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Research and Applications

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Partnering with patients and families living with chronic conditions to coproduce diagnostic safety through OurDX: a previsit online engagement tool

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ABSTRACT

Objective: Patients and families are key partners in diagnosis, but methods to routinely engage them in diagnostic safety are lacking. Policy mandating patient access to electronic health information presents new opportunities. We tested a new online tool ("OurDX") that was codesigned with patients and families, to determine the types and frequencies of potential safety issues identified by patients/families with chronic health conditions and whether their contributions were integrated into the visit note.

Methods: Patients/families at 2 US healthcare sites were invited to contribute, through an online previsit survey: (1) visit priorities, (2) recent medical history/symptoms, and (3) potential diagnostic concerns. Two physicians reviewed patient-reported diagnostic concerns to verify and categorize diagnostic safety opportunities (DSOs). We conducted a chart review to determine whether patient contributions were integrated into the note. We used descriptive statistics to report implementation outcomes, verification of DSOs, and chart review findings.

Results: Participants completed OurDX reports in 7075 of 18 129 (39%) eligible pediatric subspecialty visits (site 1), and 460 of 706 (65%) eligible adult primary care visits (site 2). Among patients reporting diagnostic concerns, 63% were verified as probable DSOs. In total, probable DSOs were identified by 7.5% of pediatric and adult patients/families with underlying health conditions, respectively. The most common types of DSOs were patients/families not feeling heard; problems/delays with tests or referrals; and problems/delays with explanation or next steps. In chart review, most clinician notes included all or some patient/family priorities and patient-reported histories.

Conclusions: OurDX can help engage patients and families living with chronic health conditions in diagnosis. Participating patients/families identified DSOs and most of their OurDX contributions were included in the visit note.

Key words: patient engagement, patient safety, electronic health record, diagnosis, diagnostic error, communication

INTRODUCTION

Patient advocates and safety experts urge patient and family engagement in the diagnostic process (DxP).[1–5] Patients and families hold unique information about their symptoms, events that occur outside the healthcare organization (such as after hospital discharge or between ambulatory visits), omissions in clinical care that may otherwise be invisible (such as missing test orders or referrals) and their experiences of care.[1,6–9] They may also have privileged knowledge about whether a diagnosis is off track, incorrect, or proceeding too slowly (eg, if they develop new symptoms). These insights may help prevent diagnostic error, a global safety priority.[1]

The US Cures Act Final Rule, implemented in April 2021, mandates timely patient access to electronic health information, including visit notes.[10] Patient access to visit notes is a widely scalable, relatively inexpensive, and largely untapped mechanism for patient engagement in diagnostic safety.[11] Reviewing visit notes can help patients remember the next steps, including diagnostic tests and referrals, and increase trust in their clinicians[3,12]—especially if written information reinforces what was discussed at the visit.[13–15] Reading notes helps patients to identify potential errors in the electronic health record (EHR), including those otherwise undetected by clinicians or healthcare systems.[11,16–18] Some patients voluntarily act on perceived inaccuracies in the EHR, such as errors or omissions that may put the DxP at risk.[18] Other research also demonstrates that patients describe unique themes in diagnostic errors and identify missed diagnostic opportunities in ambulatory care.[19]

In addition to sharing notes through the patient portal, studies show that previsit electronic surveys may improve patient-rated visit preparation and quality, respect and inclusion in care, patient-clinician communication, and visit efficiency.[20–23] Despite the central role of patients and families in the DxP,[1] few interventions use shared electronic health information to specifically and proactively engage patients and families in diagnosis at their primary care and subspecialty ambulatory visits.[1,24] Together with patients and families, we developed, implemented, and tested an online tool called "OurDX (Our Diagnosis)," inviting patient and family contributions to the DxP through a previsit survey.

Coproduction of diagnosis holds promise as a patient-centered approach that fosters transparency and collaboration with patients.[25] Coproduction also creates a shared space to hold and address uncertainty, an important contributing factor to diagnostic error.[15,17,24,26–28] Because clinicians can use patient input to cogenerate notes, it may decrease the documentation burden.[21,22,29] Building on prior research, we anticipated that the majority of patients who used OurDX would describe their visit priorities and provide a patient-reported history of present illness.[21] We also hypothesized that a substantial minority of OurDX reports would identify patient-reported DxP-related breakdowns (PRDBs), and that on clinician review, the majority of these would provide clinically relevant diagnostic safety opportunities (DSOs).[17,18,30] In-depth qualitative analysis of patient responses and stakeholder experience with the tool are reported separately. In this article, we focused on: (1) Implementation: would patients and families use the tool? (2) DSOs: could patient contributions in OurDX help detect safety issues related to the DxP?, and (3) Integration: would clinicians include patient/family contributions in the visit note?

