

Cancer trial information leaflets 'not fit for purpose': new study

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This is Professor Mary Dixon-Woods, Professor of Medical Sociology at the University of Leicester Department of Health Sciences. Credit: University of Leicester

Patient information leaflets for cancer trials are not up to the job, reveals a new study from the University of Leicester.

Research published in the international journal *Sociology of Health and Illness* reveals that patients find the leaflets far too long and incomprehensible, and even intimidating.

"These information sheets are poorly aligned with patients' information needs and how they really make decisions about whether to join a cancer trial," said author Professor Mary Dixon-Woods, Professor of [Medical Sociology](#) at the University of Leicester Department of [Health Sciences](#).

"Some patients did find them very useful, but many others paid them little attention. They preferred to rely on discussions they had with their doctor to make up their minds."

The study aimed to unravel the mystery of why cancer trial information sheets are so hard to get right. Conducted as a collaboration between the Departments of Health Sciences and [Cancer Studies](#) at the University of Leicester, it traced what happened in 13 [cancer trials](#). It looked at information sheets from the time they were prepared by the researchers leading the trials, through being reviewed and approved by research ethics committees. The study interviewed 26 patients who were approached to take part in trials and were given the information sheets.

"We found that research ethics committee examine information sheets very carefully. They are genuinely keen to make sure that patients are not misled in any way and that the information sheets are easy to read. They very often ask researchers to make changes to make sure they are suitable," said author Dr Natalie Armstrong, Lecturer in [Social Science Applied to Health](#).

"The problem is that information sheets are trying to do too many things. They end up having many of the features of a legal contract. Patients often find them far too long and incomprehensible, and even intimidating. In fact, many patients believed that the information sheets

weren't really produced for their benefit at all, but were more about researchers and institutions 'covering their backs'".

One patient in the study said: "There was a lot of jargon that didn't really necessarily need to be in there. I think that there was a lot of information that sort of baffled you."

There are things that could be done to improve cancer trial information sheets, the study concludes.

"Rather than using standardised templates, it might be better to have a list of principles that could be used when writing information sheets. It could also be valuable to involve patients themselves in helping to write and review them," commented Dr Armstrong. "But we also have to accept that [patients](#) may continue to make their decisions about taking part in trials based on trust in their doctor, no matter how well written the information sheets are. We need to find ways to support doctors when recruiting to [trials](#)."

More information: "Do informed consent documents for cancer trials do what they should?" by Natalie Armstrong, Mary Dixon-Woods, Anne Thomas, Gill Rusk and Carolyn Tarrant has been published by *Sociology of Health and Illness*. [onlinelibrary.wiley.com/doi/10 ... 012.01469.x/abstract](https://onlinelibrary.wiley.com/doi/10.1111/1470-9882.121469)

Provided by University of Leicester

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