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Implementation of Collection of Patients' Disability Status by Centralized Scheduling

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Background: Collection of disability status in electronic health records (EHRs) is critical to addressing the significant health care disparities experienced by patients with disabilities. Despite this, little evidence exists to inform implementation.

Methods: This pilot trial evaluated the implementation of collection of patients' disability status during primary care new patient registration by centralized call center staff. The study took place over six weeks at an academic hospital system in Colorado. Staff received a 30-minute training on how to ask and document disability status in the EHR. Completion rate of collection, fidelity, and concordance were assessed through chart reviews and recordings of patient registration calls. Focus groups with staff and phone interviews with patients assessed the experience of including disability screeners in patient registration.

Results: A total of 3,673 new patients were registered at one of the 53 primary care clinics during the study period. Completion of disability status in the EHR increased from 9.5% at baseline to 53.5% by the last week of the trial, which was then maintained for eight weeks. Challenges were identified in the recorded calls with fidelity of if and how the questions were asked. No patient complaints were reported, and patients reported no concerns regarding collection of disability status during interviews.

Conclusion: Documenting disability status during patient registration was effective and was not concerning to patients. To make initial steps to providing equitable care, efforts should be made to implement this type of screening universally across the clinical encounter.

Section 1557 of the Patient Protection and Affordable Care Act (ACA) prohibits discrimination in health care settings on the basis of race, color, national origin, sex, age, and disability status.[1] Although decades of evidence exist describing and addressing health care discrimination and inequities based on race, ethnicity, and sex, policy makers and researchers only recently have acknowledged discrimination and disparities in health care settings experienced by patients with disabilities.[2] For the more than 1 in 4 persons in the United States who live with a disability,[3–5] a growing number of studies demonstrate the significant disparities in care they experience. For example, women with physical disabilities are less likely to receive breast or cervical cancer screenings as compared to nondisabled women.[5–12] Similarly, patients across multiple disability groups are less likely to report satisfaction with care and more likely to report an absence of patient-centered care.[7,13–15]

Providing equitable health care services can be described as a moral imperative, but health care organizations (HCOs) are also mandated by the Americans with Disabilities Act (ADA) to provide accommodations that ensure equitable access to high-quality health care services.[16,17] These accommodations are broad and can include items such as physically accessible diagnostic equipment for those with physical disabilities, auxiliary communication aids for patients with communication disabilities, or accessible electronic and print material for patients with visual disabilities. Simply having these accommodations available is not sufficient. According to settlement agreements with the US Department of Justice, HCOs need to identify patients who would benefit from these accommodations, record that information in their charts, and ensure that these patients receive appropriate accommodations.[18]

Multiple policies recommend that HCOs collect patients' disability status. In 2010 The Joint Commission formally recommended documentation of patients' communication, mobility, and literacy disabilities in order to provide patient-centered care.[19] Documentation of patients' disability status is explicitly required of HCOs by Section 4302 of the ACA for the purpose of identifying potential disparities.[20] Finally, the US Department of Health and Human Services proposed a rule in 2014 for electronic health records (EHRs) to include disability in the demographic section, again to assist organizations in identifying patients who would benefit from disability accommodations and thus facilitate patient-centered, equitable care.[21]

Despite the moral and policy mandates, HCOs often do not systematically collect disability status. HCOs may collect some information, such as use of a wheelchair, but the accommodation questions asked may not be inclusive of a

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range of disabilities, and the data often are not consistently used to track or improve quality of care.[22] Using diagnosis codes to identify patients with disabilities is unreliable, as studies have found that providers infrequently and inconsistently use disability diagnosis codes.[23–25]

There are multiple points of patients' encounters with health care during which their disability status could be collected. One logical setting for HCOs to inquire about disabilities is when patients register or schedule appointments.[22] To provide needed disability accommodations in a timely manner, HCOs should know prior to the appointment whether a patient has a disability and requires accommodations. Storing disability status in the demographic section of the EHR with other characteristics such as race, ethnicity, and primary language allows for a common location for multiple providers to access the information.

