Documentation of Disability Status and Accommodation Needs in the Electronic Health Record: A Qualitative Study of Health Care Organizations' Current Practices

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Background: This qualitative study aimed to understand how early adopting health care organizations (HCOs) implement the documentation of patients' disability status and accommodation needs in the electronic health record (EHR).

Methods: The authors conducted qualitative interviews with HCOs that had active or past initiatives to implement systematic collection of disability status in the EHR. The interviews elicited participants' current experiences, desired features of a standard EHR build, and challenges and successes. A team-based analysis approach was used to review and summarize quotations to identify themes and categorize text that exemplified identified themes.

Results: Themes identified from the interviews included "why" organizations collected disability status; of "what" their EHR build consisted, including who collected, how often data were collected, and what data were collected; and "how" organizations were implementing systematic collection. The main purpose for collection of disability status and accommodation needs was to prepare for patients with disabilities. Due to this priority, participants believed collection should (1) occur prior to patients' clinical encounters, (2) be conducted regularly, (3) use standardized language, and (4) be available in a highly visible location in the EHR. Leadership support to integrate collection into existing workflows was essential for success.

Conclusion: Patients with disabilities experience significant disparities in the receipt of equitable health care services. To provide equitable care, HCOs need to systematically collect disability status and accommodation needs in the EHR to ensure that they are prepared to provide equitable care to all patients with disabilities.

Individuals with disabilities are one of the largest and most underserved subpopulations in the United States, facing significant disparities in health outcomes and health care access.[1–3] Approximately 26.8% of the US adult population reports a disability.[4] Studies show that persons with disabilities (PWD) are more likely to report fair or poor health, are less likely to receive preventive health care services, have higher rates of comorbid conditions such as diabetes and cardiovascular disease, and have a higher burden of disadvantages in social determinants of health compared to persons without disabilities.[1,5–8] Many factors contribute to these disparities, including barriers within the health care setting, such as lack of accessible health care facilities and diagnostic equipment, ineffective health care communication, and biases and assumptions of health care teams.[3]

Systematic documentation of patients' disability status as a self-reported demographic characteristic in the electronic health record (EHR) is a crucial first step to identifying and subsequently addressing potential care disparities that occur within health care organizations (HCOs).[9,10] Collecting information about a patient's disability status can lead to also collecting information about a patient's disability ac-

commodation needs. HCOs are federally mandated to provide patients' disability accommodations when requested.[11] In February 2022 the National Council on Disability released a Health Equity Framework for People with Disabilities outlining several priorities for advancing health equity for people with disabilities.[12] One priority called for "improving data collection concerning healthcare for people with disabilities across the lifespan"[12(p. 8)], which includes improving and increasing the collection of data through the EHR.

Research has demonstrated that patients with and without disabilities report little concern with their disability status being documented in their EHR, and clinical staff desire that disability status and accommodations be recorded in the EHR.[11,13,14] A trial in which collection of disability status was integrated during new patient registration for 53 primary care clinics demonstrated that, with a minimal educational intervention for registration staff, documentation increased from < 10% to > 50% in six weeks.[15] The health care system received no patient complaints about documentation during the study period.

Despite the national call for documentation, evidence that patient and clinical staff support collection of disability status as a demographic characteristic, and evidence that documentation can be integrated into clinical workflow processes, little is known about current documentation of patients' disability status and accommodation needs in the

EHR. The objective of our study was to understand how HCOs are implementing the documentation of patients' disability status and accommodation needs into the EHR.

METHODS

Participants

We conducted a qualitative study using semistructured interviews with health system representatives in the United States. Using purposeful convenience sampling, we recruited participants from the Disability Equity Collaborative (DEC) Healthcare Leaders workgroup. The DEC Healthcare Leaders is a national working group of health system representatives. Participants have a range of position titles, including ADA [Americans with Disabilities Act] Coordinator and Interpreter Services Director, and all were responsible for disability-related initiatives, including documenting disability status and providing disability accommodations. The DEC Healthcare Leaders workgroup developed based on word of mouth with support from a Patient-Centered Outcomes Research Institute (PCORI)–funded Engagement Award. At the time of recruitment, approximately 25 HCOs were involved in DEC Healthcare Leaders. All were invited to participate. Reasons for nonparticipation included unresponsiveness to invitations, not receiving permission from leadership to participate, and potential participants perceiving that they did not have much to contribute because their organization was not implementing collection of disability status. Interviews continued until preliminary analyses indicated thematic saturation.[16] This study was approved by the Colorado Multiple Institutional Review Board.

