

## From The Editor's Desk

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### Don't forget to connect with patient experience: conversations on trust, ties and surprise

At the time of writing, we are mourning the loss of Stephen Hawking, whose contributions to science I previously celebrated.<sup>1</sup> Based on an analogy with Hawking's theories of time and space, knowledge can improve our lives, yet what is known is changed by use in the real world. Indeed, the scaling up of innovations usually [includes measures to specifically] guard against knowledge and evidence being fractioned or changed during the process of application and transmission through professional networks and health systems, and in public discourse. Is this always desirable or effective?

We need the Hawking innovators, patients and scientists, in psychiatry. Recent research on the cultural transmission of innovation has shown how progressive and remarkable individuals (like Hawking) can have a disproportionate influence on advances in society, more so than shared social movements, as these face greater resistance, less diversity of opinion and inherent expectations of conformity. By contrast, innovators act like cultural reservoirs and incubators that permit the selection of advantages (social, cultural or biological).<sup>2,3</sup> There is an important place for more variation of views and approaches and protection of local and personalised approaches to recovery, seeing patient as innovators. Exceptional people and exceptional views should be welcomed as avenues to improve mental healthcare. Yet, much evidence is lost if it is perceived to not have generalisable survival value for large numbers of people in the health system. The role of patient experience and perspectives and choice as a determinant of which bodies of knowledge are retained and promoted – cultural selection – has not been well studied. This necessarily requires [that interventions are subject to] adaptation and refinement to meet personal needs. Information about [refining] adaptations could be especially valuable for advancing the care of complex health conditions that are persistent, distressing and challenging for clinicians. Gathering patient experiences for these conditions and similar contexts could open up new therapeutic avenues. Patient experience can also help to reconcile contradictions in the evidence.

Knowledge about the role of hospital admission in suicide prevention is controversial.<sup>4</sup> Large and Kapur (pp. 269–273) debate whether in-patient admission is a potentially harmful experience for patients who are experiencing suicidal ideas; whether admission leads to dependence and a lifting of agency and empowerment. The counterargument is that the risk of suicide is intrinsic to an illness experience. Studies of patient experiences are needed here, and these may help to deepen our understanding of what works, where and for whom. For example, suicidal patients value a sense of safety and security, connection, protection and control, and mutual recognition and confirmation, rather than technical or physical aspects of the care environment.<sup>5,6</sup> There is more to care than the technical delivery of disembodied aliquots of intervention, which can be defended as sufficiently meeting conventional standards of professional practice. Sweet *et al*'s (pp. 308–317) analysis of personal well-being networks may offer a clue as to what matters. They emphasise the importance of place and meaningful activity in recovery, and that professionals should actively assess

and enhance personal well-being networks. Diagnosis and social capital appeared not to influence personal well-being networks, but social factors such as housing, education, living alone and receipt of benefits did explain variation in well-being networks. For patients with severe mental illnesses, and greater disadvantage and isolation, professionals were an essential part of patients' social capital – a role that perhaps professionals do not recognise, that they are important as human connections – supporting patients to give meaning and value to their lives.

The clinical task is often framed as sharing evidence with patients, and applying this in clinical decisions, to optimise outcomes. This framework overly emphasises passivity and a lack of agency in patients and carers, who will make use of knowledge in different ways and add their own expertise and experience, changing interventions to best suit their personal contexts and preferences. The professional frameworks may be unreceptive to or even dismissive of [adjustments to better match] experiences. Riebeiro *et al* (pp. 279–286) show that hopelessness and depression are important predictors of suicidal ideation, self-harm and death; and that hopelessness and depression are too often treated like traits, rather than as context- and state-dependent variables. Contrary to the usual tradition of emphasising longer follow-up in studies of suicide, this research paper elegantly asserts the need for shorter-term and context-near and experience-near evaluations that better approximate the patient experience at a specific time point and in a specific place.

Akena's visual analogue scale for the assessment of depression in Kampala and Cape Town attempts to overcome literacy, cultural and methodological obstacles by the use of imagery reflective of the patients' place identity and cultural milieu. This research ensures that unusual contexts and patient experiences are captured and inform the evidence of what works. The personalised approach to psychiatry is especially challenging in the care of people with persistent depressive experiences. Two important contributions (Anderson, pp. 259–261; McAllister-Williams, pp. 274–278) grapple with conceptualising this constellation of symptoms over time and space, and the construction of 'treatment resistance'. This phrase captures the clinician's arduous task in considering intensive pharmacological intervention and extending to psychotherapies where needed.<sup>7,8</sup> There is a risk that we attend to more prominent varieties of depressive experiences that obscure more granular and localised narratives of specific places and times in the lives and recovery journeys of patients. Alliance building, overcoming breaks in the therapeutic relationship, and competent professionals availed of the latest evidence are part of what patients seek; they also want humane connections through which they are seen, known, recognised and encouraged to choose how to flourish in their chosen places, networks, and ways that are salient to their experience.

Evidence that surprises or goes against the grain is another form of independent innovation (Nelson, pp. 262–264). There is much excitement about new avenues of research on inflammation as a cause of mental illnesses, offering new therapies. Oviedo-Salcedo (pp. 318–320) did not find a high level of anti-neuronal antibodies in a cohort of patient with schizophrenia spectrum disorder, suggesting that more critical engagement with the new evidence is imperative. Depression and mania are under-recognised in people with intellectual disabilities (Cooper, pp. 295–300), and there is insufficient research on comorbid mental illnesses. Thygesen (pp. 287–294) suggest that genetic testing should be available to people with intellectual disabilities and comorbid mental illnesses; they find a higher positive yield of copy number variations compared with healthy controls, and compared with people experiencing symptoms of schizophrenia, intellectual disability or autism spectrum disorder alone. These findings raise a number of ethical questions about current provision, how to empower patients through information that offers choice, and how to take account of personal preferences.

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