

Cancer patients say ask before using medical records for research

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Oncology patients would prefer to be asked for their consent before

deidentified data from their medical records is used for research, according to a study recently published in the *Journal of Clinical Oncology*.

In an effort to generate informed opinions regarding acceptable secondary uses of deidentified [health information](#), Reshma Jagsi, M.D., D.Phil., from the University of Michigan in Ann Arbor, and colleagues examined data for 217 [cancer patients](#) (67.3 percent female; 21.7 percent black; 6.0 percent Hispanic). Patients attended day-long sessions during which they observed educational presentations and participated in small-group discussions prior to completing three surveys. Survey 1 was used as the baseline, survey 2a was given immediately following the first small-group discussion, survey 2b was given after the second group discussion, and survey 3 was given one month after the all-day session.

The researchers found that if the purpose was to ensure patients were receiving the level of care recommended by their doctors, the percentage of participants who felt comfortable with having their deidentified medical [record](#) data released to [insurance companies](#) was 79.5 percent at baseline and 72.3 percent after the discussion. If the purpose was to determine insurance coverage or reimbursement eligibility, 50.9 percent at baseline and 24.9 percent after discussion were comfortable releasing their records. The majority of participants believed it was important that doctors ask patients at least once whether researchers can use their deidentified medical record data for future research (82.2 percent at baseline, 68.7 percent immediately after discussion, and 73.1 percent at follow-up).

"Many patients indicated they fully intended to allow for their data to be used, but they wanted the respect of being told and having the chance to say no," Jagsi said in a statement. "Programs trying to facilitate use of data collected in routine patient care encounters for other purposes—even highly worthy ones like improving the quality of care

and research—need to be mindful of transparency and clarity in the communication of their goals and activities so patients don't feel violated when they find out how their data was used."

More information: [Abstract/Full Text \(subscription or payment may be required\)](#)

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