Procedures

Our study team included a qualitative methodologist with expertise in disability equity, a research assistant with qualitative experience, and a physician with qualitative training. Interviews occurred between May 2021 and April 2022 via Zoom videoconferencing and lasted 60 minutes. A semistructured interview guide elicited the following: (1) details of the participant's health system's process for documentation of patient and caregiver disability status and accommodation needs, (2) motivation for and use of this information, (3) desired features of a standard EHR build, and (4) challenges and successes with their processes. Interviews were audio-recorded and professionally transcribed. Transcripts were entered into a qualitative software program for data management (ATLAS.ti; Scientific Software Development GmBH, Berlin).

Data Analysis

Data analysis began after 10 interviews were completed. Interview transcripts were coded inductively by the study team [M.A.M., C.S., K.E.].[17] Codes were identified and created based on emergent elements in the data and used to tag relevant text from the transcripts.[18] The study team double-coded transcripts while developing the codebook and met regularly to reconcile coded transcripts and develop and refine a final codebook.[19] The remaining transcripts were then coded separately by team members, with 20% of transcripts double-coded. Following completion of coding, queries (reports of code groups of interest) were generated and then organized by concept to analyze data across participants. We used a team-based analysis approach to review and summarize quotations for these codes and concepts to identify themes and categorize text that exemplified identified themes.[17,19]

RESULTS

We interviewed 17 participants who represented 15 HCOs. Organizations represented all regions of the United States and ranged in size from 1 hospital to 40 hospitals with 900+ outpatient clinics. Overall, participants reported that documenting disability status and accommodation needs was an initiative they were or had been actively working on. Participants reported being at different stages of implementation and described a broad spectrum of levels to which systematic documentation of disability status and accommodations were established within their organization (see Table 1). For example, some HCOs had disability fields built into their EHR, but no systems or policies in places to routinely complete the fields. Five of the participant organizations had no disability category fields built into their EHR, nor had a systematic process for collecting disability status. One of these participants reported that her organization had a process in place but had discontinued collection of all demographic data, including disability status. Finally, participants represented organizations that often had many clinics and hospitals. Some reported that certain clinics or units were more successful than others with documenting disability status and accommodation needs.

The Why: Preparing for Patients

Participants universally reported that the main reason for documenting disability status and accommodation needs was to prepare for patients with disabilities. Without knowing whether a patient had a disability and accommodation needs, staff were required to quickly determine the patient's accommodation needs and then provide the accommodations in real time during a clinic visit. This led to inefficiencies—additional stress for staff and patients, disruptions and delays to the clinic schedule—which ultimately contributed to a negative experience for both the patient and care team.

> *It would be really nice in advance to know, "oh gosh, I need to have the room that's big enough for an electric wheelchair reserved for this patient." Instead of having that patient come in and go, "oh well, somebody's already in their room and we don't really have a room*

Table 1. Description of Organizations

	US Region	Size	EHR Vendor(s)	Disability Category Fields Built into EHR*	Current Status of Systematic Collection†	Disability and Accommodation Questions Prompts‡
Organization 1	Midwest	14 hospitals 150 clinics	Epic	• Deaf or hard of hearing • Blind or low vision • Communication disability • Mobility disability • Intellectual/developn disability	Patient and support person are systematically asked disability and accommodation needs.	Do you have a disability and any accompanying assistance needs?
Organization 2	East	40 hospitals 900 clinics	Epic Cerner	• Disability type captured in external tracking document	Patients are systematically asked accommodations needs.	Do you have a disability-related accommodation need?
Organization 3	Northeast	12 hospitals 60 clinics	Epic	• Deaf or hard of hearing • Blind or low vision • Communication disability • Cognitive disability • Mobility disability • Autism	Patients are systematically asked if they have a disability, and if so, what type of disability. No accommodation questions being asked.	Do you have a disability?
Organization 4	West	24 hospitals 640 clinics	Epic	• Unknown	Patients are systematically asked if they have an accommodation need. No disability questions being asked.	Do you have a disability-related accommodation need?
Organization 5	Northwest	5 hospitals 120 clinics	Epic	• Deaf or hard of hearing • Blind or low vision • Communication disability	During inpatient assessment patients are asked what their particular communication needs are.	None
Organization 6	West	8 hospitals 280 clinics	Epic	• Deaf or hard of hearing • Blind or low vision • Deaf and blind • Language needs	No current systematic process for collection	• Do you require an interpreter? • Do you require any disability accommodations?
Organization 7	Southwest	12 hospitals 700 clinics	Epic	• Deaf or hard of hearing • Blind or low vision • Cognitive disability / intellectual disability • Mobility disability • Other	No current systematic process for collection	• Will you need any assistance at this appointment due to a disability? • Nursing admission asks 6 function questions ("Do you have difficult with getting dressed?," etc.)
Organization 8	Southeast	7 hospitals 200 clinics	Epic	• Deaf or hard of hearing • Blind or low vision • Other communication needs • Language needs	No current systematic process for collection	None

