Patient and Family Advisory Council (PFAC) Toolkit

This toolkit is for PFAC members interested in bringing OpenNotes to the patients, families and clinicians in their health system.

PFACs lead the way in change

As a patient and family advisor, you clearly know what it means to be activated and engaged. Patient and family advisors and activists have always been leaders in speaking up about the need for more transparency in health care and for a partnership with clinicians in managing their care and the care of their loved ones. OpenNotes is one important step in making fully transparent care a reality.

OpenNotes is a national movement encouraging doctors, nurses, therapists, and other health care professionals to share the visit notes they write with the patients they care for.

The visit notes are more detailed than the after visit summaries patients may already receive and are part of the medical record. HIPAA provides patients with the legal right to access notes, but until recently the only option was to go through a sometimes arduous, lengthy, and costly process to obtain records. OpenNotes started in response to the desire for patients and family members to be able to easily access their full medical records including visit notes.

> "OpenNotes allows my doctors and me to be on the same page about what we discussed and how we should proceed, as well as to sort out any inconsistencies. Our family also found OpenNotes invaluable when a member became incapable of managing her own health care and information needed to be shared among multiple caregivers. I can't imagine going back to "the old days."
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> — *NAOMI PRICE, PATIENT ADVOCATE AND CONSUMER REPRESENTATIVE, NORTHWEST OPENNOTES CONSORTIUM*

To read the complete list of health care systems that share visit notes, visit opennotes.org/join-the-movement.

Patients like OpenNotes

In the 2010 OpenNotes study, 99% of patients wanted OpenNotes to continue and 85% said the availability of OpenNotes would affect their future choice of provider. Why?

- **Reading notes helps patients remember what was discussed** during the health care visit and follow up with next steps.

- Patients can **share information with care partners and caregivers**, which is especially helpful for those who are most vulnerable and those who may need help managing their care.

- Patients with access to their notes are **better at taking their medications as prescribed**.

- **Patients are able to catch errors** in their medical records, ensuring accuracy and possibly preventing further mistakes from occurring.

- Patients are able to **prepare for future visits** by re-reading previous visit notes and writing down questions.
- OpenNotes helps patients feel that they are **true and valued partners in their own health care**, invited to participate in shared decision-making.

While millions of patients have access to OpenNotes, but there are millions more who do not. There is much work to be done to bring OpenNotes to the attention of health systems and patients. **This is where you come in!**

↪ Patient FAQs (www.opennotes.org/tools-resources/for-patients/patient-faqs/).

💼 Reading your notes toolkit (www.opennotes.org/tools-resources/for-patients/reading-your-notes/).

↪ Delbanco T., Walker J., et al.,Inviting Patients to Read Their Doctors' Notes: A Quasi-experimental Study and a Look Ahead, Annals of Internal Medicine (www.annals.org/aim/article/1363511/inviting-patients-read-doctors-notes-quasi-experimental-study-look-ahead).

↪ Sharing Physician Notes Through an Electronic Portal is Associated With Improved Medication Adherence: Quasi-Experimental Study, JMIR (http://www.jmir.org/2015/10/e226).

↪ When doctors share visit notes with patients: a study of patient and doctor perceptions of documentation errors, safety opportunities and the patient–doctor relationship, BMJ Quality & Safety (http://qualitysafety.bmj.com/content/early/2016/05/18/bmjqs-2015-004697).

Roles for advisors

What roles can patient and family advisors have in OpenNotes?

At Kaiser Permanente Northwest, Naomi Price, a member of the PFAC at the time, learned about OpenNotes and brought it up as a topic for consideration at a PFAC meeting. Around the same time, the system's informatics team also became interested in OpenNotes. The PFAC strongly supported bringing OpenNotes to Kaiser Northwest and partnered with the informatics team to present on it to the Board of Directors. According to Jonathan Bullock, Program Manager for Patient and Family Centered Care at Kaiser Permanente Northwest, it was the patient presence and advocacy at that meeting that convinced the Board to go ahead with OpenNotes and led them to decide to do a "big bang" implementation, launching across the whole system at once.

1. Learn more about OpenNotes.

The OpenNotes website has a lot of good information, including publications, toolkits, and patient stories. Encourage your PFAC members to spend some time looking at the research and other information that can help move OpenNotes forward.

- Get an OpenNotes discussion on your next PFAC agenda to see how best to move forward within your health system.
- Reach out to OpenNotes to request information or a presentation from staff and/or patients.