METHODS

Codevelopment of OurDX with patients and families

We convened a multidisciplinary team including patients/families; clinicians; researchers; and experts in patient experience, user-centered design, patient safety, information technology (IT), patient engagement, and diagnostic error. The goal was to develop a streamlined diagnostic engagement tool that minimizes the burden on patients and providers, while still capturing enough information that is actionable and relevant to the visit. To design the tool, we started with previously tested items from ambulatory care previsit surveys and taxonomy from the Framework for Patient-Reported DxP-related Breakdowns[17,21] (PRDBs), which was codeveloped by patients and clinicians. We identified common PRDBs and patient-reported contributing factors to diagnostic errors, including not feeling heard, misalignment between patients and clinicians about health concerns or their importance, inaccurate or missing elements of the medical history, missing tests, outdated results, or delayed referrals, and revised the tool to focus on improving the DxP.

The first item "What matters to you" asked patients or proxies to list up to 3 visit priorities. The second item "Tell us about your health" asked participants to describe recent symptoms related to the visit, using both multiple choice checkboxes such as whether they had recent visits to an emergency department or another healthcare system for the same problem, worsening symptoms, or medication changes; and open text fields to further describe the recent history. The third item "Getting it right" asked participants whether they had experienced common problems or delays related to the DxP, as defined by the Framework for PRDBs. We prioritized a spirit of partnership between patients and providers and included a positive feedback question to also identify things that were going well. Patient contributions were recorded in the EHR, and clinicians could include them in the notes they wrote during or after the visit.

OurDX was further reviewed outside the design team by additional members of the Patient and Family Advisory Committee and clinician quality improvement leaders in participating clinics. In addition, several individuals tested the tool online for usability prior to implementation. We developed accompanying patient education materials related specifically to use of the tool and more generally to the importance of engaging patients and families in diagnosis.[31] The final OurDX tool is a short previsit survey addressing 3 domains: patient/family priorities, recent history, and potential DxP concerns, and includes both quantitative and qualitative items. Further details on the development of OurDX have been previously detailed.[32]

Implementation of OurDX

Study population

We implemented OurDX between December 2020 and March 2022, focusing on patients with chronic conditions in 3 medical and surgical subspecialty clinics in an urban academic pediatric hospital (site 1) including Otorhinolaryngology (ORL), Infectious Diseases, and Speech Pathology; and in the general internal medicine (primary care) clinic in a rural academic hospital (site 2). The site 1 specialty clinics serve a population of patients referred for specific diagnoses, second opinions, or ongoing symptoms, and all patients or their parents/proxies with a visit during the study period were eligible to participate. In order to test the tool in patients who were more likely being evaluated for active symptoms at site 2, we excluded annual wellness and preventative visits. Individuals aged 18–99 with at least 1 health condition who had $\geq$2 visits/year and were registered for the patient portal were eligible to participate. Together, our study sites enabled examination of patient/family contributions and reporting of patient/family diagnostic concerns in settings where they knew their provider well (primary care) and in those where they might be meeting the provider for the first time (subspecialty

care). Based on power calculations for the planned statistical analyses related to types of PRDBs and factors associated with identification of PRDBs, we aimed for 1000 OurDX reports at site 1 and 500 OurDX reports at site 2.

We conducted chart reviews on a subset of OurDX reports from each participating clinic. We anticipated that chart reviews for reports that included a PRDB would be more instructive than those without diagnostic concerns, and therefore focused our sampling on reports with PRDBs over those with no PRDBs. Because the total number of OurDX reports far exceeded our target at site 1 (>7000 vs 1000), we randomly sampled 30% of OurDX reports with a PRDB and matched half of these with reports that did not have a PRDB. At site 2 where the total number of reports approximated the target number (500), we sampled 30% of all OurDX reports.

IT workflows

We tolerated site-specific differences to prioritize "real-world" implementation, allowing for existing IT workflows using different EHR and patient portal vendors. Site 1 implemented OurDX using a third-party digitized intake platform (Tonic Health, Murray, UT), a system which provided the patient or proxy an email link for the survey. This approach enabled inclusion of participants even if they were not registered for the patient portal. Survey responses flowed from the survey platform to the EHR in PDF format (Oracle Cerner, Kansas City, MO). Clinicians could review, include or cite the patient's report in their note. Patients and clinicians were familiar with this workflow because it was the same one used for other existing previsit surveys in the participating clinics, and the OurDX items were added to the existing previsit surveys. Site 2 implemented OurDX through a previsit survey in the MyChart Epic patient portal, and patient responses flowed into an Epic EHR. At this site, clinicians could opt to use a "dot phrase" to directly import the patient OurDX responses into their visit note.

At each site, we calculated the proportion of eligible visits in which patients submitted OurDX reports. We also examined the proportion of reports in which each key domain was completed (priorities, histories, and potential diagnostic concerns).