Table 1. (*continued*)

	US Region	Size	EHR Vendor(s)	Disability Category Fields Built into EHR*	Current Status of Systematic Collection†	Disability and Accommodation Questions Prompts‡
Organization 9	West	3 hospitals 50 clinics	Epic	• Deaf or hard of hearing • Blind or low vision • Mobility	No current systematic process for collection	None
Organization 10	Midwest	4 hospitals 6 clinics	Epic	• Deaf or hard of hearing • Blind or low vision • Cognitive disability • Mobility disability • Mental health disability	No current systematic process for collection	None
Organization 11	Southeast	1 hospital 36 clinics	Allscripts SIS Greenway	None	No current systematic process for collection	Are there any special accommodations you need, such as an interpreter?
Organization 12	Northeast	8 hospitals 350 clinics	Epic, Cerner	None	No current systematic process for collection	None
Organization 13	Southwest	3 hospitals 55 clinics	Epic	None	No current systematic process for collection	None
Organization 14	Southwest	4 hospitals 90 clinics	Epic	None	No current systematic process for collection	None
Organization 15	Northeast	5 hospitals 60 clinics	Epic	None	No current systematic process for collection	None

* Includes the disability category fields each organization has built within their EHR.
† Describes whether an organization has an established process for systematically collecting disability status in the EHR.
‡ Includes the prompts organizations use to collect disability status and accommodation needs.
EHR, electronic health record.

that's going to fit your wheelchair. Can you just hang out here in the hall for a while?" That ends up getting their clinic behind. The patient is upset. The MA [medical assistant] usually is like, "what am I going to do? I feel really bad". . . this is not just about benefiting the patients. It's about benefiting everybody that works with them, and making it a much more positive experience. . . . Lots of things can be improved if we can just know in advance and prepare. (HCO 10)

Participants discussed the need for all team members to be aware of and prepared to accommodate PWD.

We would like to be prepared to know how many patients need to arrive with service animals. That will help a lot of our security staff, for example, if they could know ahead of time or they can just look at the medical record. If we know that the patient will be arriving with a service animal, I'm sure that some patients may have a better experience because either they will not be questioned so much or questioned in the wrong way. (HCO 12)

Proactively collecting disability status and accommodation needs also allowed participants to build reports to accurately estimate the size of their disability populations and their accommodation needs. Finally, participants expressed the desire to be able to query what and where accommodations are available within their organization, as this assisted in scheduling patients and identified needs for purchasing additional accessible equipment.

The What: The Build

Questions the Organizations Are Documenting. All organizations used patient self-reported questions for disability status and accommodation needs. Organizations were mixed in whether they asked patients both disability status and accommodation questions or just one set of questions. Because of the priority to prepare accommodations, many were inclined to ask only the accommodation questions. Although some participants reported the value of asking both sets of questions, time and effort constraints were the major drivers of asking only one set of questions.

We wanted to be able to document mobility disability or speech—or hearing disability or speech disability or intellectual disability so that we can prove to our leadership that, yes, we have patients with these disabilities. Then, we tried to pull out and separate out the accommodations because before, everything was all together. (HCO 07)

Participants reported that one of the main challenges with documenting disability status and accommodation needs was the broad diversity of disability categories and accommodation needs. Organizations varied regarding what

disability categories they were or were planning to collect (see Table 1). Participants focused on collecting what they viewed as the main disability categories, as well as disabilities in which there was a more explicit accommodation need.

