

PL014

FULLY INFORMED DECISION MAKING: PATIENT ACCESS TO THEIR HEALTH CARE DATA

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OpenNotes is an international movement advocating for greater transparency in healthcare. We urge doctors, nurses, therapists, and clinicians to share the notes they write with their patients. The goal of sharing notes is to increase the patients understanding of their care, improve communication, better engagement, bolster safety, and enable the growth of a trusting partnership between clinicians and patients.

The OpenNotes initiative began in 2010 as a year-long pilot project, with 105 primary care physicians at three diverse U.S. healthcare centers inviting 20,000 patients to read notes online through patient portals. Findings from the study suggest that shared notes improve communication, safety, patient-doctor relationships, and may help patients become more actively involved in their health and healthcare. Further research suggests that giving patients access to their notes results in safer care, more accurate records, and increased trust between patients and clinicians. And, while clinicians worry that sharing notes with patients will increase their workload, disrupt workflow, cause patients to worry or become confused or upset by what they read, research suggests that these worries are unfounded.

OpenNotes is challenging assumptions regarding user populations. Contrary to predictions that note-sharing would be a benefit primarily to tech-savvy patients, interest appears widespread (about 80% of patients in the OpenNotes trial read at least one note). Non-Caucasian patients, those speaking a primary language other than English, or having a lower level of formal education are equally or more likely to report benefits from reading their notes.

Today, more than 27 million patients in the United States have easy access to their clinicians notes through online patient portals. Relatively simple and scalable, OpenNotes is sending a powerful message about how organizational transparency and inclusivity can empower patients and doctors and improve the delivery of healthcare.