Diagnostic safety opportunities

Patient-reported DxP-related breakdowns

We defined a PRDB as previously described, "A problem or delay reported by patients that could map to any part of the DxP, as outlined in the National Academy of Medicine conceptual model."[17] OurDX focused on 3 types of PRDBs, including whether patients: (1) felt the main concern was heard, (2) experienced a problem or delay with a test or referral, or (3) experienced any "other" problem or delay related to the health concern they wanted to discuss at the visit. Patients were asked to describe each of these potential concerns in an open-text field.

PRDB verification and DSOs

Two physician-researchers reviewed 20% of OurDX reports included in chart review at each site, evaluating whether the PRDB was "probable," "possible," or "not a diagnostic breakdown" based on clinical evaluation and information available from chart review.[33] We defined DSOs as PRDBs that were confirmed on clinician review. For example, a probable DSO included a specific problem/delay related to a test that was verified on clinician review, such as a missing test order. A possible DSO included a nonspecific report of a problem/delay such as "test" or "other problem/delay" that could not be verified because no further details were found in OurDX or chart review. We estimated the proportion of DSOs at each site using the proportion of unique participants who reported at least 1 PRDB (in all OurDX reports) multiplied by the proportion of patients with DSOs verified on clinician review in the chart review sample. The 2 researchers also categorized each DSO, using the Framework for PRDBs[17] and coding as many categories as were present in the patient report.

Intercoder reliability

Based on prior research with the Framework for PRDBs, we used AC1 and kappa statistics to test for intercoder reliability, counting only complete agreement as a match.[17] AC1 was the most appropriate statistic since some categories in the framework were used more frequently than others.[6] We also report the kappa statistic since it is more commonly used and a more conservative measure. We considered agreement coefficients 0.61–0.8 as good agreement and 0.81–1.00 as excellent agreement. Any coding differences were discussed and adjudicated by consensus. Comparison of clinician coding for PRDB verification demonstrated good to excellent reliability with an AC1 of 0.83 (0.76, 0.89) and a kappa of 0.79 (0.72, 0.87). Similarly, the intercoder reliability of probable DSO categorization was excellent: AC1 0.94 (0.89, 0.98) and a kappa 0.84 (0.74, 0.94). Based on good to excellent agreement, 1 researcher coded the remainder of the OurDX reports in the chart review sample.

Integration of patient contributions

We used chart review to determine whether the information shared by patients in the OurDX report was included and addressed in the note, adapting established methodology.[21] We also used chart review to further characterize patients (including number of chronic conditions and number of prescription medications), and what happened as a result of the visit, focusing on 4 outcomes of interest: a new test, referral, procedure, or medication change. Led by a researcher with expertise in chart review,[34,35] the team convened to discuss the chart review process in detail over 3 virtual meetings. At each site, a research assistant (RA) used a standardized data extraction form in REDCap[36,37] to complete the chart review and a physician was designated to assist the RA with clinical questions.

Analysis

We used descriptive statistics to report implementation outcomes, identification of PRDBs, verification of DSOs, and chart review findings. We established a unique patient-level dataset by randomly selecting 1 visit for inclusion among those patients who had more than 1 visit during the study period (1182/6079 (<20%) of the study sample), using established methodology.[38,39] We used multivariable logistic regression to examine the association between the 4 visit outcomes and PRDBs in the chart review sample, adjusting for patient sociodemographic factors. We completed all analyses using SAS software version 9.4 (SAS Institute Inc., Cary, NC).

Ethics: The study was approved through a single Institutional Review Board process (protocol IRB-P00034869) and Data Use Agreements were established between participating organizations.

RESULTS

Study population

Among 18 129 eligible pediatric visits at site 1, 7075 (39%) OurDX reports were submitted by a total of 5731 patients and families (Figure 1). At site 2, among 706 eligible adult primary care visits, 460 (65%) OurDX reports were submitted by 348 patients (Figure 1).