> I think that the spectrum of disabilities is so broad that we will have to narrow it down to disabilities that are related to communication in general and some accommodations. (HCO 12)

Participants discussed challenges in the differences in how patients conceptualize disability. For example, some patients might not identify as disabled, yet do require disability accommodations. This was a justification for asking both disability status and accommodation needs questions.

> One of the things in health care is people confuse disability with health conditions. Obviously, you're going to have a disability that has nothing to do with, generally with a health condition. . . . Accommodations need to be functional. . . . It doesn't help to know that I have a macular condition. What's that going to tell you? Need to be large print, what do you need? It needs to be a functional. (HCO 04)

Participants noted that although asking more questions is generally better, due to time constraints, asking a smaller set of questions or one screening question is more practical. One organization identified 80 different accommodation options they would like to present in a drop-down box of accommodation options, which they said was too long and would discourage staff from using the fields.

Participants reported the need for standardized questions rather than open or free-text fields, or generic "FYI" flags. Standardized question categories allowed for queries of medical records to determine the disability prevalence within their patient population.

> Initially, what we wanted to do was maybe just have it an open field. Then, we realized that that would be really hard to run reports. Even though we don't like to put people in categories, we did leave options for people to add in "Other." (HCO 10)

Where the Questions Are Located. All participants reported that disability status and accommodation needs should be in a prominent location in a patient's chart, such as the banner or storyboard location. The challenge was that these locations can be viewed as prime real estate in their organizations.

> Something that we put a lot of time and thought into was getting that "ADA Needs" on the banner bar. Because the banner bar is a very coveted space. They don't want anybody touching their banner bar. (HCO 02)

According to the participants, a patient's disability status should be available to all providers and staff and should travel with the patient to any department or clinic in which they are provided care. Several participants mentioned the desire for a disability flag in the chart. Despite some concern for pop-up fatigue, these participants believed that it was important to err on the side of having disability status appear more frequently, stating that it was rare to receive complaints from providers about seeing disability status information too frequently.

By Whom and When Are the Questions Asked. To prepare for patients, disability status and accommodations needs ideally should be collected prior to a visit. This would require collection by registration and/or scheduling staff. Outside of these individuals, participants described a wide range of staff and providers who could ask the disability questions, including nurses and other frontline staff. In addition, participants discussed a desire for patients to document a disability and accommodation need through the patient portal.

> I honestly think it could be one of the lead MAs. Depending on the clinic. They're the ones that are responsible for that initial meeting with the patient. That's where things can go awry. If they can prepare the way, they know about rooming. They know about what these patients might need. (HCO 10)

Participants varied in terms of how frequently patients should report their disability status. Because disability status can change over time, some stated that patients should be asked at each encounter.

> Needs change over time. . . . Just because we've documented "none" at one point in time, it doesn't mean that we don't always need to verify that the information's still accurate. (HCO 07)

Due to potential changes over time, participants reported the need to capture the specific date when disability status was documented.

> There's nowhere to capture it and timestamp it and date stamp it. There's no chronological way of looking back and saying, in the last three months, when and what did people need? There's no chronological order of saying, at this admission, they needed X, Y, Z, and the next admission they needed something different. (HCO 05)

Using the EHR to Automate Accommodations. Participants reported an interest in building in EHR tools and systems that would automatically provide an accommodation when identified and recorded in the EHR. For example, one participant reported:

> If I need large-print and I have selected that in the electronic health record, can my after-visit summary print in large print? What can that selection of things do to get the output and get the accommodations to the patient without having human interaction with them? (HCO 02)

In addition, they desired being able to use collected accommodations to inform scheduling and provision of accommodations.

