The problem of patient-centred outcome measurement in psychiatry: why metrology hasn’t mattered and why it should

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Abstract. In psychiatry, there is a call for clinicians to use patient-centred outcome data routinely at the point of care to help tailor treatment plans to meet patient preferences and needs. Given that many decisions in psychiatry are constructed from patient narratives, it is critical that the conceptual, empirical, and measurement structure underlying patient reported outcome measures is robust and patient-centred. Here, we argue for the systematic accrualment of patient-centred data in psychiatry to meaningfully enhance the treatment of mental disorders. Specifically, we suggest three crucial considerations for system transformation: (1) the engagement of international patient research partners to conceptualize and prioritize outcomes; (2) the application of modern test theory to develop and evaluate patient-centred outcome measures; and (3) funding allocation accountable to evidence-based services prioritized by patients.

1. Introduction

The treatment of mental disorders is a global health challenge, costing one trillion dollars each year [1]. One in four people will experience a mental disorder at some point in their lives and 450 million people currently suffer from mental health challenges [1-3]. As a result, mental illness is the leading cause of ill-health and disability worldwide [2]. To reduce the impact of mental illness, transformative change and service redesign are necessary. In this paper, we propose three crucial considerations for system transformation: (1) the engagement of international patient research partners to conceptualize and prioritize outcomes; (2) the application of modern test theory and metrological standards to develop and evaluate patient-centred outcome measures; and (3) the alignment of funding towards outcome driven services prioritized by patients.

2. The engagement of patient research partners to conceptualize and prioritize outcomes

Patient-oriented research and clinical practice are described collectively as a continuum of research and care that engages patients as partners, focuses on patient-identified priorities, and improves outcomes
through the identification of treatment effects; mapping these effects to pathology and guiding clinical care [4]. The “patient engagement” movement was developed to enhance researcher and clinician understanding of the effects of disease and treatment on patients’ daily lives. Rheumatology, oncology, and plastic surgery are examples of fields in medicine that have successfully emphasized patient-partners in research in the last decade to improve endpoint outcome measurement [5, 6]. Through their iterative, inclusive consensus processes, outcomes important to patients such as participation, function, and fatigue have become endorsed as targets for treatment and clinical trials in both fields [7]. Systematic approaches to defining patient priorities in psychiatry have yet to be developed. However, psychiatry is not alone. In a recent editorial published in the British Medical Journal, Coulter (2017) notes that the behaviour of measuring what matters to patients is “surprisingly rare” in medicine, with a mere 11% of patient-reported outcome measures actually asking patients which outcomes are worth measuring [8].

In response to this trend, national initiatives, such as Canada’s Strategy for Patient Oriented Research [4], the Patient Centred Outcome Research Institute [9] in the United States, and the European Patients’ Academy on Therapeutic Innovation [10] have been developed to incorporate the perspectives of patients in research and help individuals feel empowered about their healthcare choices. As the demand increases for accountability of clinical mental health services to be person- and family-centred, engagement of patients at all levels of clinical research design are necessary. Yet patient engagement in isolation may not be the solution. Unfortunately, many of the outcomes in psychiatry are not directly observable. This presents systematic challenges for capturing them and characterizing treatment effectiveness. Unlike other fields of medicine, outcomes in psychiatry are predominantly latent and cannot be quantified with imaging or analytical data obtained from tests such as bloodwork. Therefore, practical reasons exist to incorporate patient-reported data to justify clinical decisions, care pathways, and research endeavors. If treatment selection or clinical efficacy and effectiveness trials are to emphasize patient-prioritized outcomes, a robust practical approach to measuring these types of outcomes in psychiatry is needed.

3. The problem with health outcomes measurement in psychiatry

Current approaches to measuring clinical outcomes in psychiatry (i.e., depression, anxiety, neurocognitive deficits) and patient-centred outcomes such as quality of life and functioning, often utilize multiple item scales or questionnaires. With multiple item scales, scores from each item are combined to give a total score. This practice may seem clinically sensible; combining multiple items reduces random error, therefore enhances scale reliability [11]. With large enough sample sizes, estimates to support the psychometric strength of the rating scale can be achieved [11]. Most clinicians invest significant faith in a rating scale that has been deemed ‘reliable and valid’. However, understanding the clinical tangibility of the total scores is necessary. For example, what does a score of 15 mean on an instrument purporting to measure depression, which ranges from 0-60? How does that same score of 15 compare to the total scores generated by dozens of other existing depression scales? Interpretation of these scores has been a longstanding challenge in psychiatry. Communicating results to patients, families, and other health professionals can often be difficult and abstract. This limits the potential to systematically convey information about treatment impact and quality assurance.