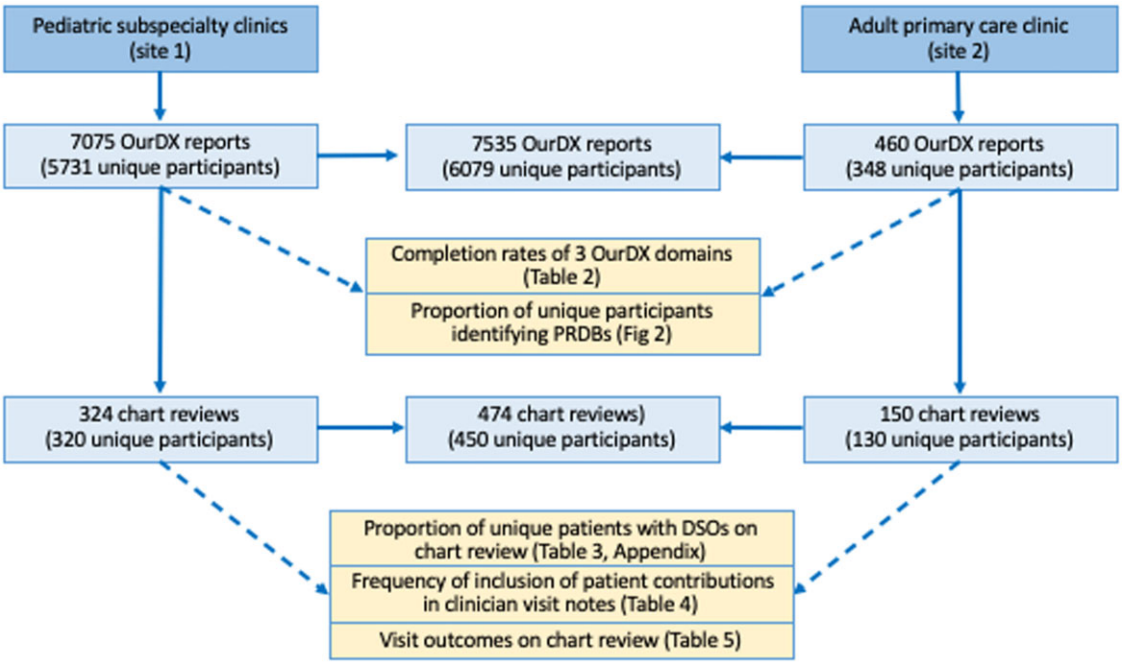

Figure 1. Study flowchart. *Note*: OurDX: OurDiagnosis; PRDB: Patient-Reported Diagnostic process Breakdown; DSO: diagnostic safety opportunity; Fig: Figure. Solid arrows denote participant flow chart (blue boxes). Dashed arrows denote source participants for study outcomes (yellow boxes).

Characteristics of participants are shown in Table 1. At both sites, approximately 80% of participants submitted a single OurDX report, 15% submitted 2 reports, and the remainder submitted ≥3 reports during the study period. We completed 474 chart reviews on 450 unique patients; 320 at the pediatric subspecialty clinics and 130 at the adult primary care clinic (Figure 1). Based on chart review, 99.4% of pediatric patients and 95.4% of adult medicine patients had an active problem or new symptom. The great majority of patients (91.6% pediatric and 97.7% adult medicine) also had at least 1 chronic condition documented in the record. The average number of chronic conditions was 1.8 ± 1.2 among pediatric patients, and 4.7 ± 2.7 among adult medicine patients. At the pediatric subspecialty clinics, the most common conditions included: developmental/genetic, ORL-related, behavioral/mental health, neurological, pulmonary, and gastrointestinal. At the adult primary care clinic, the most common conditions were: cardiovascular, endocrine/diabetes, musculoskeletal/arthritis, mental health-related, and pulmonary.

Implementation

The majority of OurDX reports at each site included responses to each of the 3 main tool domains: priorities (84% site 1 and 60% site 2); patient-reported history (quantitative "checkboxes": 91% site 1 and 80% site 2; open-ended narrative: 67% site 1 and 57% site 2); and potential DxP concerns: whether main concerns were heard: (94% and 88%), problems/delays with tests/referrals (96% and 85%), other problems/delays (94% and 86%, Table 2).

Diagnostic safety opportunities

The types and frequencies of PRDBs submitted by patients in all OurDX reports are shown in Figure 2. In total, 3.6% of pediatric patients/families and 5.5% of adult primary care participants reported that they did not feel their main concern was heard. In addition, 5.5% at site 1 and 11% at site 2 reported problems or delays with tests and referrals; and 4.0% at site 1 and 13.4% of participants at site 2 identified "other problems or delays." In total, 10.6% of unique participants at site 1 and 21.0% of unique participants at site 2 identified ≥1 PRDB.

Of 450 patients in the chart review sample, 280 reported 308 PRDBs. On clinician review, 175 (63%) of 280 patients had a probable DSO (Table 3). In addition, 106 (38%) had possible DSOs (not enough information in OurDX or chart review). Thirteen (5%) patients did not have a diagnostic breakdown on clinician review. (Note: percents exceed 100% because some patients reported >1PRDB). A higher proportion of PRDBs was confirmed as probable DSOs at site 1 compared to site 2 due to missing or inadequate (few words in open text) patient descriptions of the PRDB at site 2. Among probable DSOs, the most common types were: communication problems such as not feeling heard (61%); problems/delays with explanation or next steps (28%); and problems/delays with tests/referrals, including scheduling delays or missing test results (27%). The estimate of site-specific probable DSOs was 7.5% of unique participants at both sites (Supplementary Appendix). In addition, the estimate of possible DSOs was 3.0% of unique participants at site 1 and 13.2% at site 2.

Integration of patient contributions

Most reviewed clinician notes included all (65% site 1 and 80% site 2) or some (33% site 1 and 19% site 2) of the patient/family priorities (Table 4). A nearly identical proportion of notes addressed all or some of these priorities in the note. Similarly, most reviewed clinician notes included all (59% site 1 and 81% site 2) or some (36% site 1 and 19% site 2) of patient-reported histories. Those notes with documented patient histories likewise addressed the patient-reported issues (Table 4).

