participants emphasised, can feel satisfying at the end of a productive day, anxiety might signal new and interesting challenges, remorse for previous misdemeanors can be progress, contact with the criminal-justice system could mean legal help and protection – and the police, probation service and courts can fast track those with drink or drug problems into treatment.

Contradictory measures.

Focus group service users seemed increasingly bemused that some service providers' measures appeared to contradict each other or were incompatible. For example, reduced and safer drug use were difficult to reconcile with abstinence, and accessing treatment and support (particularly residential) was considered somewhat inconsistent with being independent.

Failure to recognise individual differences.

Participants reported frustration that many service providers' measures did not allow for individual differences and personal preferences. Whether or not somebody wanted or needed formal treatment or peer support, liked having lots of people round them, could cope with a full-time job, would be suited to voluntary work, or needed more education would depend on that individual. Furthermore, those differing wants and needs might relate to stage of recovery, gender and other demographic factors.

Outcomes that negate the agency in recovery.

Some provider-desired outcomes were simply physiological and 'automatic', occurring over time and, while markers of progress, should not be priorities. These include appetite and menstrual cycle returning.

Entrenched vulnerabilities.

The extent of some service users' vulnerabilities – and thus the height of the bar set by some recovery measures – became apparent when issues such as 'being able to trust people', 'not being lonely' and 'having good relationships with family' were discussed. Service users from all groups emphasised that some people 'cannot and should not be trusted' and loneliness is preferable to friends who 'become enemies' and family members who let them down.

Measures of recovery, by service providers

1. Reduced drug use
2. Using drugs safely
3. Achieving abstinence
4. Practising relapse prevention*
5. Reduced cravings
6. Accessing treatment*
7. Accessing peer support/self-help
8. Engaging in private therapy
9. Having good mental health
10. Being confident
11. Coping*
12. Feeling in control
13. Having self-belief
14. Having self-worth
15. Being able to trust people
16. Having emotional balance
17. Achieving self-acceptance
18. Having no anxiety
19. Dealing with past trauma*
20. Accepting responsibility*
21. Being able to manage feelings*
22. Not feeling depressed
23. Not being lonely
24. Feeling safe*
25. Having good physical health
26. Being physically active
27. Taking care of your appearance
28. Taking care of yourself *
29. Eating healthily
30. Dealing with toothache
31. Appetite returning
32. Not feeling tired
33. Going to the toilet regularly/not being constipated
34. Periods coming back (for women)
35. Sex drive coming back
36. Putting on weight
37. Feeling energetic
38. Sleeping well*
39. Having a daily routine*
40. Going to appointments*
41. Having hobbies
42. Using time meaningfully
43. Not being bored
44. Participating in education/training
45. Doing voluntary work
46. Having a paid job
47. Having a stable income
48. Not having debts
49. Being able to manage money*
50. Having stable housing*
51. Living independently
52. Keeping the house clean and tidy
53. Having good relationships with family (including partner and children)
54. Having good relationships with peers in recovery
55. Having good relationships with non-using friends*
56. Having social support*
57. Being independent
58. Not having negative relationships
59. Having honest relationships*
60. Supporting others
61. Having a role in society
62. Participating in society
63. Not causing problems to society
64. Having a good quality of life*
65. Not offending
66. Not being in contact with the criminal justice system
67. Behaving morally
68. Not feeling shame or guilt
69. Feeling positive
70. Not feeling stigmatized
71. Being self-aware
72. Having a non-addict identity
73. Having purpose*
74. Having realistic plans and goals*
75. Having hope
76. Being spiritual

* Service users had few problems with these measures.

The misattribution of feelings and behaviours.

Some service users never lost their appetite during their drinking or drug use, needed to lose weight rather than increase it, felt energetic using drugs and tired in abstinence – and many were proud to identify as an addict in recovery, and did not aspire to be part of mainstream society and its 'dubious values'.

Inappropriate language.

Participants noted that measures were designed by people who had 'no idea of their experiences'.