OpenNotes: Everyone on the Same Page

Enabling patients and healthcare providers to communicate fully and openly is essential for quality healthcare. Research indicates that inviting patients to review their medical and mental health visit notes can play a vital role in promoting trust and shared decision making. However, doctors and other providers have, by longstanding tradition, kept these notes to themselves. Over the past 10 years, through education, research and advocacy, the *OpenNotes* movement has had a remarkable impact on building fully transparent communication into care. The Covid-19 pandemic, the rise of telemedicine, and new federal legislation mandating that patients be offered ready electronic access to all their medical information make our efforts even more important. We need additional funding to make that work possible.

Leading the Charge

Based at Beth Israel Deaconess Medical Center and Harvard Medical School in Boston, the *OpenNotes* movement is recognized internationally as the pre-eminent force behind building fully transparent communication into care. Our primary focus has been on making healthcare providers and patients aware of the importance of sharing all medical information, especially office or telemedicine visit notes, and studying the effects of this fundamentally new practice.

Ideally, visit notes both tell the patient's story and describe the patient's and clinician's assessments and plans. What medications were reviewed and prescribed, and why? What tests and referrals were recommended, and why? What steps for self-care are important, and why? What is the overall plan of care? When offered and shared as "open notes," they become the connection to which patients, care partners, and clinicians can turn.

However, despite the fact that many electronic medical records have the capacity to share visit notes, the majority of doctors and other clinicians still do not to offer their patients open notes, and most patients do not recognize their value. These hidden notes represent a lost opportunity to develop more complete transparency and build better patient-provider relationships.

What difference can open notes make? Liz Salmi, a patient advocate living with a malignant brain tumor, offers an example:

> I was diagnosed with a brain tumor in my late 20's, a diagnosis for which I was totally unprepared. The hardest part was remembering important conversations with my doctor. My earliest appointments were equal parts scary and confusing. Suddenly, I had been thrust into a world for which I was not prepared, and no one in my life understood medicalese.
>
> I brought a notebook to my medical appointments, but it was hard to take notes when I was scared and crying, or faking bravery so that my doctor wouldn't be made uncomfortable by my tears.
>
> Five years after my treatment ended, I received a copy of my medical record, and it included all of my visit notes. I had had no idea my medical team had taken notes the entire time they were caring for me, and reading them was eye-opening. I always had so many questions, but no clue all along that these notes had most of the answers. If only I had seen my notes sooner…

Surveys involving thousands of patients who read visit notes reveal that:

→ More than 70% report both a greater sense of control over their health and improved recall of their plans of care;

→ Two thirds report more understanding of their medications, and more than 1 in 6 report improving their adherence to their medications;

→ More than 20% report detecting errors that may affect the safety and diagnostic accuracy of their care. Moreover, 26% of doctors report that their patients find errors that the doctors consider important;

→ Two out of 5 report sharing their notes with others, most frequently with their family care partners;

→ More than 95% report understanding their notes with little difficulty;

→ More than 95% of patients with access to notes want the practice to continue, whether or not they choose to read them.
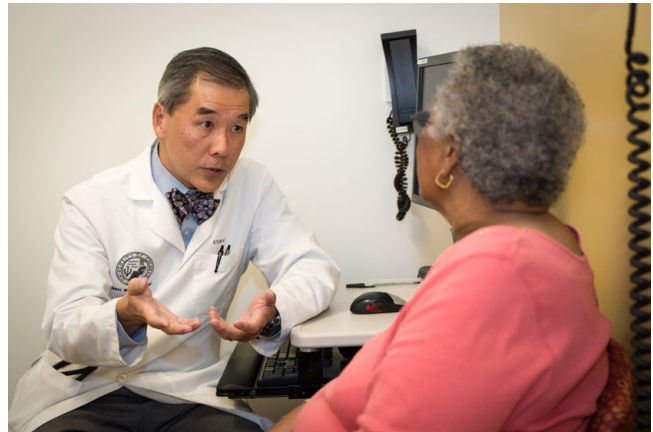
Perhaps surprisingly, those patients most at risk for poor healthcare report the greatest benefits from reading notes. These include people who identify as racial or ethnic minorities, individuals with limited formal education, patients for whom English is a second language, and those with the fewest financial resources.