Table 5 shows a chart review comparison of visit outcomes with and without PRDBs. At site 1, compared to those with no PRDB, patients or families reporting a PRDB were more likely to have a

Table 1. Patient characteristics

Patient characteristics	All participants pediatric subspecialty clinics (site 1) N = 5731	Chart review site 1 N = 320	All participants adult primary care clinic (site 2) N = 348	Chart review site 2 N = 130
Age (mean, SD)	7.14 (7.56)	7.96 (8.34)	69.79 (12.32)	69.92 (11.50)
Gender				
Male	3234 (56.43%)	184 (57.50%)	168 (48.28%)	57 (43.85%)
Female	2497 (43.57%)	136 (42.50%)	180 (51.72%)	73 (56.15%)
Race				
White	3806 (66.41%)	202 (63.13%)	342 (98.28%)	128 (98.46%)
Black	262 (4.57%)	17 (5.31%)	Race other than white	2 (1.54%)
Asian	223 (3.89%)	11 (3.44%)	(combined): 6 (1.72%)	
Other	496 (8.65%)	33 (10.31%)		
Unknown	944 (16.47%)	57 (17.81%)		
Ethnicity				
Hispanic	349 (6.09%)	25 (7.81%)	1 (0.29%)	0
Non-Hispanic	4168 (72.73%)	225 (70.31%)	347 (99.71%)	130 (100%)
Unknown	1214 (21.18%)	70 (21.88%)		
Preferred language				
English	5518 (96.28%)	304 (95.00%)	348 (100%)	129 (99.23%)
Another language	213 (3.72%)	16 (5.00%)	0	1 (0.77%)
Interpreter needed?				
Yes	146 (2.55%)	10 (3.13%)	0	0
No	5585 (97.45%)	310 (96.88%)	348 (100%)	130 (100%)
Total number of submitted OurDX reports				
1	4634 (80.86%)	316 (98.75%)	266 (76.44%)	112 (86.15%)
2	907 (15.83%)	4 (1.25%)	60 (17.24%)	16 (12.31%)
3	149 (2.60%)	0	15 ((4.31%)	2 (1.54%)
≥4	41 (0.72%)	0	7 (2.01%)	0
Total number of chronic conditions (mean, SD)		1.77 (1.17)		4.66 (2.70)
Total number of meds (mean, SD)		0.91 (1.30)		5.83 (3.84)
Did the visit involve an active problem or new diagnosis?		318/320 (99.37%)		124/130 (95.38%)
Proportion of patients with at least 1 chronic condition?		293/320 (91.56%)		127/130 (97.69%)

test (23% vs 12%), referral (22% vs 6%), procedure (39% vs 25%), or medication change (11% vs 8%) as a result of the visit. On multivariable logistic regression, adjusting for age, gender, race, ethnicity, and language preference, clinicians at the pediatric subspeciality clinics were about 2–5 times more likely to order a new test, referral, or procedure for patients with a PRDB, compared to those without PRDBs: test OR 2.2; 95% CI (1.14–4.31); referral OR 5.2; 95% CI (2.09–12.79); procedure OR 1.9; 95% CI (1.12–3.16), Table 5. In the smaller adult primary care clinic sample, there were no significant differences observed (Table 5).

DISCUSSION

This study of 7535 ambulatory visits among 6079 pediatric and adult patients in urban, rural, medical, surgical, primary care, and subspecialty clinics reveals 3 key insights related to engaging patients and families living with chronic conditions in the ambulatory DxP through shared electronic health information.

First, given the opportunity, a substantial proportion of study patients and families provided information online prior to visits to assist with the DxP. Response rates to OurDX were highest when invitations came directly from the patient's primary care physician—likely due to the positive influence of pre-existing relationships, although older patients may have also been more likely to participate than busy parents.[40–42] The majority of respondents completed all 3 domains of the tool: visit priorities, recent history, and potential DxP concerns. While open-ended text generally provided richer detail, completion rates of the "checkbox" elements of the recent history exceeded the open-ended responses at each site. The combination of both approaches is therefore more likely to yield robust information for providers than either alone.[21] Notably, respondents were most likely to respond to the "Getting it Right" multiple choice items, where completion rates at both sites ranged from 85% to 96%, indicating that most participants were willing to engage as safety partners in this format.

Second, OurDX can help identify clinically relevant DSOs among patients/families living with chronic conditions. In total, an estimated 7.5% of pediatric or adult patients/families with underlying health conditions reported probable DSOs. These most commonly included patients/families not feeling heard; problems/delays with tests, results, or referrals; and problems/delays with diagnosis or next steps. This finding is significant since not feeling heard was the most common contributing factor reported by patients who experienced diagnostic error in a national U.S. survey,[43] suggesting that earlier notification of providers when this issue arises may provide an opportunity to prevent downstream diagnostic errors.

