

Examining the ethical landscape and user expectations of mobile oncology trial recruitment applications

May 14 2019

Healthcare mobile applications (apps) have been growing in prevalence in recent years, with the promise of tracking things such as diet, fitness levels and sleep cycles in order to improve our health. Another way in which healthcare apps are being used is in the oncology trial recruitment space, a tactic that raises many ethical red flags. In a new study in the *Journal of the National Cancer Institute*, Baylor College of Medicine ethics scholar Dr. Stephanie Morain explores this phenomenon and what these app companies and consumers need to consider in terms of privacy and data protection.

Recruiting patients into oncology [clinical trials](#) can be difficult and costly, and many digital health startups and other stakeholders believe that [mobile apps](#) can help improve enrollment rates.

"With the landscape for these apps expected to expand, there is an increasingly urgent need to develop guidelines for the platforms and criteria for messaging, consent and expectations," said Morain, assistant professor in the Center for Medical Ethics and Health Policy at Baylor.

Morain and collaborators examine several key ethical issues with this model in the paper: recruitment materials, user privacy and confidentiality, conflicts of interest, misbranding of research as treatment, payment for accessing research information, and interruptions to care and research.

"There is a critical need to improve recruitment to cancer trials. While apps offer potential, they also present new challenges," Morain said.

"Given that many of the app developers may not have a healthcare or medical background, they may not be familiar with important ethical standards for research. We really need to think about effective ways to ensure ethical standards are preserved in this new space."

Morain explained the importance of ensuring apps appropriately communicate information about their goals as well as privacy protections and the difference between [clinical care](#) and research.

"We need to make sure that participants know what they are agreeing to when they download the app and understand how their data could potentially be used or shared by the developer. Additionally, a clear distinction must be made that enrolling in a clinical trial does not necessarily equate to clinical benefit to the patient. The goal of the trial is not for individual benefit, but to inform [patient care](#) in the future," Morain said.

This paper is laying the groundwork for future studies to design ethically correct apps that help patients navigate consent questions as they enter healthcare systems, Morain said.

"There is a responsibility on the stakeholders, like funding agencies and healthcare institutions, who control the path of these apps. In order to help future patients and users of these recruitment apps and advance their applicability, we need to understand how to present this information to users in an ethical, concise manner," Morain said.

More information: Stephanie R Morain et al. Recruitment and Trial-Finding Apps—Time for Rules of the Road, *JNCI: Journal of the National Cancer Institute* (2019). [DOI: 10.1093/jnci/djz076](https://doi.org/10.1093/jnci/djz076)

Provided by Baylor College of Medicine

Citation: Examining the ethical landscape and user expectations of mobile oncology trial recruitment applications (2019, May 14) retrieved 13 May 2024 from <https://medicalxpress.com/news/2019-05-ethical-landscape-user-mobile-oncology.html>

This document is subject to copyright. Apart from any fair dealing for the purpose of private study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.