How do doctors experience open notes? Many have apprehensions. They worry that patients will disturb their workflow with questions, unnecessary worries, and requests for corrections. They fear they will need to "dumb down" their notes, at times leaving out important diagnostic considerations. They expect their patients with mental illness may be damaged by what they read.

However, once they have adopted the practice, doctors find their fears are largely unrealized. Fewer than 5% of patients report being worried or confused by reviewing open notes, and the doctor's workflow is rarely disturbed. In a recent survey of more than 1500 doctors, nurses, physician assistants and psychotherapists working in systems offering open notes, 74% supported their use, and 61% would recommend the new practice to colleagues.

As one primary care doctor noted:

> I do think that education is one of the best tools we have. Notes can help patients understand the reasons why they should take and adhere to their medicines…and how that can have a huge impact on how they're doing.

OurNotes

OpenNotes is now exploring a next step in open communication and shared decision-making. We are asking clinicians and patients to create notes together. We call these "*OurNotes*."

In pilot studies in 4 sites across the country, doctors invited patients to provide a brief between-visit history and to articulate their goals for their upcoming appointment. These submissions become part of their records. Clinicians review them prior to or during visits, and then either refer to them or incorporate them into the visit note itself.

Early reports from both patients and doctors are positive, and this practice also appears particularly promising for telemedicine visits. Patients are additionally doing some of the "pre-work" typically performed by medical assistants prior to face to face visits. They update the medications they are taking, indicate which need to be refilled and, if feasible, measure and submit their weight, temperature, blood pressure, and even their blood sugar or oxygen saturation if indicated.

The sites that initially piloted *OurNotes* (Beth Israel Deaconess Medical Center, the Dartmouth-Hitchcock Clinic, U. Colorado Medicine, and U Washington Medicine) are now expanding this practice. And in April, 2020, Sanford Health, the large, primarily rural health system spanning several midwestern states, decided to offer *OurNotes* to 750,000 patients preparing for telehealth or in-person visits.

Ingredients for Success

The *OpenNotes* approach advances patient, family and clinician involvement by creating partnerships among healthcare delivery systems, clinicians, patients, care partners and emerging technologies. Thanks to our efforts over the past decade, 50 million patients in the US have gained access to their electronic visit notes. Our work targets a wide range of clinical settings, types of patients, organizational constraints and electronic health record (EHR) vendors. Our teams offer educational and implementation resources to patients, clinicians and health systems at no extra charge. We advise both public and private organizations.

Serving as a resource to both lay and professional audiences, the prize-winning *OpenNotes* website (www.opennotes.org) houses a wealth of articles and toolkits designed for patients, their care partners and health professionals.

Additional educational initiatives include newsletters, webinars and addresses at major conferences and meetings. Active use of social media spreads both the *OpenNotes* mission and specific techniques for implementing and refining the practice.

Finally, *OpenNotes* conducts research into the effects of transparent communication. More than
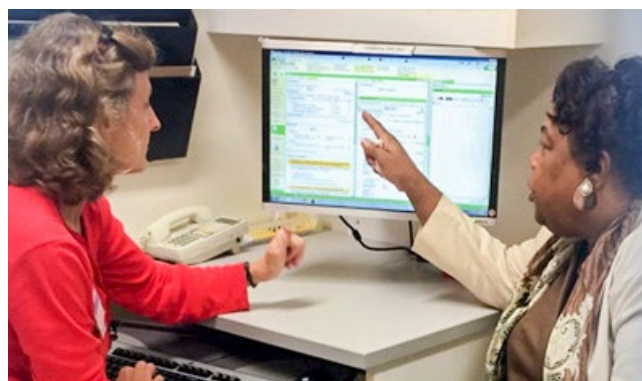
85 articles by the *OpenNotes* team published in major medical journals have gained widespread attention in print and social media.