Our findings build on prior research demonstrating that 6.4% of all patients who read notes (and 10.7% of patients with fair or poor self-reported health)[17,18] report DxP-related breakdowns *retrospectively*—after the visit. This study advances the field by (1) testing a DxP engagement tool and eliciting PRDBs *prospectively* before the visit, thus bringing PRDBs to clinicians' attention at the point of

Table 2. OurDX domains, items, rationale, and patient completion rates

OurDX domain	Patient contribution	OurDX item	Rationale (goal of item)	Site 1 completion rate $N = 7075$	Site 2 completion rate $N = 460$
Share what matters most to you (priorities)	Patient/family visit priorities (free text)	What are the most important things you would like to talk about at your visit?	Help patients to feel heard;[17,43] align patient-provider visit agendas.[46]	5906 (83.5%)	276 (60.0%)
Tell us how you have been (recent medical history)	Medical history (checkboxes)	Over the last 6 months (or since your last visit in this clinic), have you had any of the following? (New/worsening symptoms; chronic conditions; tests or procedures; visits to UC or ED or another hospital or HCP for the same problem; medication changes; other; none)	Help clinicians quickly flag visits that may be at higher risk for a diagnostic breakdown,[19,69] and to improve accuracy of the history by capturing symptoms in the patient or proxy's own words.	6451 (91.2%)	367 (79.8%)
	Medical history (free text)	Please tell us more about how you have been since your last visit		4724 (66.8%)	264 (57.4%)
Getting it right (potential diagnostic process concerns)	Main concerns heard? (yes/no/have not discussed concerns yet)	Thinking about the main symptoms or health concern(s) you want to discuss at your upcoming visit: Do you feel like your main health concerns (or what matters most to you) have been heard by your healthcare providers so far?	Enable early detection of PRDBs with the potential for high impact on the DxP[17]	6664 (94.2%)	407 (88.5%)
	Problems or delays with tests/referrals? (yes/no)	Have you had any problems or delays with tests or test results or referrals/appointments related to the health concerns you want to discuss at your visit?		6803 (96.2%)	393 (85.4%)
	Other problems or delays? (yes/no)	Have you had any other problems or delays related to the health concerns you want to discuss at your visit?		6667 (94.2%)	395 (85.9%)
	Description of problem or delay (free text)	Please tell us more about the most important problems or delays you noted above.	Details of PRDBs may facilitate response at the point of care, and offer a structured opportunity to address uncertainty in diagnosis[26]	419 (57.0%)[a]	96 (87.3%)[a]
	Description of what's working well (free text)	Is there something in particular that is going well for you in your care?	Appreciative inquiry: Identify things that are going well; feedback about helpful behaviors and experiences[70]	1377 (19.5%)	201 (43.7%)

[a]Denominator restricted to those participants reporting a problem or delay.

care, where they can be acted upon; (2) focusing on patients and families living with chronic conditions; and (3) adding clinician review of PRDBs to determine probable and possible DSOs. While the overall estimate of probable DSOs was similar at both sites, the adult primary care site had more possible DSOs. This may be due to greater medical complexity (as evidenced by substantially greater number of chronic conditions in this population), greater comfort reporting breakdowns to a primary care provider with whom

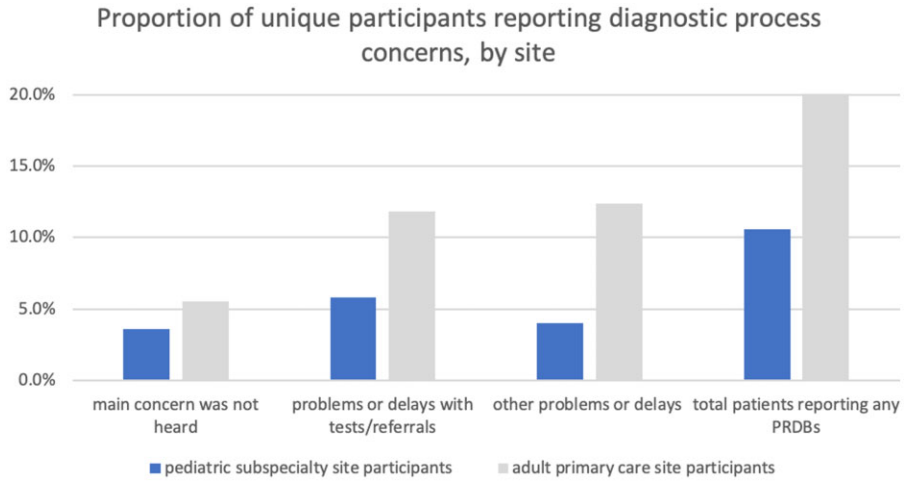

Figure 2. Proportion of unique participants reported diagnostic process concerns, by site. *Note*: PRDB: Patient-Reported Diagnostic process Breakdown.

