The Voice of the Patient and the Electronic Health Record

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Abstract

The patient's voice, which we define as the words the patient uses found in notes and messages and other sources, and their preferences for care and its outcomes, is too small a part of the electronic health record (EHR). To address this shortcoming will require innovation, research, funding, perhaps architectural changes to commercial EHRs, and that we address barriers that have resulted in this state, including clinician burden and financial drivers for care. Advantages to greater patient voice may accrue to many groups of EHR users and to patients themselves. For clinicians, the patient's voice, including symptoms, is invaluable in identifying new serious illness that cannot be detected by screening tests, and as an aid to accurate diagnosis. Informaticians benefit from greater patient voice in the EHR because it provides clues not found elsewhere that aid diagnostic decision support, predictive analytics, and machine learning. Patients benefit when their treatment priorities and care outcomes considered in treatment decisions. What patient voice there is in the EHR today can be found in locations not usually used by researchers. Increasing the patient voice needs be accomplished in equitable ways available to people with less access to technology and whose primary language is not well supported by EHR tools and portals. Use of direct quotations, while carrying potential for harm, permits the voice to be recorded unfiltered. If you are a researcher or innovator, collaborate with patient groups and clinicians to create new ways to capture the patient voice, and to leverage it for good.

Enabling patient autonomy or "listening to the patient's voice" has many benefits like reduced disease-related loneliness, better integration of life and disease, person-centered support, more trusting relationships, and development of life skills.[1] We use the patient's voice as a metonym for the patient's choices and preferences in regard to care and outcomes as well as the literal words and phrases patients use in notes and messages. The patient's voice is a small part of the electronic health record (EHR)—too small in our opinion. Measured by characters or words, the patient's voice is drowned out by the sheer volume of material in the EHR including myriad test results, medication and diagnosis lists, templates, and copy/pasted text frequently unchanged from one note to the next.[2] This editorial is a call to action to make the patient's voice heard in the EHR for clinical informatics innovators and researchers and for those funding their work.

Why is making the patient's voice heard in the EHR important? To date, we've focused on the voice of the clinician, his/her observations and assessments, and the results of diagnostic testing as the critical part of the record. While these data are important, the relative underrepresentation of the patient's voice affects us negatively in the following ways:

1. For Clinicians, the patient's voice is extremely valuable to make a proper diagnosis. Contextualizing care incorporates information on the life circumstances and behavior of patients (also known as contextual factors) into the diagnostic and therapeutic decisions. Capturing more of

the patient's voice will add in this process. Patient-reported symptoms are often the only clue identifying the underlying problem or diagnosis. A patient's articulated sense of bodily changes or novel symptoms may mean the difference between early detection of a malignancy or late diagnosis with an advanced illness that may be difficult to treat.[3] One example is ovarian cancer, a leading cause of cancer death in women, which has no recommended screening test.[4] Ovarian cancer is an example of the importance of the patient's voice: In a primary care practice, prior to any diagnosis, women later diagnosed with malignancies had significantly more symptoms of higher severity and shorter duration than women with benign masses. One of founders of Johns Hopkins Hospital, Sir William Osler, taught us more than a century ago "the patient is telling you the diagnosis."[5]

Capturing the patient's voice has become more challenging as our communication skills, which are key to eliciting and responding to what patients say, may have declined over time. During medical education, these skills can be underappreciated and undertaught to trainees.[6] The current model of high-volume, short visits with overly burdened primary care providers may have blunted or extinguished their skills. For these reasons, increasing the patient voice (►Table 1) in the EHR has become more imperative.

2. For Patients, their treatment priorities and desired outcomes must guide treatment decisions and their modifications. Patient preferences, shared decision making,[7] and patient-reported outcomes are well known, beneficial con-

cepts, but are not yet fully implemented in clinical practice.[8] Patient preferences are also key elements of patient-centered care and deserve a prominent place in the EHR.[9] Especially preferences for end-of-life decisions and care must be documented in EHRs and communicated to other EHRs in standardized ways similar to other key information.[10] Underrepresenting the patient's voice and autonomy will worsen outcomes for patients. Experienced clinicians must listen to and learn from patients. Contextualizing care is a process of incorporating information about the life circumstances and behavior of individual patients, termed contextual factors, into their plan of care. Capturing more of the patient's voice will add in this process.