Currently, no standards exist for health care systems on how to collect disability status within the health care environment. Evidence does exist for how to collect patients' race, ethnicity, and sexual orientation and gender identity.[26–29] In those studies, staff training on how to collect these data increased completion rates. This article describes the development and implementation of staff training materials to introduce collection of patients' disability status by centralized schedulers through applying lessons and evidence from documentation of other demographic characteristics.

METHODS

Study Context

In January 2019 we conducted a pilot trial evaluating the implementation of collection of patients' disability status during all new patient registration calls at all of the primary care clinics in the University of Colorado Health (UCHealth) System. UCHealth is an integrated health care system with primary care clinics across Colorado. Beginning in 2011, UCHealth migrated all primary care clinics to a phone-based centralized registration and scheduling model referred to as PatientLine. PatientLine agents work in one of two centralized call centers and are organized into "neighborhoods" where specific agents serve specific clinics. At the beginning of the trial, PatientLine served 47 UCHealth primary care clinics. During the course of the trial, UCHealth acquired 6 more clinics, for a total of 53 clinics by the end of the trial. This study was approved by the Colorado Multiple Institutional Review Board as expedited research. Patient interviews were approved as Not Human Subjects Research/Quality Improvement.

Disability Questions

UCHealth uses the Epic EHR software (Epic Systems Corporation, Verona, Wisconsin). Prior to the pilot, UCHealth integrated a disability status field with nine response options into the demographic section of patient charts for the purpose of recording patient disability status (Table 1). Recording one or more of these response options was available through the Epic "registration wizard" platform. The disability response options are based on previous research conducted by the study team that engaged multiple stakeholders in a multiphase process to identify disability status questions.[30] Six of the response options correspond to six disability categories: hearing, vision, mobility, communication, cognition, and activities of daily living (identified as "manual dexterity" within the UCHealth EHR). These disability categories and questions were previously identified by stakeholders as appropriate for collection of disability status in the health care setting, and are similar to both the World Health Organization's recommended set of disability questions and the American Community Survey disability questions.[30] In addition, there are "other disability," "no disability," and "no response/decline to answer" options. Prior to our pilot study, no agent had received training or instruction to complete the disability fields. As a result, the disability field in Epic was not only underutilized, but many of the agents were unaware it existed. The field was accessible to other team members, such as clinic staff and providers, to view and to complete. (See Table 1 with the response options and corresponding questions.)

Stakeholder Advisory Board

We convened a Stakeholder Advisory Board (SAB) that we engaged at multiple time points throughout the pilot. The SAB consisted of four patients and caregivers for patients with disabilities, two Disability Accessibility Coordinators from the health care system, four providers, four representatives from PatientLine, and two practice administrators. During the planning phase of the study, institutional stakeholders expressed that their two main concerns with implementation of collection of patients' disability status were the length of time to complete the questions and how patients would respond to the questions. Specifically, they were concerned about the possibility of agents asking all patients all six of the disability category questions. In response, the SAB and research team agreed that the pilot would have two phases, each three weeks long. In Phase 1, agents asked all six specific disability questions plus the "other" disability question following the six specific questions. In Phase 2, schedulers asked the "other" disability question as a screener, followed with the full set of six disability questions if a patient answered affirmatively to the screener question (Table 1). To address stakeholders' concerns about patients' response to collection of disability status, we built in methods to collect patients' perceptions and to review recorded calls.