Table 3. Verification and categorization of Diagnostic Safety Opportunities (DSOs) based on clinician review of Patient-Reported Diagnostic process-related Breakdowns (PRDBs) in chart review sample

	Total patients with PRDBs in chart review ($n = 280$)		Patients with PRDBs in chart review, site 1 ($n = 213$)		Patients with PRDBs in chart review, site 2 ($n = 67$)	
	n	%[a]	*n*	%[a]	*n*	%[a]
PRDB verification						
Probable DSO	175	62.5	150	70.4	25	37.3
Possible DSO	106	37.9	61	28.6	45	67.2
Not a diagnostic breakdown	13	4.6	11	5.2	2	3.0
Probable DSO categorization						
Access to care	13	7.4	10	6.7	3	12.0
Medical history	6	3.4	6	4.0	0	0.0
Tests/referrals	47	26.9	38	25.3	9	36.0
Communication	106	60.6	89	59.3	17	68.0
Explanation and next steps	49	28.0	47	31.3	2	8.0
Other	1	0.6	1	0.7	0	0.0

[a]Total percentages exceed 100 because some reports include >1 PRDB. In total, 294 chart reviews for 280 patients included 308 PRDBs.

patients have an established relationship than with a specialist they may be meeting for the first time, or site-specific differences such as COVID-19 impacts on staffing causing scheduling delays.

OurDX is a tool that can be used to support coproduction of safety.[17,44] For example, patient-reported histories may improve the accuracy of medical histories when documented in participants' own words, and patient priorities may better align patients and providers at the visit. OurDX quickly flags for providers those visits where patients have been recently seen for the same problem at another urgent care visit or emergency department, since this is a known risk factor for diagnostic error.[19,45] We were intrigued that visits in which patients reported PRDBs resulted in 2–5 times the likelihood of tests, referrals, or procedures in some clinics. Clinicians may have also acted on PRDBs in ways that would not be detected on chart review. For example, they may have listened more carefully, checked for understanding, tracked down delayed test results, or assisted with tests or referrals that were already ordered but not completed. These outcomes were beyond the scope of our study but merit further research. Even without a formal tool, simply asking patients whether they felt their main concern was heard at the end of each symptomatic visit may help identify situations requiring greater attention to improve the DxP.

Third, in the majority of cases, when patients and families contributed visit priorities or recent histories through OurDX prior to the visit, they were included in the clinician note. This is significant because integrating patient priorities and patient-reported histories may decrease the likelihood of misalignment between patient and clinician priorities or inaccurate clinician symptom reporting in the EHR, each known hazards to diagnostic error or delay.[17,46] These findings were demonstrated irrespective of the site-specific technologic capability to import OurDX information directly into the note. While it is possible that the same content was covered in the visit as in OurDX, completing OurDX likely primed patients and families to identify and discuss the issues most important to them.[21–23,47] It also enabled DxP feedback at the point of care, which is otherwise rare.[48–53]

Strengths and limitations

Although this is a large study of both adult and pediatric patients in urban, rural, medical, and surgical subspecialty clinics and primary

Table 4. Inclusion of patient contributions in clinician notes

Items	n[a]	Pediatric subspecialty visits ($n = 324$)	n[a]	Adult primary care visits ($n = 150$)
Note included patient priorities	294		119	
Yes, all		191 (65.0%)		95 (79.8%)
Yes, some		97 (33.0%)		22 (18.5%)
No		6 (2.0%)		2 (1.7%)
Note addressed patient priorities	293		120	
Yes, all		192 (65.5%)		96 (80.0%)
Yes, some		95 (32.4%)		22 (18.3%)
No		6 (2.1%)		2 (1.7%)
Note included patient-reported history	255		113	
Yes, all		150 (58.8%)		91 (80.5%)
Yes, some		91 (35.7%)		21 (18.6%)
No		14 (5.5%)		1 (0.9%)
Note addressed patient-reported history	255		113	
Yes, all		142 (55.7%)		91 (80.5%)
Yes, some		98 (38.4%)		21 (18.6%)
No		15 (5.9%)		1 (0.9%)

[a]The n for each outcome was based on number of participants that provided the relevant information in the OurDX report, and the number of judgments available on chart review. In rare cases (<5%) the chart review outcome was uncertain and was not included in results.

Table 5. Multiple logistic regression analysis of 4 visit outcomes comparing patients with and without PRDBs in chart review

Result of visit	Pediatric subspecialty clinics ($N = 320$)					Adult primary care clinic ($N = 130$)				
	Patients with PRDBs (%) $n = 213$	Patients without PRDBs (%) $n = 107$	Odds ratio	95% CI	P-value	Patients with PRDBs (%) $n = 64$	Patients without PRDBs (%) $n = 66$	Odds ratio	95% CI	P-value
Medication change	11.3	8.4	1.28	0.56–2.91	.557	42.2	36.4	1.18	0.56–2.47	.66
Test ordered	23.0	12.2	2.21	1.14–4.31	.019	54.7	51.5	1.11	0.55–2.27	.767
Referral made	21.6	5.6	5.17	2.09–12.79	<.001	32.8	39.4	0.77	0.36–1.63	.499
Procedure planned	39.0	25.2	1.88	1.12–3.16	.018	3.1	0	n/a	n/a	n/a