Executive Director Cait DesRoches, DrPH, and its two founders, Tom Delbanco, MD, MACP, and Jan Walker, RN, MBA, lead *OpenNotes*. Each is a senior faculty member at Harvard Medical School and widely recognized as a change agent (see page 8). Overall, *OpenNotes* currently includes 7 Harvard faculty and 8 staff located in Massachusetts, California, Louisiana, Oregon, and Sweden. They include clinicians, researchers, consumer advocates, social scientists and health information technologists.

The Future

Many celebrate *OpenNotes* achievements, but if our goal is to truly embed the benefits of fully open communication into practice, we are just beginning. Effective adoption has been sporadic. Despite upcoming regulations, resistance to meaningful implementation will likely persist, and it may even grow. Past experience shows the difficulties associated with building fundamental change into medical practice.

The new regulations need to be accompanied by a broad campaign that results in effective implementation. The "how to" is by no means simple. Site by site, it is affected by leadership, by behavior patterns among health professionals, by patient populations served, by resources available, and by different types of electronic records. But *OpenNotes* is uniquely qualified and positioned to

stimulate, assist, and evaluate efforts to implant the new practice. And as we detail on page 6, we will do this through a diverse set of initiatives, each targeting clearly defined needs.

Financial Support for *OpenNotes*

Not only is health care under enormous stress, but *OpenNotes* is also at a critical juncture in its evolution, both programmatic and financial. For its first decade, the principal source of funding was generous support from an unusual consortium formed by the Robert Wood Johnson Foundation, the Gordon & Betty Moore Foundation, the Peterson Center on Healthcare, and the Cambia Foundation. Their mandate was for *OpenNotes* to reach an ambitious goal: spread access to open notes to 50 million Americans. In 2019-20 with this goal attained, their support ended.

Several other philanthropies have contributed to our efforts, and we have also received individual donations, many targeting specific elements of our work (see page 8). Currently, we have private and federal grants for projects addressing care partners, adolescents, patients with mental illness, minority patient populations, patients nearing the end of life, and patient safety.

OpenNotes is aggressively exploring a range of revenue-generating models, including memberships, speaking fees, consultancy and crowd-sourced donations. While these avenues
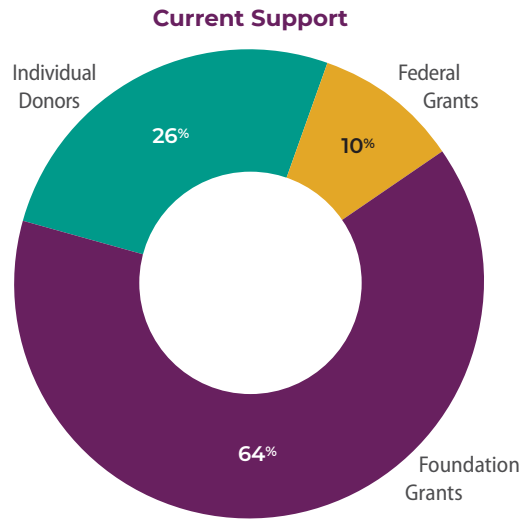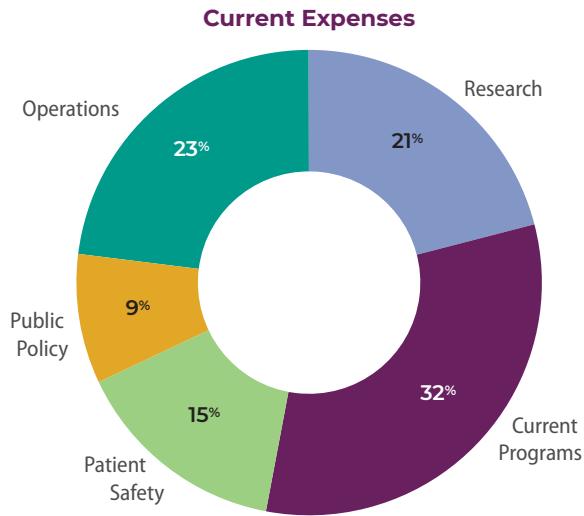
are promising, the near-term potential for substantial revenues from such efforts is limited.

