Opt-in approach best for donating biospecimens

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Cancer patients consenting to donate their removed tumour tissue following surgery, considered the act 'no big deal' when compared to dealing with the diagnosis of cancer, a recent study has found.

St John of God Subiaco Hospital Research Network Director Adjunct Professor Nikolajs Zeps introduced an 'opt-in' approach model to a small cohort of 18 patients having tumour tissue removed during surgery for colorectal cancer in the last 12 months.

"For use of biospecimens opt-in consent is a far safer and more engaging way to do it and it avoids potential complaints about using a person's DNA without their permission," Prof Zeps says.

He says the difficulty with an opt-out situation is that it is not evidence of anything and a person may not have been aware there was a choice.

"If a specimen is analysed and converted to data, then this can be stored for a long time as although the specimen may be completely consumed, the data remains."

Chair of Health Research at Murdoch University Professor Anne Williams, who ran the study, says it is ethically, legally and morally important to ensure that people agree to their tissue being used for research purposes.

More than 80 per cent of patients were not fussed about donating

"We wanted to see if an opt-in approach was acceptable and whether patients felt empowered by being able to tick the box for 'Yes' I want to donate, before they had their surgery," she says.

"Patients said that they knew how important it was to help others through the donation of surgical tissue, but that at the time they were asked for consent, over 80 per cent indicated it was not considered to be a big deal compared to dealing with the diagnosis of cancer."

Prof Zeps says there is a lot of debate about the timing of asking for consent and who should do it and when.

"Our research has debunked both of these assumptions showing that patients want their doctors to do the consent and that there is no such time as a good time and during routine processes is no worse than any other time," Prof Zeps says.

Prof Zeps says the study has assisted in refining the processes further and providing evidence to regulators and ethics committees that it is acceptable to use a more straightforward amount of information in the first place.

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