Developing and Implementing Training

We developed a 30-minute training consisting of didactic material and video vignettes developed and filmed with members of the SAB. We adapted initial training content

Table 1. Disability Questions and Associated Recorded Responses in the EHR

Disability Question	Response Field in Epic
Prompt prior to disability questions: *These questions will help us know how to train our staff better and figure out how to be most helpful to our patients.*	
Are you deaf or have serious difficulty hearing?	Deaf/hard of hearing
Are you blind or do you have difficulty seeing, even when wearing glasses?	Blind/visual impairment
Do you have serious difficulty walking or climbing stairs?	Mobility disability
Do you have difficulty remembering or concentrating?	Cognitive disability
Do you have difficulty dressing or bathing?	Manual dexterity disability
Using your usual language, do you have difficulty communicating (for example, understanding or being understood)?	Communication disability
Due to a disability, do you need any additional assistance or accommodations during your visit?*	General disability
	Other: _________
	No response/refuse to answer

* In Phase 1 this question was asked at the end of the six disability questions. In Phase 2 this question was asked first. If a patient answered affirmatively, the agent would ask the full question set.
EHR, electronic health record.

from existing training available in the Health Research and Educational Trust Disparities Toolkit regarding documentation of race and ethnicity.[31] Our training introduced the disability questions the agents were now required to ask for all newly registering patients. The training instructed agents to state the following prompt informing the patient why the disability questions were being asked: "*These questions will help us know how to train our staff better and figure out how to be most helpful to our patients.*" We adapted this prompt from previous research on increasing patients' comfort with disclosing race and ethnicity.[26]

In addition to introducing the disability questions, the training addressed four other areas: (1) why disability status is being collected at registration, (2) how patients feel about being asked to disclose their disability status, (3) what an agent says if a patient requests a specific disability accommodation, and (4) what to do when patients say they do not have a disability, but the agent thinks they might. Finally, the training provided tips and strategies for communicating over the phone with someone with a communication disability. We developed training videos to provide examples of mock phone encounters and included real patients with disabilities. We presented drafts of the training content and format to the SAB for feedback and approval. We piloted the training with three PatientLine agents prior to implementation.

A member of the study team conducted the in-person training to PatientLine agents responsible for scheduling for all UCHealth primary care clinics. The training materials were available through the system's intranet portal for agents unable to attend the in-person training. We provided paper table tents to agents at the beginning of the trial that we then updated between Phases 1 and 2. These visual reminders contained the prompt and question sets corresponding to Phases 1 and 2 of the study. (All training materials are available upon request to the corresponding author.)

Outcomes and Data Sources

Our primary outcome of interest was the effectiveness of the intervention to increase completion rate of the disability field. We defined completion of the disability field by a recorded response of affirmative to one of the disability questions, "no disability," or "declined to answer." As secondary outcomes, we were interested in (1) the fidelity of the agents asking the questions and recording the response in the EHR, (2) the time required to ask the disability questions, and (3) PatientLine agents' and patients' perceptions of collecting disability status during new patient registration. We collected both quantitative and qualitative data from multiple data sources to address these outcomes. (See Table 2.)

Epic Electronic Health Records. The EHR provided data for disability field completion rates. We accessed the Epic data through a HIPAA–compliant limited data set compiled by the University of Colorado's Health Data Compass (HDC). HDC is the enterprise health data warehouse that integrates patient clinical data from the EHR, making it available to researchers. We identified newly registering adult patients in Epic if they had a "New Visit to System" flag, were over 18 years old, and had no encounters recorded in Epic prior to the baseline period (beginning September 1, 2018).

PatientLine Internal Records. PatientLine provided internal records, including recordings of all calls, which provided agent-level phone encounter information. From the encounter-level data we collected call length, completion rate by agent, and fidelity of asking the questions and recording a response using a sample of call recordings. The

Table 2. Outcomes, Data Sources, and Timing of Collection

Outcome	Data Source	When Collected
Completion rate of the disability field	Epic EHRs	Following our maintenance period, we pulled 36 weeks of data—22 weeks in the baseline period, 6 weeks for the pilot trial, and 8 weeks of maintenance.
Fidelity of agents asking the questions and recording responses	PatientLine internal records, which included recordings of calls	Due to an error in the PatientLine internal software, we were not able to identify newly registering patients for the first 10 days of Phase 1. As such, results are based on 32 of the 42 days in the pilot trial.
Time required to ask the disability questions	PatientLine internal records, which included recordings of calls	Due to an error in the PatientLine internal software, we were not able to identify newly registering patients for the first 10 days of Phase 1. As such, results are based on 32 of the 42 days in the pilot trial.
PatientLine agents' perception of collecting disability status	Focus groups with agents	We conducted the focus groups within 3 weeks of completing the pilot trial.
Patients' perception of collecting disability status	Interviews with patients	Within 2 weeks of when the patient was registered, we contacted patients to participate in an interview. We identified the patients through a review of the EHR data.