> We would love it that if it says assisted device, that maybe you could even click on that and that would tell you where or how to get that. That would be the next dream build is that patient who's interacting with MyChart could then get the resources they need within the chart, right? . . . At the very least, the clinics would be able to identify within their own clinic. Making a list of "okay, room 104 and 107 are perfect for patients with electric wheelchairs. Reserve those at 1:00, reserve those at 3:00 for these particular patients." (HCO 10)

The How: Implementation

Without Leadership Support, Collection of Disability Status Will Not Happen. Participants reported that leadership support was critical for successful implementation of documentation of patients' disability status and accommodation needs. Participants reported that their organizational leadership often believed that there was not a policy requirement for documenting disability. This, combined with the reality that documenting disability status or accommodation needs requires staff time, meant that leadership was often unsupportive of systematic collection.

> *It's viewed as, "This is something that we don't really have to do, so we're not going to do it." There was a big initiative to streamline the amount of clicks that nurses had to do, so basically, anything that wasn't explicitly required somewhere, they threw it out. . . . Unfortunately, they decided that it wasn't a requirement. (HCO 07)*

Participants reported that their EHR vendors did not offer standardized tools to collect disability status, so many relied on their internal EHR build teams to build the fields. This process was viewed as laborious and costly.

> *We wanted it to function like that, and so we were told at the time we can't do all those things. "It's going to cost too much because it's not regular—it's not part of the regular features. It would be a custom build. We're not willing to do that right now." (HCO 08)*

Strategies to gain buy-in and support included engaging key organizational committees and champions from across the organization and integrating disability status into existing diversity, equity, and inclusion efforts.

> *My main focus right now is how can we educate our leadership in actually embracing disability as part of the important category of data collection. When we are talking about health care disparities, equity, social determinants, intersectionality, all of that, we should include disability in the conversation. (HCO 03)*

Another proposed strategy for gaining leadership buy-in was improving and increasing policy requirements for collection.

> *I think we need a regulatory requirement to have to do it. . . . It needs to be couched like how we had to start documenting race and ethnicity. We had to start doing that. It was very clear that everybody had to do it, so everybody's doing it. (HCO 07)*

Several participants reported that their organization began documenting disability due to a patient ADA lawsuit or a Department of Justice consent decree.

> *It did come out of a class action that we were a part of. Basically, they told us one of the requirements in that was we have to ask all of our patients about their disability-related accommodation needs. (HCO 02)*

Training Is Important for Successful Implementation. Participants thought that trainings on documenting disabilities and providing accommodations should be a part of new employee orientation as well as included in annual trainings that are required for staff and providers.

> *What's working well is that we took the time to in-service, to do training for a couple of our call centers. . . . I think taking the time to train the call centers created a big difference . . . for the past three, four years as part of the annual core competencies, as part of our language in-services that we do twice a year. We go unit by unit to in-service, to educate a little bit of this, and I think that's how we got things changed a bit. (HCO 12)*

A key component of the training should be to increase staff and provider knowledge about disability and comfort with asking about disability status and accommodation needs. This included educating staff on why they are collecting the information. Participants reported that staff will sometimes guess or assume a patient's disability status by looking at a patient, rather than asking. This was due in part to concerns about offending patients by asking about disability status or accommodation needs.

> *They want to be nice, and they feel like asking if somebody needs any disability-related accommodations is somehow rude. I've heard that resistance from staff is they don't want to insult the patient. They want to avoid, maybe, some sort of confrontation or negative perception. They want to do the right thing, but they also don't want to insult anybody. (HCO 07)*

Finally, participants cited the importance of educating their patients about why the information was being collected.

> *I'd really like to see a training for individuals who would be collecting the information on the front lines as well as educating our community as to why these questions are asked. It's really because we want to provide the best service. We want them to have a good experience and our employees to have a good experience. (HCO 15)*

Integration into Workflow Can Mitigate the Extra Time and Energy Required. Participants reported that a top barrier for systematic collection of disability status was the time and effort required to document disability status and accommodation needs.

> *I think it was with the rollout people saying, "Are you kidding me? We're having to do so many new things and so many things all at once. We just cannot add this one more thing that's not an absolute necessity right now." (HCO 08)*

Participants reported that having disability status and accommodation needs collection integrated into an efficient workflow process was essential for successful implementation.

