

New guidance on data sharing will minimize risks to patient privacy

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New guidance published in the British Medical Journal this week sets out how personal information from clinical trials should be shared to help minimise risks to patient privacy.

Many peer reviewed journals now require authors to be prepared to share their raw, unprocessed data with other scientists or state the availability of raw data in published articles, but there has been little guidance on how such data should be prepared for sharing.

So Iain Hrynaszkiewicz and colleagues offer practical advice for anonymising (or de- identifying) data to ensure patient privacy when sharing clinical research.

They advise researchers to seek informed consent about data sharing from patients involved in [clinical trials](#) before studies begin.

They list 28 items of personal and clinical information that can make patients identifiable in anonymised datasets, and recommend that, unless patients have explicitly consented, all direct identifiers such as names should be removed from datasets.

And if three or more indirect identifiers such as age and sex are given about any patient, the researchers should ask an independent expert or an ethics committee to assess the risk of breaking confidentiality before sharing the data.

They also recommend that researchers should make explicit statements in research articles that have linked raw data, about patients' consent to the sharing of those data.

This, say the authors, should be the minimum standard for ensuring that participants' privacy is not put at unnecessary risk.

In an accompanying editorial, Trish Groves, *BMJ* deputy editor says the *BMJ* is now adopting some of these recommendations. For example, the *BMJ* strongly supports the view that researchers should seek informed consent to data sharing from research participants up front, at the recruitment stage. The journal will also expand its advice to authors about data sharing, and will extend its data sharing statements to include explicit information about consent.

Provided by British Medical Journal

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