> *"The concept of sharing clinic notes with patients will allow patients/caregivers to participate to a greater extent in their own care. As a patient, I am very excited to be able to review my clinic notes "at my own leisure" since all of the information is not always easy to absorb at the time of the visit. As a patient/ family advisor, I participated as part of the committee planning OpenNotes at UVM Medical Center. These meetings involved a lot of discussion between physicians, staff, and patient/family members. This allowed everyone to consider different viewpoints about the best way to roll out OpenNotes, tailoring it to our specific medical center. I highly recommend that other centers considering OpenNotes include patient/family input in the planning process."*
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> *— MARGERY ROSENBLATT, UNIVERSITY OF VERMONT MEDICAL CENTER PATIENT/FAMILY ADVISOR*

2. Speak up about OpenNotes.

Develop a plan with PFAC members about the steps you'll take to communicate with key health system decision makers.

- Invite health system leadership including the Chief Information Officer, Chief Medical Information Office and/or Chief Medical Officer to a meeting to discuss OpenNotes.
- Use the OpenNotes slides provided in the Implementation Toolkit (opennotes.org/tools-resources/for-health-care-providers/ implementation-toolkit/) to create a presentation.

3. Build partnerships to advance OpenNotes.

Talk with PFAC members and health system leadership about the best way to bring OpenNotes to the attention of the health system's Board of Directors or other decision making body.

- Write a letter to the health system's President or CEO and Board members requesting they consider implementing OpenNotes.
- Request time on the Board's meeting agenda to make a presentation in collaboration with health system leadership.

4. Advise throughout the process.

To ensure the success of OpenNotes, a health system should include advisors throughout the planning and implementation process.

- If the health system forms an OpenNotes work group, at least two advisors should be on it.
- Patient/family advisors should be included in presentations to staff and relevant hospital committees about OpenNotes.
- Advisors in an OpenNotes work group can report back regularly to the full PFAC and get their input as needed.

- If no work group is formed, press for regular updates to, and feedback from, the PFAC.
- PFAC members can also give feedback on how consumer-friendly and useable the patient portal is, and on communications materials developed to inform patients about the availability of notes.

The University of Vermont Medical Center plans to launch OpenNotes in mid-2017. In 2016, UVM Medical Center formed an OpenNotes work group that included 3 patient/family advisors and representatives from departments across the system. The group was charged with making recommendations to the system's leadership. PFAC members will continue to participate in the workgroup as it transitions to an oversight role.

"Having Patient/Family Advisors as part of the working team was invaluable as we worked to make recommendations for what OpenNotes will look like at the UVM Medical Center. Thy were incredibly committed to the process, skilled at asking the difficult questions and respectfully challenging the group when there was resistance or reluctance, and also very interested in working towards solutions that would meet the needs of both patients and providers. I feel confident in saying that we would not have been able to move forward as quickly or as unified as we have been without the voice of the patient at the table."

— AMY COHEN, PATIENT- AND FAMILY-CENTERED CARE PROGRAM MANAGER

5. Help spread the word.

The PFAC has an important role in informing and educating patients and families about OpenNotes and about the importance of registering on the patient portal. In addition to individual advisors sharing information through personal networks, you can work with your health system's marketing and communications staff to develop materials including:

- an OpenNotes web page for your health system's external website and for the patient portal;
- posters, flyers and fact sheets for waiting and examination rooms;
- information for waiting room and patient room televisions;
- newsletter articles;
- stories for your health system's social media channel;
- outreach to local media to get them interested in your OpenNotes story;
- advisor information tables in highly-trafficked areas; and
- advisors and staff to assist patients in registering for the patient portal using on-site computers.

Beth Israel Deaconess Medical Center's (BIDMC) hospital-wide PFAC has provided feedback on OpenNotes and recommendations for improvements. Members also advised the OpenNotes research team on projects related to patient experience, safety, and coproduction of notes.

BIDMC patients have also publicly shared their OpenNotes experiences, in partnership with staff, at conferences and in articles.

Stay in touch with OpenNotes.

If your system decides to implement OpenNotes, please let us know! We have many useful resources and can connect your system with other similar health care systems that have implemented and/or have faced similar challenges and concerns. When your system does implement, we will want to publicize that on our website and in conjunction with the communications department at your system.

If your system has OpenNotes but is not on our map (www.opennotes.org/join-the-movement), please let us know! We work hard to publicize organizations that share notes. We see it as a strong signal that the organization is very patient- and family-centered!

Share your story with us as a way to join the movement to make OpenNotes the standard of care for all patients across the country.

For more information, contact: Deb Wachenheim, Manager of Stakeholder Engagement, dwachenh@bidmc.harvard.edu.