EHR, electronic health record.

research team developed a structured data collection tool to record fidelity to the question set, concordance with the Epic data, and other notable observations about the agent-patient encounter. Two research team members [M.K.H., K.E.] listened to and collected fidelity data from a random 8% sample ($n = 113$) of registration calls.

Focus Groups with PatientLine Agents. Following completion of the pilot, the study team [M.H., K.E.] conducted three mini–focus groups with agents ($N = 10$). The objectives of the focus groups were to understand, from the agent perspective, implementation experience, patient response, and use of the disability questions beyond the pilot study.

Patient Interviews. We conducted brief phone interviews with patients who had completed new patient registration during the pilot trial time period to understand their perceptions and comfort with being asked to disclose disability status during the registration call. Interviews were conducted by a research team member [K.E.] with 20 patients, 10 with a disability recorded in the EHR and 10 without. Patients received a $50 gift card in appreciation of their time.

Data Analysis

We compared completion rates, operationalized as proportion of calls with a response to the disability questions, between Phases 1 and 2, baseline and maintenance periods, using a two-sample test of proportions. All tests were two-sided, with significance set at $\alpha = 0.05$. We completed all analyses using Stata 14.2 (StataCorp LLC, College Station, Texas). We used descriptive statistics to quantify the findings from the PatientLine records, including differences in length of the calls, agent-level completion rate, and fidelity to asking the questions in the recorded calls.

Focus group and interview recordings were professionally transcribed. The research team [M.A.M, M.K.H., K.E.] coded the transcriptions by using an inductive, open-coding process.[32] The process began with the team independently reviewing a subset of the transcripts to identify codes, followed by the team meeting to collaboratively identify a consolidated codebook. When the team determined that the codebook was comprehensive, the team applied it to the remainder of the transcripts. The team entered coded transcripts into Atlas.ti (Scientific Software Development GmBH, Berlin) for data management, analyzing data within and across participant groups to identify consistent themes.

RESULTS

Across three days in January 2019, the team trained a total of 63 PatientLine agents who served 53 primary care clinics in the UCHealth System. Data collection began a week after the training and lasted six weeks, with three weeks per phase. The PatientLine agents were instructed to complete the disability status questions for all newly registering patients for one of the primary care clinics. The following are the results for our outcomes of interest. Throughout the trial we encountered unexpected implementation and data collection challenges. We have noted these challenges throughout the results section. (See Table 3 for a description of the qualitative and quantitative results, and the contextual factors that influenced the results.)

Completion of the Disability Field

In the six weeks of data collection during this study, a total of 3,673 new patients were registered at one of the 53 primary care clinics served by PatientLine. The average patient age was 43.3 years old, 51.6% were female, 76.4% identified as white, and 73.7% of the patients had commercial

Table 3. Qualitative and Quantitative Findings and the Contextual Factors Affecting the Outcomes

