Multisite data linkage projects in mental health research

Registers based on electronic health records have substantially enhanced the capabilities of mental health research. These registers can be further supported by linked administrative data, generating evidence with a high level of external validity, reproducibility, and applicability for policy making.1 This approach has been achieved for a single site through the Clinical Record Interactive Search (CRIS) research platform at the South London and Maudsley National Health Service (NHS) Foundation Trust (SLaM; a large mental health provider serving 1.4 million residents in south London, UK).2 Since 2008, the CRIS platform at SLaM has supported more than 200 research publications, many of which used linked national administrative data, including the National Pupil Database,3 Hospital Episode Statistics,4 and the National Cancer Registry.5

Replication of such linkages at other sites is technically straightforward and would allow valuable opportunities for improving generalisability and cross-testing hypotheses. It is also good policy to provide access to regional level data that local decision makers can use to directly care for their populations, as recognised by the launch of The Lancet Regional Health. In 2018, a Medical Research Council award supported SLaM and King's College London (London, UK) to provide such a programme, assisting other mental health NHS trusts by use of CRIS-like databases with the legal and governance pathways required to replicate pre-existing SLaM-CRIS linkages. However, although successful in its deliverables, this programme was complex and time consuming, and, in our view, ultimately unsustainable nationally without a change in approval processes. In particular, one of the principal obstacles to achieving wider coverage is the current requirement to complete full applications on research ethics and legality for each new data owner (NHS trust), even if the linkage protocols are identical.

The implementation of multicentre clinical trials once faced similar challenges, which were resolved by reformed processes of UK ethics and governance that allow new sites to be added with a simple addendum once the main centre receives approval. We propose that this model could be easily extended to data linkage initiatives when a protocol has already been approved and when new sites adopt identical procedures for linking to a common source. This process would reduce the administrative and legal burden for NHS trusts and substantially improve the equality of data provision. Thus, this strategy would address the current situation in which only wealthier trusts aligned with large academic centres can afford the dedicated time and resources required to navigate approval processes (arguably unethical in its own right and perpetuating an impoverished national evidence base).

With longstanding, in-depth data from electronic health records accumulating from all mental health services and complementary national resources, the UK has unprecedented opportunities to host innovative mental health research. However, current governance frameworks risk unwittingly perpetuating regional inequalities unless moves are made to facilitate multisite linkage projects.

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