We strongly believe we must retain our financial independence from commercial interests and preserve our reputation as an "honest broker," free from all potential conflicts of interest. We are therefore pursuing new philanthropic support for our next major efforts: *OpenNotes* is seeking $5 million to maintain and expand its groundbreaking work over the next 5 years.
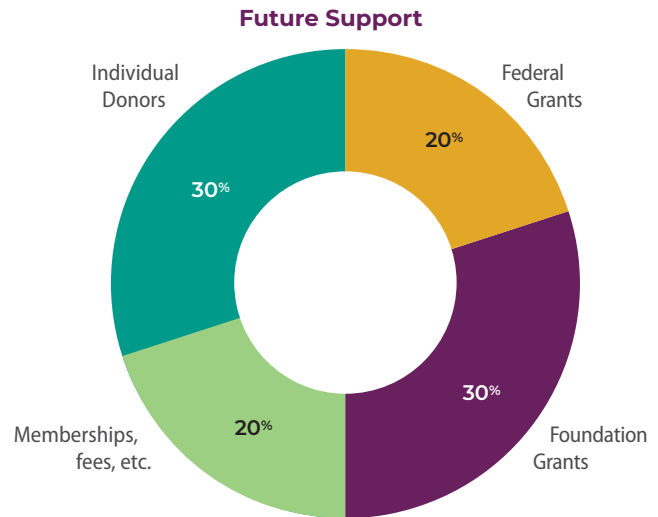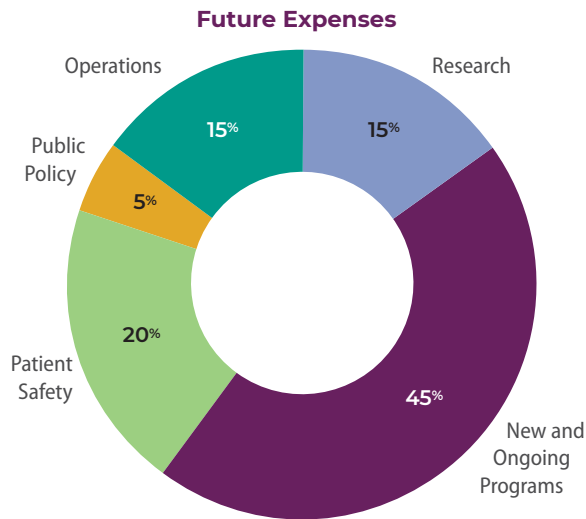
At a time of extraordinary societal stress, we are convinced that building open notes into care will improve its quality, its safety and its overall value. *OpenNotes* is uniquely equipped to lead the charge toward full transparency in healthcare. We are the only not for profit organization dedicated to this mission. We are not afraid to challenge long-standing medical traditions. We have already had striking success in promoting a new culture of open communication and partnership between clinicians and patients. We plan now to build this as a new standard of care. We believe the benefits of our work will be transformative, improve healthcare, and in some cases, save lives.

Current and Future Financials

Current Expenses and Support

Current Expenses

Operations 23%
Research 21%
Public Policy 9%
Patient Safety 15%
Current Programs 32%

Current Support

Individual Donors 26%
Federal Grants 10%
Foundation Grants 64%

Future Support and Expenses

Future Expenses

Operations 15%
Research 15%
Public Policy 5%
Patient Safety 20%
New and Ongoing Programs 45%

Future Support

Individual Donors 30%
Federal Grants 20%
Memberships, fees, etc. 20%
Foundation Grants 30%

New Initiatives

OpenNotes Best Practices

OpenNotes will collaborate with up to 10 *high performing healthcare organizations* that agree to explore, mount, and then share how they created exemplary implementations of fully shared medical records. We will select geographically dispersed organizations serving diverse patient populations and using a variety of electronic health record systems. Forming a collaborative that *OpenNotes* will coordinate, the systems will work together to document and disseminate their achievements and consult informally with other institutions.