Key Findings	Quantitative Findings	Qualitative Findings	Contextual Factors Affecting Intervention and Outcomes
Completion rates of the disability field significantly increased during and after the intervention period.	Completion rates: 9.5% in baseline period; 53.5% in maintenance Significant discrepancy (53.1%) between what was observed on the call and what was recorded in EHR	Agents reported that although they more frequently collected disability status, they still had calls in which they forgot to ask the questions. (focus group data) Agents reported some confusion as to where the disability fields were located in the EHR. They also wondered whether the questions would be more appropriate for a clinical setting. (focus group data)	There were multiple challenges with using EHR and PatientLine data to measure effects, including the following: • Cannot determine when the disability status field is completed or by whom. • New clinic acquisition to UCHealth during the study period meant that there was a group of previously established "new patients" who were not asked any of the demographic questions. • Patients are not asked any demographic question for same-day sick visits. • In the EHR data, there is no explicit way to identify when a patient becomes a new patient. This field was not functioning for the first part of the trial for the PatientLine data. • A "yield sign" appeared next to the disability questions in the new registration wizard in the middle of the intervention (day 5 of Phase 1). • New patient registration wizard platform was not uniform across agents.
Training made a difference.	Agents who completed in-person training had a significantly higher completion rate (68.8% vs. 61.2%, $p = 0.002$) than agents who did not participate.	Agents who participated in the training reported that they felt that the training adequately prepared them. (focus group data)	Training all agents in person was difficult due to the following: • Agents worked at two call centers and from home and had different shift schedules. • Call centers' main metric was number of calls, and so it was costly to have agents take time for training. • Frequent turnover of agents
Patients had little to no concerns being asked disability status, but agents still expressed some discomfort with the questions.	In observations of the calls, only 1 of the 64 patients questioned why the data were being collected. The patient was fine with disclosing her disability status when provided the explanation.	Agents reported no concerns from patients about asking the questions. They did report some level of discomfort still and wondered if the questions were better suited for a clinical setting. (focus group data) No patient reported any concerns with disclosing disability status. (interview data) UCHealth and PatientLine received no patient complaints.	Collecting disability status is a new process. Despite receiving training on how to handle different types of callers, agents had received no prior training regarding talking to patients with disabilities.
The longer question set increased call times. Similar rates of disability were reported with the screener question and long version of the question set.	The longer question set took more than 3 times longer to ask than the screener question (median: 62 vs. 18 seconds). Disability rates were 5.2% and 4.3% with the longer question set and screener question, respectively.	Agents reported that they preferred asking the screener question rather than the long set. (focus group data)	Because the call centers' main metric was number of calls, the agents and leadership preferred the screener question.

EHR, electronic health record.

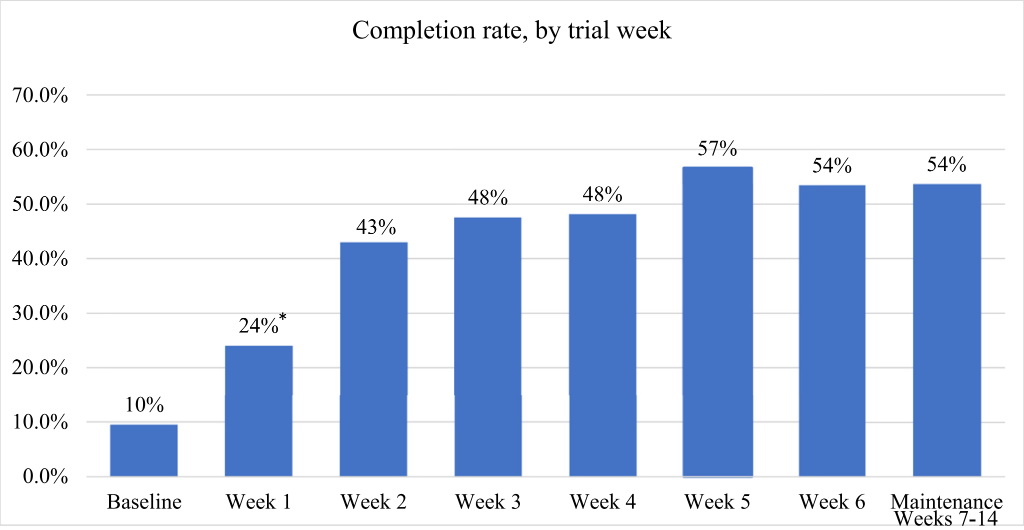

Figure 1: This chart shows the completion rate of the disability field in the electronic health record by trial week. Total *N* by week: week 1 = 562, week 2 = 639, week 3 = 618, week 4 = 573, week 5 = 643, week 6 = 638, maintenance weeks = 4,229. * Disability yield flag in Epic registration wizard appeared on day 5 during week 1.