> *The challenge is that documenting disability status isn't really part of anybody's workflow. . . . my nurses don't really have a workflow to always inquire about disability status. . . . It's not really part of their workflow and because of that, even if they do find that they're aware of something, being able to get to the field to document is like literally one, two, three clicks. You have to go through three different screens to get to where you need to document, and that requires the nurse to leave the flow sheet that they were already on. Not only is it not part of their workflow, per se, it requires a lot of extra effort. (HCO 07)*

One participant described how several departments in her organization saw the value and efficiency in knowing if a patient had a disability or accommodation needs up front

and being able to prepare for the patient. Because of this, they did not view it as burdensome to integrate collection into their workflow routines.

> *I do have a few areas that have developed workflows surrounding being asked about accommodations, so it's specifically my cardiovascular testing area and radiology, just because they recognize the value of asking that question before the patient gets there so that they can have the Hoyer lift or something available and at the ready if somebody comes for a procedure. They found out the hard way how difficult it is to scramble at the last minute when somebody arrives, and they need a lift to get to a piece of equipment and they didn't ask the questions. . . . they recognized the value for efficiency for their staff. (HCO 07)*

DISCUSSION

Currently, there is no known estimate of how many HCOs are systematically collecting patients' disability status and accommodation needs. Based on the authors' experience conducting research in this area, discussions with EHR vendors, and leading a national workgroup on the topic, we believe that few HCOs are currently systematically collecting disability status and accommodation needs in the EHR. Given this, the HCOs represented in the current study who are collecting this information are likely early adopters of the process and offer important insights on how to effectively implement collection.

The HCOs varied in the disability categories they were collecting, as well as how they were implementing collection. Despite this, all unanimously stated that their main priority for collecting disability status and accommodation needs was to identify patients who require disability accommodations, with tracking quality of care as a secondary goal. Given this priority, participants agreed that collection should ideally occur prior to the clinical encounter, which would allow clinic teams to be prepared with appropriate accommodations. This belief is supported by previous research stating that clinic staff and providers desired knowing patients' disability status and accommodation needs early and often.[11]

Participants reported that systems and processes are needed to consistently document patients' disability status and accommodation needs. In addition, participants reported the need to have disability status and accommodation needs information be prominently displayed in a patient's EHR, even going so far as to state that pop-up alerts may be warranted. With the current epidemic of burnout experienced by health care teams, it is not surprising that HCO leadership is hesitant to invest time and energy into collection of disability status and accommodation needs.[20,21] But the participants reported the belief, with several having concrete examples, that having information about a patient's disability status and accommodation needs actually led to more efficient care. More research is needed to determine the least burdensome and most efficient processes for collecting and sharing information with the care team about patients' disability status and accommodation needs.

One of the barriers stated by the participants was the lack of clear federal policies on documentation of disability status. Many federal agencies, such as the Health Resources and Services Administration, mandate the collection of demographic data such as race, ethnicity, primary language, and sexual orientation and gender identity by grantees and those receiving federal funds.[22] Unfortunately, similar mandates have not been made for documentation of disability status, which consequently stalls the advancement of health and health care equity initiatives targeted toward PWD. In July 2022 the Office for the National Coordinator for Health Information Technology released their newest interoperability standards, which included a standardized disability data element.[9] This is an important step in setting national policy standards and guidelines for documentation of patients' disability status and accommodation needs in the EHR. As a result, we have found an increase in interest in how to implement collection of disability status in the EHR from health systems, as well as increased investment from EHR vendors to build tools to collection disability status. Additional federal agencies following suit would provide needed clarity and guidance for health systems.

Limitations

There are several notable limitations to this study. We used a convenience sample of HCO representatives who were actively engaged in a learning collaborative aimed at improving equity of care for PWD. Most of the organizations were large health systems or hospitals, with none representing only outpatient or solo practices. The participants may not be representative of all organizations or clinic settings. Future research should explore documentation in varying settings.

CONCLUSION

Accurate identification of disability status and accommodation needs and systematic collection in the EHR remains a major challenge to mitigating existing disparities.[10,23] Routine collection of this information will enhance HCOs' ability to understand the needs of their patient populations and proactively provide accommodations to ensure equitable access to health care services. In addition, systematic collection of disability status will facilitate future research and quality improvement initiatives that seek to increase our understanding of existing disparities, implement interventions to mitigate these disparities, and evaluate the impact of these interventions. Through improved policies, standardized and systematic collection methods, and recognition by leadership of the importance of this initiative, HCOs can leverage the EHR to improve care for this important, underserved population.

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