3. For Researchers, the patient's voice is an extremely valuable information source for the learning health care system. We learned about the myriad manifestations of coronavirus disease (COVID) by patients sharing with us their experiences and symptoms. The frequency of the word "cough" in emergency room chief complaints may—in retrospect—offer new insight into the timing and scope of the COVID pandemic. Since the patient's voice in the EHR is so scant to date, researchers have taken to social media—not linked to patient's chart—to learn about patient's thoughts on the early pandemics,[11] preventive measures such as social distancing,[12] financial pressures from COVID,[13] mis- and disinformation,[14] and to surveil other outbreaks.[15] Adding the patient's voice to the EHR will allow researchers to link their voice to health outcome for new discoveries.

4. For Informaticians, the patient's voice offers clues for diagnostic decision support and for predictive analytics

Table 1 Where can we find the patient voice in the EHR?

Location		Directly entered or filtered by clinician	Structured	Direct quotation	Examples
Messages	Portal messages	Direct	Rarely	Always	"I started feeling bloated recently"
	Telephone message	Filtered	Rarely	Occasionally	Patient called reporting abdominal pain for 2 weeks
Notes	Chief complaint	Filtered	Occasionally	Usually	"Stomach pain"
	History	Filtered	Occasionally	Occasionally	Well and without abdominal pain until 2 months ago
	Review of systems	Filtered	Usually	Occasionally	CV: neg. Resp: neg. GI: pos.
	Our Notes	Direct	Never	Always	"I want to discuss my new belly discomfort"
Scanned documents	Patient created lists	Direct	Never	Usually	1. Bloating 2. Not as hungry 3. Flu shot
	Emails	Direct	Never	Usually	"Lately my stomach has been bothering me…"
Questionnaires	e.g., Audit, Pro	Direct	Usually	Rarely	How often do you have 5 or more drinks? Never [x], Less than monthly [ ], Monthly [ ], Weekly [ ], Daily [ ]

Abbreviation: EHR, electronic health record.
Notes: Location: Where in the EHR the voice of the patient can be found.
Directly entered: Patient enters the text.
Filtered: Patient voice paraphrased or directly quoted by clinician.

that are not included in the remainder of the EHR. Without these patient-generated clues, informaticians may miss opportunities to alert physicians of potential diagnostic errors and to arrive at more accurate predictions. For example, a patient may report "diminished appetite" several days before vital signs and laboratory tests suggest impending sepsis. In the absence of the patient's voice and with an EHR progress note stating only "no acute events over night," we miss these clues and the opportunity to intervene. With the advent of machine learning in health care, we must build systems that learn from ALL available data including the patient's reported symptoms and outcomes. This can only happen if we include the patient's voice in the EHR and allow artificial intelligence to learn from it. Adding the patient's voice will also allow our machine learning models to be more accurate faster.

5. Finally for All of US: All of us—when we enter the health system in need of care—we are vulnerable and want and need to be heard and have our complaints acknowledged. However, in ambulatory practice, physicians spend only 27% of their time on direct clinical interactions with patients compared to 49.2% on paper or EHR work.[16] The small window of opportunity to listen to the patient has effects on patient and physician satisfaction,[17] outcomes, prescribing practices, and malpractice risks. One of the most important things clinicians do is to listen. Patients come to clinicians with wants and needs and they desire, expect, and need to be heard. Listening has value beyond its crucial role in diagnosis: The act of listening makes patients feel valued and heard. However, with the Information Blocking Rules, the immediate sharing of electronic health notes to patients makes them realize that they have hardly been heard at all.

While scarce in the EHR today, some of the patient's voice may be found in the EHR—if one knows where to look. However, most clinical and research uses of patient data are not using the information added directly by the patient. Researchers and clinicians focus on the clinician-generated notes, which have a fundamental flaw. In the recapping of the patient's story, it becomes significantly altered. Often parts not deemed relevant are omitted, symptoms are emphasized differently influenced by the clinician's knowledge, and the stories are tersely summarized. Just as in the game "Telephone," the message is changed in the re-telling. The unfiltered voice of the patient might tell a different story.

