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Trust and transparency

Medicine is a practice built on trust—from patients and from society in general—and this is especially true for psychiatry, in which trust has been forfeited in the past. Transparency is the foundation stone of trust. In research, this can be manifest at various stages. Clinical trials and, increasingly, other studies should have preregistered protocols against which the final write-up can be checked, so that findings not meeting the researchers' expectations are not hidden. Psychiatry does not have objective biomarkers; outcome measures are therefore based on so-called self-report. Whether the data are collected by a clinician, a trained researcher, or the participants themselves, they come from the participant describing their mood, feelings, and state of mind. We trust that the different scales used in psychiatry research produce findings that are generalisable for, at least, certain subgroups, if not whole populations. Validation studies, including of translations and cultural adaptations, are an important element in building trust in the research process.

Participants in psychiatry research trust that their data will be managed ethically and confidentially. However, they also have a right to expect the best use to be made of their data. An obvious failure of such trust is when research is not published, perhaps because a study proved too ambitious and recruitment targets could not be met or too many people were lost to follow-up. Such data need not be wasted: options now exist for publishing such studies, and their data can then be integrated into meta-analyses and inform future research.

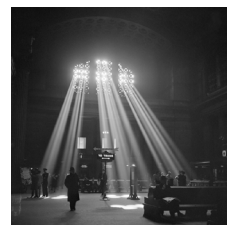
Research papers, even when well reported, publish only summary findings, such as numbers of men and women, numbers of patients in different age groups, and clinical scores at different timepoints. To achieve the full potential of mental health research, individual patient data are needed for other researchers to use and integrate in further work. Getting better value from research is essential in an area as poorly funded as mental health. However, the situation is complex, and a fair, safe, and sustainable solution depends on balancing several competing interests. The possibility of making data available to future researchers, some outside the original study, should be discussed with participants when informed consent is obtained. The extent to which anonymity can realistically be guaranteed must be part of this discussion.

Principles of fairness need also be considered carefully when it comes to the original researchers who have invested resources in a study. These groups might argue that they need time to analyse the data in more ways than can be reported in a single paper, before making them available to other researchers. When exactly should they be obliged to open their data to others?

These conflicting priorities are recognised in the data sharing requirements of *The Lancet Psychiatry* and other journals. Seven questions need to be answered, with the overall options ranging from all data being shared immediately with anyone (with a link to a permanent, secure database), to data being available on reasonable request, to no data made available under any circumstances. Authors are not expected to justify their answers; simply to report their policy. Is this enough? As with many guidelines, compliance is variable. A major problem is that even allegedly freely available data are not in a format that can be easily reused, often because of insufficient metadata—labels, codes, etc. Another problem is that authors might prevaricate or simply not respond to requests for data sharing.

How can we improve this situation? First, build trust with all members of the mental health community, by showing that data will be handled with care, but also teach that the most valuable data are those with the fewest restrictions on reuse. Participants from the All Our Families pregnancy study in Canada or the UK Household Longitudinal Study panel could not have foreseen that their data collected before 2020 could be complemented by new surveys and provide valuable insight into the effects of the COVID-19 pandemic on mental health. Co-production is a key part of trust building: service users and survivors are increasingly engaged in research, but there is much more that can and should be done in this area.

Above all, researchers need to honour their commitments to participant privacy while also being generous with sharing data to maximize their impact. Journals can encourage but cannot enforce this alone. The research community must work towards a clear policy that facilitates the optimal use of the information provided by participants to build and maintain trust in the whole research process. George Orwell wrote that "Good prose should be transparent, like a window pane." The same is true of good science. ■ *The Lancet Psychiatry*



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For data sharing statements for clinical trials see www.icmje.org/news-and-editorials/data_sharing_june_2017.pdf

For All Our Families see [Articles](#) page 405

For the UK Household Longitudinal Study see [Articles](#) *Lancet Psychiatry* 2020; 7: 883–92