New study shows patients need help understanding online test results

December 13 2017

Although patients increasingly use online portals to access their test results, do they really understand what the results mean for their health and what steps they should take next? To help explore this question, researchers from Baylor College of Medicine conducted a study to explore patients' experiences and preferences when accessing their test results delivered to them via online portals. The study appears in the *Journal of the American Medical Informatics Association*.

"We looked at a large sample of patients who received test results through online portals to explore their emotional responses, their understanding of results and what actions they took. This analysis is quite timely because patients currently have unprecedented access to their health information, including their test results, and we must ensure that data is meaningful and useful for them," said lead author Dr. Traber Davis Giardina, assistant professor of medicine and researcher in the Houston VA Center for Innovations in Quality, Effectiveness and Safety (IQuEst).

A surprising result of the study was that about a fourth of participants who received a normal test result experienced negative emotions, such as anxiety, similar to those who received abnormal test results via the portals, explained Giardina.

"Clearly when patients use a portal to check test results, they have feelings of uncertainty even when results are normal," Giardina said. "That may be because the way information is being presented to patients

in portals makes it hard for them to understand the results and how each result relates to their health."

Unsurprisingly, Giardina said that about half of the participants searched online to figure out what their test result meant both in terms of the language and what it meant for their health. Thus, materials that have been vetted by their physician or the healthcare system might provide patients with best resources.

Based on study data, researchers created a framework for practice and policy recommendations that can help guide the way the portals are developed and used.

Their key recommendations are as follows and organized along eight components:

- Hardware and software: Ensure the portal is available on both large-format computers and hand-held devices.
- Clinical content: Provide patients with easy access to high-quality educational websites.
- Human-computer interface: Provide patients with access to an explanation of test results directly from results screen.
- People: Ensure patients have direct, easy-to-access "human" support services.
- Workflow and communication: Provide personalized or contextual information to help patients know what to do in light of the results.
- Internal organizational policies, procedures, and environment: Develop local policies and procedures to create standardized language guiding patients to a specific follow-up contact for any questions. Provide patients with educational content on portal-related support when they are having face-to-face visits.
- External rules and regulations: Create national consensus and

standards on timing and best practices for portal release of normal and abnormal test results to patients.

- Measurement and monitoring: Create mechanisms to evaluate patients' experiences related to test results notification in portals and use this data to help developers improve portal usability and design innovations to promote patient understanding.

"Our prior work shows how delays in follow-up of abnormal test results are common and can lead to patient harm. Providing patients with online access to their test results is a good first step, and now we need some national standards and consensus on best practices to ensure progress," said senior author Dr. Hardeep Singh, chief of the Health Policy, Quality and Informatics Program at the Houston VA's IQuEst and associate professor of medicine at Baylor. "Studies like this help change the norm, and our recommendations offer a starting point for ensuring that patients use online portals successfully."

More information: Traber D Giardina et al. Patient perceptions of receiving test results via online portals: a mixed-methods study, *Journal of the American Medical Informatics Association* (2017). DOI: 10.1093/jamia/ocx140

Provided by Baylor College of Medicine