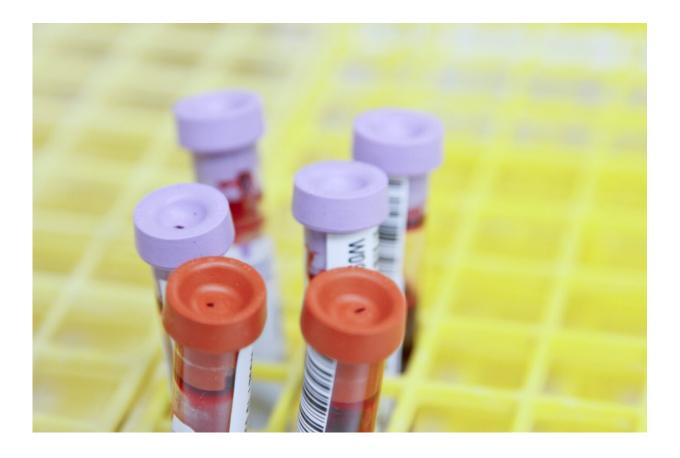


Patients found to overwhelmingly prefer immediate access to test results, even when the news may not be good

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In April 2021, new federal rules went into effect mandating that health care providers make nearly all test results and clinical notes immediately



available to patients. Evidence suggests that patients may gain important clinical benefits by reviewing their medical records, and access through electronic patient portals has been advocated as a strategy for empowering patients to manage their health care and for strengthening patient-clinician relationships. However, concerns remain about the effects of releasing test results to patients before clinicians offer counsel or interpretation.

In a recent multisite survey of more than 8,000 patients who accessed their test results via an online patient portal account, researchers at Beth Israel Deaconess Medical Center (BIDMC) and colleagues found that users overwhelmingly supported receiving the results immediately, even if their provider had not yet reviewed them. The findings, published in *JAMA Network Open*, showed only a small subset of patients reported experiencing additional worry after receiving abnormal test results. In addition, pre-counseling by the health care team before tests were ordered was linked to reduced worry among patients with abnormal results.

"Online patient portals have emerged as important tools for increasing patient engagement," said co-senior author Catherine M. DesRoches, DrPH, executive director of OpenNotes, the international movement based at BIDMC focused on increasing information transparency in health care, and associate professor of medicine at Harvard Medical School.

"They enable patients to access information, participate in medical decision-making and to communicate with clinicians. Prior studies performed by OpenNotes investigators established immediate release of clinical notes as a recommended best practice. However, releasing test results to patients immediately, often before a clinician can provide counseling and context, was yet to be studied widely and remains controversial."



To assess patient and caregiver attitudes and preferences related to receiving test results through the patient portal, DesRoches and colleagues delivered surveys to more than 43,000 patients and care partners who accessed their test results via an online patient portal account between April 2021 and April 2022. The survey was fielded in four geographically diverse medical centers; University of California, Davis Health, University of Colorado Anschutz Medical Center, University of Texas Southwestern Medical Center and Vanderbilt University Medical Center. Adapted from a previously validated instrument, the 29-question survey covered topics including test result information, result review behavior, education and follow-up by providers, the effect of reviewing results on health and well-being, and user preferences for receiving future test results.

Of the 8,139 <u>survey respondents</u>, 80% reported reviewing at least one test result in the past month. Most respondents (57%) reported normal findings. When asked about their preferences for contacts about future test results, 90% of respondents with normal results indicated they would prefer receiving their result via the patient portal. Nearly all respondents, 96%, indicated a preference for receiving results through the patient portal as soon as they are available, even if their provider had not yet reviewed them.

With respect to patients' worry, fewer than 8% reported being more worried after viewing test results. Among respondents who reviewed a result before being contacted by a provider, almost half reported feeling less worried after reviewing their results through the portal. Among those reporting not normal results, most (84%) reported less or no change in their level of worry. However, respondents who viewed not normal results were more likely to report being more worried, or much more worried, than those reporting normal results (17% versus 5%).

The <u>survey results</u> suggest that patients receiving not normal results are



indeed at increased risk for worry. Nevertheless, more than 95% of participants who received abnormal test results reported preferring to continue to receive immediately released results through the portal.

"Respondents overwhelmingly preferred to receive test results through the patient <u>portal</u>, even if it meant viewing results prior to discussing them with a health care professional," said co-author Liz Salmi, communications and patient initiatives director of OpenNotes at BIDMC.

"As health care systems continue to navigate this new era of health information transparency, balancing patients' expectation of immediate access to their information with the need to manage increased worry is important. Additional research is necessary to better understand the nuance of worry from receiving abnormal test results, especially as it relates to revealing information about a newly diagnosed condition such as Huntington's disease or cancer."

More information: Perspectives of Patients About Immediate Access to Test Results Through an Online Patient Portal, *JAMA Network Open* (2023). DOI: 10.1001/jamanetworkopen.2023.3572

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