Building trust for online health research

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Bioethicists call for collaborative consent to ensure ethical practices while leveraging the Web's research potential

Status updates, patient forums, blog comments – among the incredible amount of personal information on the Web is a potential trove of health data. Bioethicists writing in *Science Translational Medicine* acknowledge the value of this resource but argue that to be ethically acceptable for use in research, traditional models of informed consent must be adapted to suit the dynamic online environment.

"Context is crucial to what people reveal about themselves on the Web, and it should be central to how informed consent is obtained," says co-author Jeffrey Kahn, PhD, MPH, the Levi Professor of Bioethics and Public Policy at the Johns Hopkins Berman Institute of Bioethics. "The Web is inherently interactive, and that can be used in innovative ways to create a collaborative consent process that will build trust, a key element in making Web-based research more useful, more user-friendly and ultimately more respectful of the rights and interests of individuals whose information is collected," Kahn says.

In the essay, titled "Caught in the Web: Informed Consent for Online Health Research," Kahn and his co-authors argue that traditional approaches to informed consent for research do not translate effectively to research taking place in the online environment. Likewise, they say typical consent agreements found on the Web are opt-in or opt-out models used in consumer contexts, which do not meet the ethical standards for informed consent in research.

Kahn offers the scenario of a researcher collecting information openly shared on Facebook or a patient community forum, removing individuals' names, and using that data in a study; did users who posted online give consent for such research use of their information? "The central ethical question is whether a person sharing information online in a non-research context has consented to research use of that information, and the answer is 'no'," Kahn says. "The Web should not be turned into the Wild West of health research; rather, its unique features must be used to effectively and creatively satisfy the ethical requirements of the research consent process," he adds.

"At a minimum, transparent disclosure of the research uses of online personal data is required," write Kahn and his co-authors, Effy Vayena, PhD, senior fellow at the Institute of Biomedical Ethics, University of Zurich, and Anna Mastroianni, JD, MPH, professor in the School of Law and Institute for Public Health Genetics, University of Washington.

The authors note a recent controversial proposal in the European Union on the processing and 'free movement' of data beyond the original context and intention of

the Web user. The proposal includes a digital "right to be forgotten," requiring that users have the option to permanently delete personal data from the Web.

"We want Web-based research to move forward, because it offers unprecedented depth and breadth of information, with potential applications to health research that will improve our understanding across a wide range of areas as we enter the age of Big Data," Kahn says. "Giving users more control in a more robust and transparent consent process will build trust, which is crucial to all research, whether online or not."

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