Table 4. Patient Characteristics Among Newly Registering Patients

Patient Characteristics	Statistic
Number of newly registering patients,* *N*	3,673
Female, *n* (%)	1,894 (51.6)
Age in years, mean (SD)	43.3 (16.6)
Race, *n* (%)	
White	2,806 (76.4)
Black	99 (2.7)
Asian	118 (3.2)
Other†	362 (9.9)
Unknown/Not recorded	288 (7.8)
Ethnicity, *n* (%)	
Hispanic	315 (8.6)
Non-Hispanic	3,075 (83.7)
Unknown/Refused	283 (7.7)
Payer, *n* (%)	
Commercial	2,707 (73.7)
Medicare	458 (12.5)
Medicaid	255 (6.9)
Self-pay	5 (0.1)
Other	111 (3.0)
Unknown/Not recorded	137 (3.7)

* Patients newly registering with UCHealth between February 4, 2019, and March 15, 2019.

† Includes American Indian/Alaskan Native, Multiple Race, Native Hawaiian/Other Pacific Islander, Other.

SD, standard deviation.

insurance (Table 4). Across both phases, 45.8% of patients had a recorded response to the disability questions, compared to 9.5% in the 22 weeks of baseline prior to the study commencing. There was a significant increase in completion from Phase 1 to Phase 2 (38.7% vs. 52.9%, $p < 0.001$). In the 8-week maintenance phase following Phase 2, 53.7% of patients had a recorded response, which was consistent with the percentage reached during Phase 2 (Figure 1).

On day 5 of Phase 1 a yield sign appeared in Epic next to the disability status questions. This was a visual reminder to the agent to complete the disability status questions. Our institutional partners had requested placement of the yield sign 9 months prior to study commencement. There was no indication prior to this pilot study of when the yield sign would appear, and therefore the study team was unaware that this would be implemented during the pilot trial. Reviewing the response rate by week, there was a substantial increase from week 1 to week 2, which coincides with the introduction of the Epic yield sign. However, the statistically significant difference comparing Phase 1 and Phase 2 remains despite the exclusion of the week 1 data (45.2% vs. 52.9%, $p < 0.001$).

Across both phases, 4.8% of patients reported at least one disability (5.4% during Phase 1 and 4.3% during Phase 2, which was not statistically significant). By age category, 3.3% of patients 18–54 years old reported a disability, 8.6% of 55–84 years, and 35.7% of ≥ 85 years. The most prevalent disability categories by age group were cognitive and intellectual disability for 18–54 years, and mobility and hearing disability for ≥ 55 years.

A total of 98 PatientLine agents completed new patient registration calls during the study period, 48.9% of whom received in-person training by the members of the study team in January 2019. During Phase 1, the average number of calls for newly registering patients was 4.4 per agent (standard deviation [SD] 3.3, range 1–16). In Phase 2, the average number was 12.7 per agent (SD 8.6, range 1–42). Agents averaged a 68.0% completion rate of the disability status field during new patient registration. Agents who completed the in-person training had significantly higher completion rates (68.8% vs. 61.2%, $p = 0.002$) than those who did not. We were unable to determine whether the agents who did not complete in-person training reviewed the training materials online. Another challenge was that the tool within the PatientLine internal records used to indicate a patient was newly registering was not functional for the first 10 days of Phase 1, which was approximately half of that phase. Therefore, the results presented in this article using the PatientLine internal records for Phase 1 are based on only half of the available days (Table 2).

Length of Calls and Fidelity of Asking and Recording Responses

The study team reviewed a total of 113 audio-recorded patient registration calls (Phase 1: 53, Phase 2: 60). Of the 113 calls, 33 resulted in reporting a disability in the EHR, 40 recorded "no disability," and 40 had no recorded response. Of the calls in which the disability questions were asked, the median length discussing disability was 62 seconds in Phase 1, compared to 18 seconds in Phase 2.