One place in the EHR where the patient's unfiltered and unedited voice can be found verbatim is EHR portal. Patient messages to providers through the portal offer a glimpse into the patient's narrative but are rarely used in informatics research. Many patient messages are never read by a physician as they are routed to others like schedulers, clerks, pharmacists, or nurses, further diminishing their value.

The OurNotes movement, which asks clinicians and patients to collaborate in the creation of notes, developed from the OpenNotes movement.[18] The OurNotes concept is fairly new and not yet broadly adopted, but offers the opportunity to capture the patient's perceptions including improvement or worsening of symptoms, changes in health, treatment effects, and quality of life.[19] However, the patient portal offers many opportunities to engage the patient and explore his/her preferences. We could develop asynchronous tools to solicit patient information such as satisfaction with life and health status after an intervention or a new prescription, health concerns and their priorities prior to a visit, or goals for their health and well-being. We can use the portal to collect the patient's concerns and incorporate them directly in the encounter note.[20] This approach not only preserves the patient's voice, but it also reduces the provider's documentation burden. Novel interactive voice tools offer the opportunity to take the patient's voice and transform it into text using speech recognition.[21]

For many organizations, solutions like Dragon Ambient eXperience (DAX) are still in the experimental domain. DAX is a voice-enabled artificial intelligence solution which listens to clinician-patient encounter conversations and prepares the encounter note for the provider. Tools like DAX may not only prepare notes that could contain the original statements by the patient but could preserve audio and transcripts for future research into what the patient's voice is telling us.

Not surprisingly, there are problems with including the patient's voice in the record. For example, it has been recommended not to quote patients verbatim because of concerns for creating disrespect or health inequities.[22] Paraphrasing patients may be a solution and may turn the patient's voice into medically actionable data. For example, "My stomach has been hurting for a while" may translate after eliciting more details into "The patient reports left lower quadrant cramping pain for three days." However, respectfully and professionally used, direct quotations are good at capturing the patient's perceptions of his/her symptoms and health. Quotations may serve as important data for readers of the chart, who may form their own opinion about what those symptoms mean. One of the authors (T.H.P.) has used direct quotations in notes for years without any patient complaints.

Another problem with the patient's voice can be that it is not always pleasant or nice. A study from the University of California in San Diego among negative portal messages from patients, common words included […], expletives and/or profanity, and words related to violence.[23] The portal messages also add an additional burden on clinicians that frequently is responded to after-hours and on the weekend adding to provider burden and burnout.[24] Female physicians are more affected as they spend more time working in their EHR inbaskets because staff and patients are more likely to make requests of female primary care providers.[25] To add more of the patient's voice, we must first address the burden posed by rising volumes of messages via EHR portals. One solution could be a better combination of professional team members with varying skills and all operating "at the top of their license." If not, providers will suffer from the constant, asynchronous barrage of messages.[26]

The voice of *all* patients regardless of their language, age, income, or health and socio-technological literacy must be heard.[27] This in turn demands that equity is applied to the ways the patient's voice is brought into the EHR. Portals must permit a broader set of languages to be used. Education is

needed for patients with lower technical skills. Age-aligned software to allow older patients to access the portal is needed.[28] Access to technology must be provided to those without.[29,30] Providing all patients the ability to have their voice heard, we need to—as stated in the AMIA Code of Ethics —"[e]ngage with patients, guardians, and their authorized representatives so as to support inclusion, promote equity, advance accessibility, and avoid bias and discrimination."[31]

In summary, increasing and adding verisimilitude to the meager representation of the patient's filtered and altered voice in the EHR has enormous potential. We envision using the patient's voice to capture early symptoms of cancer or early signals of a novel pandemic and to make the patient's story available to better, more accurate predictive analytics. However, achieving the promise of the EHR and the learning health system will only occur if we can research and implement ways to add the patient's voice to the EHR without creating additional burdens to providers. Clinicians, researchers, and innovators need to seek patient groups and clinicians to explore how to capture more of the patient's voice and to leverage it for good.

Protection of Human and Animal Subjects
This article does not involve human subjects and was not reviewed by the University of Washington Human Subjects Division for that reason.

Conflict of Interest
None declared.

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