The utility of patient-reported outcome measures in mental health

For decades, clinician-rated outcome measures have been the central source of data informing clinical practice and policy. Patient reported outcome measures (PROMs) more directly assess the lived experiences of service users, capturing their perspectives on their health status and essential subjective constructs such as goal attainment, quality of life and social inclusion. Patient reported experience measures (PREMs) assess their experiences of using health services, including communication, responsiveness and recovery orientation.

Here we argue for the systematic implementation of co-developed, user-selected PROMs and PREMs; identify implementation challenges; and propose future priorities. By "co-developed" we mean that people with lived experience, including but not limited to peer researchers, should be meaningfully involved in each stage of measure development and evaluation. Involvement may range from providing advice to help reduce bias favoring clinician priorities, through to peer researchers fully leading the process of developing patient-generated PROMs (PG-PROMs). We also emphasize the distinction between PROMs/PREMs in which service users have played a primary role in the selection of specific measures to be used versus those in which measure selection has been clinician-driven.

We identify three rationales supporting widespread routine use of PROMs/PREMs: ethical, clinical and institutional. The ethical rationale is that lived experience is necessarily central in and aligns with both the vision of recovery and the rights-based global movement towards increased participation and leadership by users of mental health services[1]. Patient-rated data should be the main source of information informing clinical decision-making, with clinician-rated data re-positioned as secondary or adjunctive.

Clinically, empirical studies reveal significant discordance between assessments by clinicians and service users on a broad range of issues, such as health and social needs. The use of PROMs/PREMs helps identify these discrepancies and acknowledges multiple perspectives. Measurement-based care, which includes systematic integration of PROMs/PREMs during service encounters to inform treatment, enhances structural accountability by supporting regular consultation with service users regarding their progress towards self-defined rather than clinician-identified goals. This ongoing dialogue, in turn, leads to improved communication and therapeutic alliance, key components of personalized psychiatry[2].

At the institutional level, PROMs/PREMs render sociopolitical processes more visible. Service user movements have criticized the primacy given to clinician perspectives, which results in the epistemic injustice of service user perspectives being de-prioritized or de-legitimized[3]. Co-developed PROMs/PREMs have the potential to collect different and more ecologically valid, and hence more relevant, information than clinician-rated measures – thereby contributing to the goal of measuring what matters instead of what is easiest to measure. Aggregated patient-reported data capturing information beyond the traditional clinical domains also make institutional processes visible and can inform system transformation. If the goal of mental health services is to support people in living lives of their own choosing, then improvements in patient-reported outcome and experience assessments is the best measure of service success.

International reviews find that PROMs/PREMs are underutilized[4]. Implementation barriers include attitudinal, availability, usage and feasibility challenges. Clinical ambivalence can reflect unstated paternalistic beliefs that service users cannot accurately prioritize and report their own experiences. Service user involvement in the development and selection of

patient-rated measures is limited[5] and replicates traditional disempowering processes. Despite recent global harmonization initiatives[6], there remains a lack of consensus on which measures to use. Finally, experiences from countries early to develop routine outcome monitoring infrastructure – such as Australia (https://www.amhocn.org), Canada (https://www.ccim.on.ca), Israel (https://www.health.gov.il) and the Netherlands (https://www.phamous.nl) – identify significant feasibility barriers to routine collection and use, including limited access to complete PROMs/PREMs and difficulties in segmenting of data for constructive use by all stakeholders.

We propose four future priorities for supporting PROM/PREM implementation. First, a much greater focus on co-developed PROMs/PREMs is essential. Involvement of service users and peer researchers helps ensure that the highest-valued domains of outcome and experience are assessed, and that language used is sensitive and person-centered. Assessment domains may include areas traditionally neglected in clinician-driven measures, such as support for medication discontinuation. Measures which are not co-developed may simply provide a patient-rated version of a measure that nevertheless reflects clinician, not patient, priorities. The lack of meaningful service user involvement and leadership in PROM/PREM development risks undermining the claims we make here about the value and importance of PROM/PREM integration.

Second, it is equally fundamental that individual service users play a primary role in the selection and prioritization of measures to assess their clinical progress, to avoid the use of measures that they might find disempowering. The latter may include being asked to rate progress in a domain of low personal value or, worse, being required to self-rate on a construct perceived as strengthening rather than challenging traditional epistemic and power hierarchies within psychiatric services. In addition to service user involvement in selecting measures, novel approaches are emerging to capture individual differences in value that service users attribute to a variety of domains of experience and outcome. An example is the INSPIRE assessment of clinician support for recovery (https://www.researchintorecovery.com/inspire), in which service users rate recovery support only in domains which matter to them, producing a score reflecting personal values and priorities. Other approaches include goal attainment scaling and individualized outcome measurement[7].

Third, the widespread use of mental health apps provides new opportunities for easily collecting, analyzing and presenting ecologically valid PROMs/PREMs which can support self-management, shared decision-making and recovery processes[8]. Similarly, machine learning approaches to aggregating big data could revolutionize the understanding of various trajectories of recovery and complex patterns of multiple influences, leading to treatment optimization and better prediction of prognosis[9]. This can help fulfil the potential of continuously learning mental health systems which adapt, innovate and improve services through continual harnessing of data and analyses informing constant discussion between key stakeholders.

Finally, there is a need to develop international consensus on the choice of PROMs/PREMs, which involves addressing challenging questions: How to capture and use aggregable data whilst supporting individualized assessment? How to assure meaningful involvement and relevant accessible PROMs/PREMs for a heterogenous group that can vary considerably in a range of ways? How to balance the traditional priority given to psychometric robustness, which results in more subjective domains being less assessed, with the reality that many aspects of the human condition are difficult to measure yet are intrinsic to mental health services? Given that PROMs/PREMs are primarily developed in higher-resource countries and then translated, how can the ethnocentric dominance of Global North values be adjusted to address cultural and geopolitical differences?

These future priorities for supporting PROM/PREM implementation can help make a reality the vision of routine outcome collection, management and sharing to facilitate more equitable and higher quality of care. The long-term promise of PROMs and PREMs is to locate service users exactly where they should be in the mental health system: at its centre.

David Roe[1,2], Mike Slade[3], Nev Jones[4]
[1]Department of Community Mental Health, University of Haifa, Israel; [2]Department of Clinical Medicine, Psychiatry, Aalborg University, Aalborg, Denmark; [3]School of Health Sciences, Institute of Mental Health, University of Nottingham, Nottingham, UK; [4]School of Social Work, University of Pittsburgh, Pittsburgh, PA, USA

1. World Health Organization. Guidance on community mental health services: promoting person-centred and rights-based approaches. Geneva: World Health Organization, 2021.
2. Bhugra D, Tasman A, Pathare S et al. Lancet Psychiatry 2017;4:775-818.
3. Slade M, Sweeney A. World Psychiatry 2020;19:389-90.
4. De Bienassis K, Kristensen S, Hewlett E et al. Int J Qual Health Care 2021;33:mzab002.
5. McNeill M, Noyek S, Engeda E et al. Qual Life Res 2020;30:983-95.
6. McKenzie E, Matkin L, Sousa Fialho L et al. Psychiatr Serv (in press).
7. Pesola F, Williams J, Bird V et al. Int J Methods Psychiatr Res 2015;24:257-65.
8. Shadmi E, Gelkopf M, Garber Epstein′ P et al. Psychiatr Serv 2017;68:1312-14.
9. Chekroud A, Bondar J, Delgadillo J et al. World Psychiatry 2021;20:154-70.