Commentary calls for greater transparency in highlighting social value of research

May 1 2013

In a commentary published in the May issue of *Mayo Clinic Proceedings*, UC Davis bioethicist Mark Yarborough proposes that more information about the social value of individual research studies be made available to prospective research participants during the informed consent process so they are more aware of the degree to which a study has the potential to improve health for all.

"Clinical research as a whole drives important, even lifesaving, drug discoveries," said Yarborough. "But not all clinical trials are created equal, and our current regulatory practices don't provide participants with sufficient information to assess choices about volunteering for clinical trials."

As an example, Yarborough compares research with a high social value, such as the use of stem cells to improve quality of life for Huntington's disease patients, with "me too" drug studies, which have less social value as they are conducted to obtain data that allows a new drug to compete in the health-care marketplace even though existing effective and often cheaper therapeutics are already available.

While the stem cell study holds promise as a novel and effective therapy for affected individuals worldwide, the drug study may lead to a more expensive drug than existing drugs already on the market, which can result in higher co-pays and higher insurance premiums. In this scenario, Yarborough said patients have not improved their health but have worsened their financial well being. He asks, how many patients would

want to volunteer for a study that helps a drug company do this?

Yarborough believes it is possible to improve the informed consent process so that it includes a clear declaration about whether a clinical trial is investigating a way to potentially improve current medical care and explains why it does—or does not—have the potential to achieve this outcome.

"We owe the public honest disclosure about why any given trial is being conducted so that potential volunteers understand the extent to which a trial, if completed, could promote the common good," Yarborough said. "The informed consent process is one way to give prospective research participants greater awareness of unimportant, important and very important research conducted within an institution."

Yarborough hopes his commentary generates discussion and ultimately consensus in the scientific community about the best ways to increase transparency in research to help build public trust.

More information: The commentary "Increasing enrollment in drug trials: The need for greater transparency about the social value of research in recruitment efforts," is available online at dx.doi.org/10.1016/j.mayocp.2013.03.001

Provided by UC Davis