OpenNotes Patient Safety

To mobilize patients in making care safer, *OpenNotes* will work with several organizations to design and test new processes for *reporting and correcting patient-identified mistakes*. We will include strategies for improving diagnostic accuracy and for using notes to improve patient safety between visits, such as inviting patients and care partners to report on missed test results and incomplete referrals for specialty consultations or other investigations.

OpenNotes Learning Collaboratives

Collaboratives can generate experimentation, learning and processes that prove relevant well beyond the group itself. *OpenNotes* will develop a collaborative focusing on *patients traditionally underserved by healthcare organizations*. It will work to give patients with limited English language proficiency or health literacy effective access to notes; to build trusting relationships between clinicians and patients who have historic reasons for mistrust; and to develop ways to bring open communication to those patients without online access to computerized records.

We plan also to form collaboratives that address particular challenges for open notes, including the care of adolescents, care at the end of life, mental illness, and cancer.

Each will include patients and family members, as well as clinicians and other organizational representatives. *OpenNotes* will convene and support these groups, will lead development of "best practices toolkits" and other resources reflecting the groups' experiences, and will disseminate their work products broadly.

OpenNotes Scorecard and Recognition

Working closely with governmental and other national organizations, *OpenNotes* will develop a measurement *system* designed to become a publicly reported *national OpenNotes Scorecard*. Designed to stimulate competition and encourage widespread adoption, the Scorecard will assess progress toward integrating transparency into clinical practice. Measurements will include patient/family and clinician education, technology enhancements, and implementation across all outpatient clinical services.

Closely related to this effort, *OpenNotes* will build a recognition program that identifies and celebrates systems and organizations mounting *outstanding open notes practices*.

OpenNotes supporting care partners

The vital role played by family members and other care partners who support sick patients is gaining far wider recognition. So too are the stresses associated with performing caregiving tasks effectively, and these have been heightened enormously by the current pandemic. *Inviting care partners to read their family member's open notes* can benefit patients, care partners and clinicians. But electronic health records rarely facilitate secure and appropriate care partner access to medical records. Many institutions do not provide such access at all.

OpenNotes is already working on a series of innovations designed to support care partners, and in the future we plan to broaden our work in this area with delivery systems, local and national patient and family advisory councils, and electronic health record vendors at the leading edge of such efforts.

Developing and monitoring public policies

OpenNotes recognizes the importance of public policy in spreading transparency. New technologies continue to outpace policy changes, and patients' need both for information and privacy safeguards could easily become afterthoughts. *OpenNotes* has no financial conflicts of interest, and we are asked often to *take an active role in the public policy arena*. Extending our relationships with providers, patients, industry, policymakers, and others, we shall act as a neutral convener to develop effective policies and tools and monitor their effects.

Comments from Patients

Below are patient quotes from diverse settings, including several safety net hospital clinics.

Weeks after my visit, I thought, "Wasn't I supposed to look into something?" I went online immediately. Good thing! It was a precancerous skin lesion my doctor wanted removed (I did).

———————————

In his notes, the doctor called me "mildly obese." This prompted immediate enrollment in Weight Watchers and daily exercise. I didn't think I had gained that much weight. I'm determined to reverse that comment by my next check-up.

———————————

I read your "Open Notes" in preparation for my check-up next week, and I'm quite sure nothing has changed, with the exception that I gained back 4 pounds (which I'm working hard to lose now!). Honestly, I think you could "cut and paste" from last time. I'm feeling fine, still working out, still mysteriously cycling each month (not on the bike path), rash is still gone, etc. Shall I reschedule for 3-6 months, or do you still want me to come in anyway?

———————————

It really is much easier to show my family who are also my caregivers the information in the notes than to try and explain myself. I find the notes more accurate than my recollections, and they allow my family to understand what is actually going on with my health, not just what my memory decides to store.

Sometimes I forget what is said to me because it is emotional, and it is so nice to be able to go back and read exactly what my doctor was telling me.

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This service is very helpful. I really like the fact that my children can also read my doctors' notes. I really appreciate you have a navigator translating them into Spanish. Cool!

———————————

As time passes, questions arise as to whether you are following the doctor's recommendations. Referring to the notes get you back on track, remind me to get tests done before next appointment and avoid having to call the office for any questions I may have.

