

Patients reading visit notes report striking benefit over time

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A new study of more than 20,000 adult patients, led by Jan Walker, RN, MBA, co-founder of OpenNotes, found that reading office visit notes offers considerable benefits for patients, particularly those from underserved populations. The study, "OpenNotes After 7 Years: Patient Experiences With Ongoing Access to Their Clinicians' Outpatient Visit Notes" published today in the open access *Journal of Medical Internet Research (JMIR)*, is the first large-scale assessment to date of patients' experiences with a broad range of clinicians working in practices where shared notes are well established.

Among the survey respondents, 98 percent thought online access to visit notes was a good idea. Seventy-three percent of those reading notes rated the practice as very important for helping them take care of their health and feeling more in control, and 66 percent reported it helped them remember their plan of care. Regardless of whether or not they chose to review their notes, 63 percent of respondents rated the availability of notes as very important for choosing a future provider.

"This study is the first to include large numbers of [patients](#) reading notes across medical, surgical, and mental health specialties. These patients may have been reading their notes for several years; the participating institutions implemented OpenNotes across their ambulatory practices by 2014," said Walker, who is a health services researcher in the Division of General Medicine and Primary Care at Beth Israel Deaconess Medical Center (BIDMC) and an Associate Professor of Medicine at Harvard Medical School. "Across three geographically

diverse patient populations and various demographic subgroups, patients told us that the benefits of note reading are widespread."

Moreover, the study showed that those from traditionally underserved groups, including people with lower incomes or who spoke a language other than English at home were most likely to report benefits.

"I have noticed in my own care of patients, and from my prior research, that better preparation for clinical visits empowers a patient to gain greater benefit from the physician interaction," said OpenNotes Advisory Board Member Lisa Cooper, MD, MPH, who is the Bloomberg Distinguished Professor of Medicine at Johns Hopkins. "The OpenNotes approach is a great example of how removing barriers to health knowledge has multiple impacts on the wellbeing of patients, particularly those from vulnerable populations."

The researchers conducted an [online survey](#) between June and October 2017 of patients offered open notes throughout three [health systems](#) that adopted the practice several years ago. Participating health systems were Boston-based BIDMC and its affiliates; Geisinger, a large rural integrated health system in Pennsylvania; and University of Washington (UW) Medicine in Seattle, which includes both private and community-funded safety net practices affiliated with UW.

Focusing on clinically important issues, the report strongly suggests that transparency helps patients feel more engaged in their care. This finding is important given increasing evidence that engaged patients are more likely to adhere to treatment plans and medications, follow through on screening and prevention protocols, detect and prevent errors, and adopt more effective management strategies for chronic illnesses.

"Open notes are such a valuable tool for me," said Stacey Whiteman, who has multiple sclerosis and related health issues. "I appreciate being

able to share my notes because it is hard to explain what I am going through; when I share my open notes it is easier for others to understand my pain and symptoms. Notes have been especially helpful with my family because my illness is hard to understand."

Eligible patients were aged 18 years or older, had logged into the secure patient portal at least once in the previous 12 months, and had at least one ambulatory visit note available in the previous 12 months. The [survey respondents](#) represented urban and rural settings, varied levels of education, and broad age and racial distributions. The main outcome measures included patient-reported behaviors and their perceptions concerning benefits versus risks.

"In the United States today more than 38 million patients can access their clinician notes through secure patient portals. And now we've learned that the benefits persist over time and are true of visits to all kinds of doctors and other clinicians," said study co-author and OpenNotes co-founder Tom Delbanco, MD, MACP of BIDMC and John F. Keane & Family Professor at Harvard Medical School. "This represents a profound culture change in the practice of medicine, and the patients who participated are telling us it is here to stay."

More information: Jan Walker et al, OpenNotes After 7 Years: Patient Experiences With Ongoing Access to Their Clinicians' Outpatient Visit Notes, *Journal of Medical Internet Research* (2019). [DOI: 10.2196/13876](https://doi.org/10.2196/13876)

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