

# The role of new technologies in monitoring the evolution of psychopathology and providing measurement-based care in young people

Two of the most important innovations in clinical psychiatry over the last decade have been the deployment of youth-focused early intervention services and the development of a clinical staging framework for clinical care and pathophysiological research<sup>1,2</sup>. Together, they engage young people in active clinical care, promote secondary prevention strategies and provide the platform for more detailed clinical research.

These developments respond directly to the epidemiology, namely, that most mood and psychotic syndromes have their onset in adolescence and are associated with social and educational impairment and other at-risk behaviors (notably suicidal thoughts and behaviors, and alcohol and other substance misuse)<sup>3</sup>.

Critics of these proactive innovations highlight possible adverse effects, including premature assignment of specific diagnoses, unwarranted exposure to medicines and inappropriate deployment of specialized health resources. The true value of these developments can only be determined by detailed longitudinal assessment of the relevant clinical, social and occupational outcomes<sup>4</sup>. For the individuals most affected, and their families and carers, this means a commitment by service organizations to serious long-term partnerships in which the relevant data are collected.

To conduct meaningful analyses, we need detailed data tracking over the 5-15 year period after onset (i.e., from adolescence to age 30 years). We also require linking of data from multiple informants (individuals, family members and carers, clinicians, as well as health care and related social, educational and employment-based organizations).

Data collection methods demand highly personalized and flexible approaches, so that the maximum data is collected not only at key points of biological or social transition, but also when a young person is exposed to a major new risk factor, experiences a major deterioration or receives an effective intervention.

Previously, such responsive longitudinal research, and innovative clinical practice, relied largely on cohort studies confined to highly specialized clinical centres. Additionally, these studies required large investments in trained research staff, but typically resulted in only a limited number of data entry points over the course of illness. These traditional methods struggle to provide sufficient data for the type of modelling exercises that are now required to describe the many possible trajectories that are possible during this key developmental period<sup>5</sup>.

So, in the 21st century, is it possible to improve the quality of such fundamental health services<sup>4,6</sup> and conduct such essential clinical and linked pathophysiological research at scale? As we now have the digital technology tools, the answer can be “yes”<sup>6</sup>. That is, it is possible to access the digital infrastructure, combined with security and privacy systems and ethical frame-

works, to conduct both enhanced clinical care and longer-term research.

Personal digital technologies can regularly collect both subjective and objective data from young people, include complementary information from families and carers, and be linked to smart health information systems. We have demonstrated that, when these tools are co-designed with young people, and implemented in genuine ethically-based partnerships, they have the capacity for extensive uptake in relevant population groups<sup>6</sup>.

In our own clinical work, we have emphasized the power of such technology-based approaches to track multiple dimensions (i.e., illness type, stage and course; social and occupational function; suicidal thoughts and behaviors; physical health; alcohol and other substance use) concurrently<sup>4</sup>. Linking clinical tracking to mobile personal technologies which collect additional objective data adds depth to these approaches<sup>7,8</sup>.

So, for the first time, we can track – in real time, in great detail and at scale – emerging psychopathology in young people. The populations of great interest can include those seeking health care, as well as those who are “at risk” (due to exposure to known genetic, familial or environmental risk factors). The changing patterns of relevant symptoms, syndrome clusters, linked behaviors (e.g., alcohol or substance use; self-harm or suicidal behaviors) or physiological markers (e.g., 24-hour patterns of motor activity) can be directly followed<sup>8</sup>. These patterns in “at-risk” or already unwell cohorts can then be compared with normal youth who are passing through this same developmental period.

The data derived from such endeavors present major opportunities to move beyond those simplistic or diagnostically-siloed approaches that have characterized many previous clinically-oriented cohort or broad population studies. When combined with other powerful design strategies (i.e., genetic, longitudinal twin, family, clinical intervention or concurrent neurobiological assessment studies), as well as new data analytic approaches<sup>5</sup>, it is likely that we will be able to move beyond our current broad descriptive efforts and delineate much clearer paths to the onset and course of major mood and psychotic syndromes.

In our systems, this personal data acquisition process (and any subsequent transfer to a third party or consolidation within any other deidentified data set) is controlled by the young person. However, with appropriate permissions, it can also be embedded within smart health systems. This has the real advantage of providing the technical basis for genuine and real-time measurement-based care. When each new care decision is made collaboratively, and on the basis of shared and highly personalized data, the potential to improve long-term clinical and functional outcomes may be realized. Additionally, ongoing youth participation in such data acquisition exercises is greatly enhanced

when we focus, first, on the provision of optimal care and, second, on deepening our understanding of these complex illness trajectories.

These activities cannot only be conducted at scale, but can also be implemented in a wide variety of settings. Importantly, digital technologies are not simply a luxury tool of affluent youth in developed countries. As telecommunication infrastructure is now an essential component of economic and social development in many economies, they are rapidly becoming an everyday part of life in most regions of the world. As recognized by the World Economic Forum<sup>9</sup>, as long as the major ethical, equity and privacy challenges are addressed, they are the tools most likely to bring effective mental health care not only to young people during the period of peak onset of mental ill-health, but also more rapidly to the world's eight billion people.

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