Another concern for psychiatry and health outcomes measurement is that increasing pressure exists to record patient-reported data electronically in real time. A recent article in the New England Journal of Medicine suggests that real time collection of person-reported data can improve patient quality of life, enhance patient-physician communication, reduce emergency department utilization, and lengthen survival [12]. However, one of the biggest challenges in psychiatry is how to collectively identify patient outcomes that are important to stakeholders, let alone quantify these outcomes robustly in real time. It is unlikely that meaningful quantification of outcomes in psychiatry can occur if key stakeholders do not speak the same language or share the same conceptualization and targets for care. We emphasize that establishing a common measurement language with interpretable units is crucial for linking patient-centred research, clinical, and policy activities. The realization of these units in practice can provide
significant value added to current approaches to psychiatric care. This will be in line with a fundamental application of metrology to social sciences that has been well documented for decades:

"Such adoption [of the units] immediately imposes the duty to obtain the various standards that is, the national prototypes by which units can be translated into practice for application in other fields” [13] (p.51).

4. Solutions to health outcomes measurement in psychiatry
Fortunately, psychometric approaches, such as Rasch Measurement Theory (RMT) [14], exist as solutions to this problem. RMT has unique properties that are invaluable to fields where outcomes are mostly latent and inferred from the patient [15]. These include references for traceability and means of evaluating measurement uncertainty for both patients and items. As well, RMT methods embrace the opportunity for key stakeholders to work together to hypothesize and experimentally test the composition of a variable of interest and how it can be mapped hierarchically along a clinical continuum.

Should the items in a rating scale be unidimensional and represent a harmonized hierarchy, total scores are interpretable and can therefore directly inform treatment. The implications for this are profound. Meaningful scale scores allow patients, health practitioners, administrators, and policy-makers to work collaboratively towards common goals and be accountable to each other. Specifically, the hierarchy of items can inform where a patient is at on the continuum and provide indication for where they are going in either direction along the health continuum. This approach to measurement provides clinicians and patients with a compass and interpretable language, pointing the way forward for innovation and evidence-based care. As a result, the application of metrological standards to psychiatry has significant potential to ensuring greater quality, accountability, and accessibility of what Canada’s Strategy for Patient Oriented Research (SPOR) calls:

“the right care at the right time for the right patient”[4].

In the light of pressure for demonstrating outcomes and performance standards in the field, psychiatry is ideally placed to consider the application of metrology for its future. Based on well documented standards form the late 1960s [13], we propose the following broad aims for measurement standards to be considered by psychiatry:

- The development of a scheme to produce outcome measures that have been approved by all stakeholders for which the instrument has been developed, specifically patients.
- The development of the organization necessary for translating and practicing metrological accuracies derived from clinical outcome measures developed in the field.
- The specifications for accuracies required for various contexts of use in mental health care.
- The training of psychiatry and mental health professions in applied metrology to equip clinicians with the skills necessary to select outcome measures that are fit for purpose for their context of use and clinical service intentions.

5. Applied patient-centred outcome funding allocation
The routine use of robust patient-centred outcomes in psychiatry also provides an opportunity to help drive how health care is funded [16-18]. Globally, benchmarking standards are ensuing to promote high performing health care systems that achieve better access, improved quality, and greater efficiency of care. The United Kingdom, Netherlands, Finland are examples of nations that have witness significant changes in health practice and outcomes which can be attributed to a range of policy initiatives and incentives to support and reward high quality outcome driven activity. As an example, the Netherlands have built a nationwide infrastructure to collect of patient-reported data to organize mental health care. Annually, 50% of 1,000,000 treatments performed yearly in the Dutch mental health care have complete outcome data on patients that can be evaluated [19] . This data includes assessment of symptomology and functioning in patients at regular intervals. Feedback is immediately given to clinicians to ensure
that progress towards treatment goals is monitored, clinicians are motivated to continue the chosen treatment or investigate alternative treatments in a shared-decision making capacity with patients. The strength of the Dutch approach has been to work collaboratively with patients, clinicians and stakeholders to select outcome domains and measures. However, increasingly the quality of the measures in the field that are commonly used has been critiqued [8]. Opportunity exists to organize data from this benchmarking exemplar for various sections in mental health to iteratively test the extent to which the measures meaningfully capture the outcomes they purport to measure. This would create a common language of performance between patients, clinicians, researchers and key stakeholders. As well, this would allow for the comparison of performance metrics reported by clinical services to evidence-based guidelines, in turn informing funding decisions. This is critical because without a measurement and benchmarking system there is limited ways to:

- Provide a sound basis for communication of treatment decisions and effectiveness between stakeholders;
- Use a commonly accepted measurement approach that can inform health services and treatments, compare individuals over time, and compare systems or services.
- Provide a measurement basis which will permit and encourage the interchange of meaningful scientific and clinical information.
- Development for a standard for how services are funding based on performance and quality of care.

Through benchmarking, there is the potential to learn how well psychiatric interventions perform and align to outcomes that are meaningful to the patient. Benchmarking has been used rigorously by other areas of social science such as Education [20] to monitor progress of stakeholders. Under the assumption that outcomes are derived from rigorous patient-centred conceptual and measurement models, benchmarking can inform the allocation of funding towards the areas of greatest need. This ensures decision makers and psychiatrists are equipped with the evidence needed to develop plans for how to make improvements or adapt best practices to optimize the mental health and wellbeing of patients.

6. Application of patient-centred outcome measurement in transformative change and service redesign: an exemplar in psychiatric program innovation and evaluation

In September 2014, a proposal entitled Transforming Access to Health and Social Services for Transition-Aged Youth (12-25) was submitted to the Select Standing Committee (SSC) on Children and Youth in British Columbia, Canada. The proposal called for the creation of a network of health and social service centres across Canada that would provide youth- and family-centred services to young adults with mental health disorders. The proposal resulted in the establishment of the Canadian “Foundry” and funding support for eleven sites. With the goal of implementing timely, evidence-based, and youth and family-centred services across the province, the Foundry team recognized early in 2016 that there was a significant gap in the literature regarding the mental health needs of these key stakeholders. Not surprisingly, the team also identified a lack of measurement tools fit for purpose to measure mental health outcomes for youth.

Early in project conception, the Foundry prioritized (1) patient and family engagement, (2) measurement rigor, and (3) allocation of funding to patient priorities. The model of care addresses a critical research-to-practice continuum gap by:

- Developing a patient-reported data system that enables real time data to be collected to inform services and immediate psychometric validation of the outcomes measures using Rasch measurement methods. The goal of this approach is to produce estimates for items and total scores that are fit for purpose to measure the mental health needs of youth receiving Foundry services, thereby allowing for comparisons between patients, services, and clinical sites.
• Using patient reported data to develop a real time evolving profiles of the mental health needs of youth from both the perspectives of patients and their families.
• Allocating funding to services that reflect the immediate needs of youth and the services needed to support them along the full range of the health continuum.

In this novel initiative, patient-reported information is gathered daily about patient-outcome performance and provides real-time evidence for clinical decision makers and researchers to advance care based on a rigorous understanding of measurement and how it can be used to enhance the health of this population. Psychometric summaries, using Rasch measurement theory, in parallel with regular patient, family, and stakeholders advisory council meetings, ensures quality assurance standards and funding are in place to support patient needs and priorities. The value in this approach lies in the identification and presentation of clinical data that can be successfully applied to clinical decision making and system design.

7. Conclusion
In 2017, many countries are presented with ideal political climates that prioritize patient-oriented and outcome-driven care in medicine. Accurate measurement can increase the quality and impact of patient-oriented research and clinical care. Yet, measurement control in psychiatry poses many challenges as the measurement objects are often not directly observable. Fortunately, promising approaches to address these challenges now exist and are being readily adopted by other areas in the social sciences. It is therefore an excellent time to mobilize metrology infrastructures and intelligence to tackle challenges in measuring patient-reported outcomes in psychiatry. Similar to Canada’s Foundry initiative or the Netherlands’ use of benchmarking standards, collaboration efforts between clinicians, patients, policy makers, and metrologists has potential to lead to improved quality of care for individuals living with mental illness globally. Reliable, comparable and efficient use of diagnostic and therapeutic methods across all areas of psychiatry can improve health care, limit costs and foster excellence in patient-centred research and innovation.

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