We observed 48.2% agreement between the content of the recorded calls and what was entered into the EHR. In other words, in 51.8% of the calls, what the agent asked or what the patient reported was different from what was recorded in the EHR. Of patients who reported a disability during a call, 58.3% had either no disability or no response recorded in the EHR. Of the persons who reported "no disability" on the call, 22.5% had a disability entered into the EHR. Among the patients without a recorded response in the EHR, our review of recorded calls found that 42.5% had been asked disability questions by the agents. Finally, in 52.1% of the calls in which the agents did not ask the questions, a response (either disability or no disability) for the patient was recorded in the EHR. Of note, it is possible that the disability status was recorded during a follow-up call or by a health care team member outside of PatientLine, as the EHR does not record when the field was completed or by whom.

Across the 64 reviewed calls in which the disability questions were asked, only one patient asked the agent why the questions were being collected. With the explanation provided by the agent, the patient had no concerns with disclosing his disability status. When reviewing the calls, the research team noted that the agents deviated from the scripts and prompts 56.5% of the time. The modifications were categorized into two groups. The first was rewording of the questions and prompt language. The second category was the agent expressing concern and hesitancy about how the patient might perceive the questions. (Table 5)

Experiences with Collection of Disability Status

Focus Groups with Agents. The study team conducted a total of three mini–focus groups with 10 agents. In discussing the implementation of collecting disability status, the agents reported minimal difficulties with asking the questions. Some agents reported forgetting to ask the disability questions. They reported that no patient had questioned or refused to answer the questions and that the initial training appropriately prepared them. Despite this, agents reported some confusion as to where to record the disability status responses in the Epic registration wizard. During the discussion, it was unclear whether the agents had similar or different versions of the registration wizard. All agents reported a willingness to continue to collect the disability status questions. They indicated a preference for the screener question over asking the full disability question set.

Interviews with Patients. The study team conducted a total of 20 interviews with patients, 10 with a disability recorded and 10 with "no disability" recorded. Patients across all of the interviews reported that they did not remember being asked the disability questions during patient registration. When asked about how they felt about being asked the questions, they reported no concerns with disclosing whether or not they had a disability. The only potential concern they reported was regarding how the HCO would use the data. When presented with the prompt that was provided to the agents, the patients reported that the prompt would be sufficient in quelling their concerns.

DISCUSSION

Comprehensive, consistent, and accurate collection of patients' disability status is critical in ensuring equitable and accessible health care for patients with disabilities. With this relatively brief intervention, we increased the completion of the disability demographic fields from a baseline of 9.5% to > 53.5% in just several weeks for newly registering patients. This was maintained for eight weeks after the trial officially concluded. In comparing the full question set to the screener question, agents overwhelmingly preferred the screener question. The full question set might be more sensitive in identifying disability status, but if agents are less likely to ask the full set of questions, then the screener question is the better option for comprehensive, consistent collection.

Our prevalence of disability status among newly registering patients was low (< 5%), whereas national disability estimates are closer to 19%.[4] Yet, the prevalence of disability was not significantly different between the full question set (Phase 1) and the screener question (Phase 2). There are a few possible explanations for this finding. We had low rates of patients with Medicare and Medicaid insurance, populations with higher rates of disability, and higher rates of young patients with private insurance—a population with low rates of disability. The disability rates by age group in our sample are actually comparable with disability rates by age group in the state of Colorado,[33] suggesting that the disability questions are accurately identifying patients with disabilities.

One of the main barriers cited by health systems and providers regarding collecting disability status is a concern

Table 5. Examples of Agents' Lack of Consistency and Discomfort Asking Disability Questions as Recorded from Call Observations

Agent Expressing Discomfort Asking Questions	Deviation from Disability Questions Script
You are not required to answer these questions either, so if you're not comfortable you can refuse . . .	Do you have any disabilities, like issues hearing or seeing or walking or any of that, that you want to disclose?
I do have a couple of questions in regard to disability, if these questions make you uncomfortable, again, you don't have to answer.	Does he have any hearing, visually impaired, mobility disabilities, anything like that at all?
I have a couple of questions I'm required to ask about disability . . .	As far as disability needs, are you blind or deaf or anything?
Okay, a couple more questions; again feel free not to answer . . .	So as far as disability, do you have any needs, blind, deaf/hard of hearing? Would you need any accommodations, a bump (?), wheelchair?
. . . They are completely optional, so you don't have to answer these questions.	Do you have any disability, like hearing?

