

Embarrassing illnesses no bar to information sharing

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People with potentially 'stigmatizing' medical conditions are just as likely as those with less stigmatizing illnesses to allow their personal information to be used for health research. A new study, published in the open access journal *BMC Medical Ethics*, found that the purpose of the research and the type of information to be collected were more important in determining patients' consent choices. In particular, they were very wary of allowing their personal information to be put to commercial use.

Donald Willison, Senior Scientist with the Ontario Agency for Health Protection and Promotion, Canada, led a team of researchers who surveyed 1137 people who either had potentially stigmatizing conditions (HIV, alcoholism, [chronic depression](#) or [lung cancer](#)) or lower-stigma conditions ([hypertension](#), [breast cancer](#) or diabetes), as well as a reference group of healthy people. They presented the subjects with a series of situations and asked them to indicate how much control they would want over the use of their [personal information](#) in each case.

According to Willison, "Across scenarios, consent choice profiles were very similar for all health conditions. They were also very similar to the profile of the reference group. These findings surprised us. It may be that, across health conditions, those who were more privacy-sensitive were less inclined to participate in the study, or it may just be that, where people believe that their information will be put to constructive use, people are equally willing to allow their information to be used, regardless of their health condition."

The researchers found people wanted more control in research scenarios involving profit or those that linked health information with income, education, or occupation. Focus groups were held with some of the respondents where they were asked to explain their choices. One participant from the HIV group said,

"I think the simple answer is that physical tissue sample is just a piece of what you are, what you might be...where the rest of the information [education, income, and employment] is more of who you are. People are more afraid of the revelation of who you are than what you are."

Speaking about the results, Willison said, "Individuals should be offered some choice in use of their information for different types of health research. In some cases, like population health research, that may be limited to selectively opting-out of research projects. In other cases, like linkage of biological samples with one's health information, the process would likely continue to require an opting in, perhaps through a broad consent for a range of uses. Just what choices would be offered would have to be determined through further engagement with the public and other stakeholders. Many questions remain, including how best to capture the opinions of those who are more privacy sensitive."

More information: Consent for use of personal information for health research: Do people with potentially stigmatizing [health conditions](#) and the general public differ in their opinions? Donald J Willison, Valerie Steeves, Cathy Charles, Lisa Schwartz, Jennifer Ranford, Gina Agarwal, Ji Cheng and Lehana Thabane, *BMC Medical Ethics* (in press), www.biomedcentral.com/bmcmedethics/

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