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Having OpenNotes has changed my relationship with all my providers in a positive way. It has made me more open to talking with providers. I feel like I can trust what the providers are saying, but also that my providers trust and listen to what I am saying.

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I want to be a partner. I want to be on board with my health. I don't want to be in the dark. I don't want the doctors to have access to things I don't. I want to know.

Leadership Biographies

Catherine DesRoches, DrPH, Executive Director, *OpenNotes*

Cait DesRoches is Associate Professor of Medicine at HMS and a distinguished health services researcher with expertise in emerging trends in health care delivery. In 2017 she came to lead *OpenNotes* from Mathematica Policy Research, a national firm with extensive expertise in social policy research. She served there as Senior Fellow studying the use of electronic health records by hospitals and physicians, the effect of healthcare organizations on physician clinical practice, physician capacity to provide coordinated patient-centered care, and primary care workforce issues. Dr. DesRoches has extensive experience in leading and managing interdisciplinary research aimed at improving health system performance and quality of care. A graduate of the University of Massachusetts, School of Public Health, and the Joseph P. Mailman School of Public Health at Columbia University where she received her doctorate, Dr. DesRoches has worked at the Harvard T.H. Chan School of Public Health, and has held faculty positions at Vanderbilt University, Simmons College of Social Work and HMS. Much of her work has focused on electronic health record adoption and organizational change.

Tom Delbanco MD, MACP, Co-Founder, *OpenNotes*

Tom Delbanco is the John F. Keane & Family Professor of Medicine at Harvard Medical School (HMS). Educated at Harvard College and the Columbia College of Physicians and Surgeons, he completed his residency training in internal medicine in NYC. In Boston, Dr. Delbanco created one of the first primary care practice and teaching programs at an academic health center, founding the Division of General Medicine at Beth Israel Deaconess Center that he led for over 30 years. He developed the HMS General Medicine Faculty Development and Fellowship Program that has trained more than 300 physicians for research careers. Dr. Delbanco co-founded and subsequently was elected President of the Society of General Internal Medicine (SGIM). He developed the Picker Institutes and *Clinical Crossroads*, a series published for 18 years in the Journal of the American Medical Association. He has led four Salzburg Global Seminars, authored more than 200 scholarly papers, and co-edited four books. In 2009, Dr. Delbanco and Jan Walker founded *OpenNotes*. In 2020, the American College of Physicians awarded Dr. Delbanco its highest annual honor, the John Phillips Memorial Award.

Jan Walker, RN, MBA, Co-Founder, *OpenNotes*

Jan Walker is Associate Professor of Medicine at HMS. Her primary research interests are in patients' perspectives on care, the use of information technologies to improve their experience, and strategies to reorganize and improve primary care practice. Ms Walker formerly served as Vice President for Client Services and Research at the Picker Institute, an organization devoted to measuring patient experiences and incorporating the patient perspective into care. She was the founding Executive Director of the Center for Information Technology Leadership at Partners HealthCare, and also directed the national program evaluation for the Albert Schweitzer Fellowship. Educated at the University of Kansas (BSN) and Boston University (MBA), she has a clinical background in nursing. Her publications have focused on patient perspectives on hospital care, interoperability among critical elements of the health system, and patient insights into new electronic technologies. In 2009, Ms Walker and Dr. Delbanco founded *OpenNotes*.

Funders

Agency for Healthcare Research and Quality

Cambia Health Foundation

Candace and Howard Wolk

Carol Hillman

CRICO Strategies

Drane Family Fund

Florence and Richard Koplow Charitable Foundation

Gordon and Betty Moore Foundation

James A. Guest

John A. Hartford Foundation

Judith A. and Lionel P. Fortin

Keane Family Foundation

Leslie and Bruce Male Foundation

New York State Health Foundation

Peter Mosheim

Peterson Center on Healthcare

Shah Family Foundation

Blue Cross Blue Shield Association

The Commonwealth Fund

The Linde Family Innovation Grants Program in Primary Care

The Robert Wood Johnson Foundation

The Wang Foundation

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