regarding whether the questions will offend patients. In our study, there were no reported complaints from the patients despite potentially up to 3,673 patients being asked the disability questions. This finding was reinforced in both our qualitative interviews with patients and in our focus groups with agents, and aligns with existing literature.[34,35] A previous study found that patients report high level of comfort with disclosing disability status, higher in fact than disclosing race or ethnicity.[35] Therefore, we are confident that the benefits of collecting disability status outweighs any potential minor discomfort.

Although we found a significant increase in the reporting of disability status of the patients with this intervention, we identified discrepancies between what occurred on the call and what was recorded in the EHR upon review of audio-recorded clinical encounters. One key finding from the reviewed calls was hesitancy expressed by agents related to asking about disability status during the calls. Despite the training attempting to assuage this discomfort, agents continued to express concern that the questions might be sensitive. Data on patient race/ethnicity have been routinely collected by these agents for multiple years, yet those questions were not concerning to the agents in our focus groups. Additional training and increased experience with asking the disability questions would likely ease these concerns.

An additional finding from the recorded calls was the inconsistency in how the agents asked the questions. Because the agents were in a call center and thus disconnected from the point of care delivery where accommodations would be provided, it is possible that they were less invested in ensuring that the questions were asked in the same manner and of all patients. Although there are benefits to knowing patients' disability status prior to clinical encounters, there could also be benefits of using multiple systems for data collection (for example, collection during the patient check-in or rooming processes, or asking the patient to complete a questionnaire within the patient portal). No single method is likely to be sufficient, and a multipronged approach is needed for comprehensive, consistent collection and recording of disability status.

As with all research, there are several possible limitations in this study to consider. First, we experienced difficulties accurately identifying newly registering patients. There was an automated PatientLine process to identify new patients, but it was not functional for 10 days at the beginning of the trial. In addition, our EHR characterized a patient as new if they had not had any clinical encounters in our health system within the prior seven years. However, it is possible that an already-established patient simply did not have any medical visits in that time period. Second, UCHealth was actively acquiring additional community primary care clinics during this trial. Established patients of these newly acquired clinics would not be considered new and thus would not have been asked the disability status questions by our agents. In both of these situations, our $> 50\%$ completion rate would underestimate the true completion rate. Also, it is impossible to determine when the disability field is completed in our EHR or by whom. Thus, it is possible that another provider completed the disability field at some point prior to our analysis of the data. This could account for the poor fidelity between the questions that were asked and the responses recorded. It is important to note that although some clinic leadership was aware of the trial, no other clinic staff or providers were aware of the study. Therefore, there should be no spillover effects of our intervention.

In the midst of the COVID-19 pandemic, there has never been a time when it is more imperative to collect patients' disability status to ensure that they receive equitable health care.[36] Comprehensive, consistent collection of patients' disability status is the only means to track, at an organization level, whether patients receive equitable, high-quality health care. Furthermore, collection and recording of patients' disability status is the crucial first step to identifying and providing patients the disability accommodations they need. When a patient identifies as having a disability, the health care system should be prepared to offer disability accommodations. This will likely require follow-up questions to the disability status questions, which would likely differ by health care setting and clinic. For example, a geriatric clinic might have a wider range of types of accommodations available as compared to a general primary care clinic.

CONCLUSION

The findings from this study provide evidence that (1) patients are comfortable disclosing disability status, (2) a screener question is likely acceptable, and (3) collection across multiple methods and settings should be explored. These are critical findings for HCOs ready to implement collection of disability status. Next steps include consistent notification of members of the health care team of positive disability screens and connection of the reported disability to appropriate accommodations. Only then can we hope to deliver comprehensive, equitable, patient-centered care to persons with disabilities.

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