

Study finds patients give 'broad endorsement' to stem cell research

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In an early indication of lay opinions on research with induced pluripotent stem cells (iPSCs), which are stem cells made from skin or other tissues, a new study by bioethicists at Johns Hopkins University indicates that despite some ethical concerns, patients give the research "broad endorsement".

During focus group discussions patients were largely in favor of participating in iPSC research even if personal benefit was unlikely, though they raised concerns about consent, privacy and transparency when considering donating tissue for this research. The bioethicists report their findings in the journal *Cell Stem Cell*.

"Bioethicists, as well as stem cell researchers and policy-makers, have discussed the ethical issues of induced [pluripotent stem cells](#) at length, but we didn't have any systematic information about what patients think about these issues, and that is a huge part of the equation if the potential of this research is to be fully realized," says Jeremy Sugarman, the senior author of the report and the Harvey M. Meyerhoff Professor of Bioethics and Medicine at the Johns Hopkins Berman Institute of Bioethics.

Unlike human [embryonic stem cells](#), iPSCs are derived without destroying a human embryo. Research with human iPSCs is valuable for developing new drugs, studying disease, and perhaps developing medical treatments. Sugarman explains that, while far off, scientists are hopeful that iPSCs could someday be used to develop organs for transplantation that the body's immune system will not attack, because they can be created from the person's own cells.

The study reveals the importance of prior informed consent for those asked to participate in it. According to the report, consent was highly important for patients in all five of the focus groups that were convened. Some patients even

suggested that proper informed consent could compensate for other concerns they had about privacy, the "immortalization" of cells, and the commercialization of [stem cells](#).

There was a "strong desire among participants to have full disclosure of the anticipated uses," the report notes, with some participants wanting to be able to veto certain uses of their cells. The authors acknowledge the "practical difficulties" of this request but hope that their findings will "prompt investigation into creative approaches to meeting these desires."

The study also revealed another side to some patients' selfless motivations to participate in research as they might relate to eventual commercialization. The report quotes one participant as saying, "It won't be just taken to become a money maker and the very people who need it the most will no longer be able to benefit from it" and another, "...it was a donation. It's a humanitarian effort."

The authors also note that the unique characteristics of their small study could have influenced the results; for instance, the fact that it was conducted in Baltimore, Maryland, among patients who have received care at Johns Hopkins, where the first immortal cell line was created from tumor cells taken from Henrietta Lacks, put related issues at the forefront of many focus groups. "The idea that donated cells would potentially live forever was unnerving to some participants. In particular, the story about the creation of the HeLa cell line from Henrietta Lacks' cervical cancer tissue, taken without consent, was raised in four out of the five focus groups," the report states.

Additionally, the report indicates that the opinions that were expressed by patients may be influenced by their health, and whether or not they have personal experience with a debilitating illness, as some of the participants did.

"It seems fair to say that everyone experiences serious illness in their lives, whether themselves or through someone they know and care about, and this influences their opinions of healthcare and research," Sugarman says. "This study is a first step in getting crucial information about what values are factored into a decision to participate in iPSC research, and what those participants expect from the experience."

More information: [www.cell.com/cell-stem-cell/fulltext/S0092-9600\(13\)00555-9](http://www.cell.com/cell-stem-cell/fulltext/S0092-9600(13)00555-9)

Provided by Johns Hopkins University School of Medicine

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