Note: Age, gender, race, ethnicity, and language were adjusted in models of site 1; age, gender, and insurance type were adjusted in models of site 2. "n/a" indicates not applicable—odds ratio could not be calculated because there were 0 procedures planned for patient visits with no PRDBs at site 2.
Abbreviations: PRDB: Patient-Reported Diagnostic process-related Breakdown.

care, the study was conducted in 2 U.S. academic medical centers and the views of participants may not reflect those of all patients and families. Like other portal-based or previsit survey studies, compared to nonrespondents, respondents at site 1 were more likely to be non-Hispanic white and English-preferring.[54,55] We could not ascertain the characteristics of nonrespondents at site 2, but participant characteristics were similar to those in other published electronic surveys at this site.[56] Use of the patient portal is known to be lower among elderly patients, those who prefer a language other than English, or those of racial or ethnic backgrounds historically at greater risk for health disparities.[57–59] The response rate was similar to or higher than expected for online surveys at the primary care site treating primarily older patients with multiple chronic illnesses, and at the pediatric site, where patients and families were invited to participate regardless of portal registration.[56,60–63] Future studies with more diverse patients and families are needed, since participants were mostly white and English-preferring, especially at site 2.

OurDX was implemented during the COVID-19 pandemic, and PRDBs related to access or test/referral delays may therefore be more pronounced than usual. Importantly, because patients have unique insights about the DxP, particularly related to events occurring between visits or at different healthcare centers, PRDBs could not always be confirmed by OurDX or chart review. Probable DSOs are therefore likely an underestimate and merit further research such as in-depth patient interviews.

Future research and application of OurDX

OurDX was developed and tested with patients and families, and demonstrated consistent performance in this study with respect to DSOs among patients with underlying health conditions at 2 sites. It can be used in concert with other tools designed *by* patients *for* patients to help prepare for visits or to ask the provider about other possible diagnoses.[2,64,65] These tools can help patients organize their thoughts and visit priorities and structure their contributions in ways that may be most helpful to providers. OurDX adds the opportunity to share concerns about the diagnostic process and to send all the previsit information to providers electronically. The items can be embedded in other previsit surveys to streamline demands on patients (and potentially increase uptake), but such surveys still need to be balanced against other work that patients/families are asked to

do to avoid overburdening them.[66] This may be particularly important for patients who have chronic conditions or other competing responsibilities. Finally, patient engagement tools like OurDX also need to be carefully considered in the context of other quality measurements to avoid "metric myopia" and emphasize instead transparency, civility, and what matters most to patients and clinicians.[67,68]

Within these constraints, we anticipate that OurDX could be useful in other settings where new diagnoses are likely; or with patients/families who have complex care, frequent visits with different providers, or are at risk of diagnostic delay. These might include urgent care visits, additional subspecialities such as oncology or geriatrics, or extending OurDX use to care partners of older patients or those with memory loss/cognitive dysfunction to share their previsit contributions and concerns (especially if they are not able to attend the visit)—as a few examples. However, the tool needs further evaluation in additional settings before it can be used more broadly.

CONCLUSION

Patients hold unique information that may help keep the DxP on track. At a time when health information transparency is at the forefront of policy shifts, patient contributions to safety through OurDX included not only the identification of potential breakdowns but also positive coproduction of safety, such as helping to ensure accuracy of the medical history in participants' own words and an opportunity to better align visit priorities between patients and providers. Engaging patients and families living with chronic conditions using OurDX prior to symptomatic ambulatory visits can help clinicians quickly flag DxPs at risk at the point of care, where they can be acted upon. In particular, the opportunity to identify patients who do not feel heard in the DxP may help address a common patient-reported contributing factor to diagnostic error. The majority of patients/family-identified concerns were verified as probable DSOs on physician review, and most clinician notes integrated patient/family contributions, underscoring the potential for coproduction of diagnostic safety.

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AUTHOR CONTRIBUTIONS

SKB conceived the study design, participated in data analysis, and drafted and revised the manuscript. YD was responsible for data analysis and reviewed the manuscript. CMD served as a study advisor, participated in data analysis, and reviewed the manuscript; NH contributed to data collection and reviewed the manuscript; BM contributed to data collection and reviewed the manuscript; LHN oversaw data analysis and reviewed the manuscript; EJT served as a study advisor, participated in data analysis, and reviewed the manuscript; FB participated in study design, data collection, data analysis, and reviewed the manuscript.

SUPPLEMENTARY MATERIAL

Supplementary material is available at *Journal of the American Medical Informatics Association* online.

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CONFLICT OF INTEREST STATEMENT

None declared.

DATA AVAILABILITY

The data underlying this article are available in the article and in its Supplementary material.

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