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# Documenting Disability Status in Electronic Health Records



## INTRODUCTION

Approximately 1 in 4 Americans lives with a disability, equating to approximately 67 million Americans.<sup>1,2</sup> The population of persons with disabilities includes a wide variety of disabilities, including those with mobility, communication, hearing, cognitive, visual and mental health disabilities. Disabilities can be acquired at any point of a person's life or can present in early childhood.

A growing body of literature finds that people with disabilities experience disparities in health and health care outcomes. For example, compared to non-disabled people, people with disabilities are more likely to have a greater number of chronic conditions, and have higher rates of asthma, hypertension, emphysema, cardiovascular disease, diabetes and arthritis.<sup>3</sup> People with disabilities are more likely to rate the quality of their health as fair or poor.<sup>4,5</sup>

While multiple factors contribute to poor health outcomes, **inadequate access to high-quality, equitable health care is one of the major barriers.**<sup>6</sup> People with disabilities are more likely to report difficulty finding a clinician.<sup>3</sup> When they do access care, they report low satisfaction with the quality of care and communication they receive.<sup>3,7</sup> Persistent disparities in cancer screenings, such as Pap tests<sup>8</sup> and mammography exist.<sup>9,10</sup> A significantly larger percentage of people with disabilities have at least one hospitalization and emergency department visit within a year as compared to people without disabilities.<sup>3</sup> People with disabilities have a greater odds of hospital readmissions and are more likely to experience an adverse medical event in the hospital.<sup>11,12</sup> To begin to address these disparities and improve patient outcomes, healthcare organizations need to systematically collect patients' disability status.<sup>13</sup>

Scant evidence exists to inform best practices for collecting patients' disability status. The following document is a synthesis of existing data as well as learnings from health systems across the country who are actively working on implementing the collection of patients' disability status in their organizations. The document should be regarded as guidelines that can be adapted to the local context. As more organizations and health systems begin to document patients' disability status, the more we can learn from each other, as well as begin to improve the care and health of those with disabilities.

[www.DisabilityEquityCollaborative.org](http://www.DisabilityEquityCollaborative.org)

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## 1. Why is it important to collect patients' disability status?

### Documentation of disability status is necessary for addressing disparities and improving care

In order for clinics and organizations to identify and address potential disparities in care experienced by people with disabilities, patients' disability status needs to be systematically and accurately documented. First, documentation of disability status is necessary in order to identify where the disparities exist and the extent of the disparities. Documentation of disability status is then necessary for designing and measuring the effects of initiatives and efforts to improve care delivered to patients with disabilities. Finally, the information can be used to identify people who are at risk for disparate impacts of social determinants of health.

### Documenting patients' disability status assists with provision of disability accommodations

According to several federal laws, health care organizations and clinics are required to provide patients with disabilities equitable health care. This includes the provision of disability accommodations, auxiliary aids, and services. To provide these resources to patients who require them, health care organizations first need to ask patients if they have a disability (collect disability status) and if so, whether the patient requires health care accommodations.<sup>14</sup> Example accommodations include but are not limited to: ASL interpreter, extended appointment times, transfer assistance to the exam table, sound amplifiers, readers and note takers, etc.

## 2. What are the mandates for providing accessible healthcare?

Multiple federal laws require health care organizations to provide accessible and equitable health care services to persons with disabilities. The following is a quick snapshot of some of these requirements.

- The Rehabilitation Act of 1973, Section 504<sup>15</sup>
  - Prohibits discrimination against people on the basis of disability
  - Applicable to all programs and activities that receive federal funding from the United States Department of Health and Human Services (HHS) or are conducted by HHS
- Americans with Disabilities Act (ADA) of 1990<sup>16</sup>
  - Created federal civil rights protections that prohibit discrimination against people with disabilities
  - The ADA applies to any organization that provides services to the public, which includes all healthcare services
  - The ADA states that health care organizations must provide full and equal access to people with disabilities
- Affordable Care Act (ACA) of 2010, Section 1557<sup>17</sup>
  - Prohibits discrimination on the basis of race, color, national origin, age, **disability**, or sex by health programs and activities covered by the ACA
  - Requires covered entities to provide appropriate auxiliary aids and services, such as alternative formats and sign language interpreters, where necessary for effective communication

*In addition to these federal laws, states may have laws and statutes requiring the provision of accessible care.*

### 3. Are there legal requirements for documenting disability status?

First, it is important to note that it is not illegal to ask patients about their disability status.

- Section 4302 of the ACA requires the collection of disability status by organizations that receive federal funding.<sup>18</sup> The intent of this statute is to identify and address health and health care disparities. This has been mainly applied to national surveys. Some have interpreted this statute to apply to health care organizations as well.
- In several cases in which health systems were found to **not** be accessible to patients with disabilities, the Department of Justice stated that health care organizations need to collect disability status in order to identify patients who require health care accommodations.<sup>19</sup>
- In July 2022, the Office for the National Coordinator for Health Information Technology released Version 3 of their interoperability standards. Included in this is the documentation of patients' disability status.<sup>20</sup>

### 4. How does disability relate to other patient characteristics?

Disability is a patient-reported demographic characteristic like race, ethnicity, preferred language, gender identity, sexual orientation, etc. For some people with disabilities, disability is a part of their identity, just like their race, ethnicity, sexual orientation, or gender identity. Any processes for documenting other patient demographics could incorporate documentation of disability status. Additionally, disability status should be displayed in the electronic health record (EHR) in the same location as other demographic characteristics.

### 5. Can a clinician assess a patient's disability status?

Like other demographic information, disability status must be patient-reported. Disability status is different from a clinical assessment that is used to inform care provision. As such, there is not a reliable method to use clinical charts and diagnosis codes to determine a patient's disability status.<sup>21,22</sup> Additionally, disability status should not be obtained through insurance status or disability benefits. Benefits assessment is a separate evaluation process and cannot be combined with collection of patients' disability status.

### 6. What questions should we ask?

Currently, there are no requirements for which disability status questions to use. We present 3 lists of disability status questions, as well as some general best practices. Each question set has 6 questions. These questions are not representative of all disability categories. Notably, the questions are not inclusive of Autism Spectrum Disorder or other social disabilities, learning disabilities, and mental health disabilities.

Our team, as a part of the Disability Equity Collaborative Documentation Workgroup, interviewed representatives from 15 health care systems about their process for documentation of patients' disability status. We found that almost all systems collected hearing and vision disability information and most collected cognitive, mobility and communication disability information. Other disability



categories mentioned included: Autism Spectrum Disorder, learning disability, intellectual/developmental disability, and an Instrumental Activities of Daily Living (IADL) question on doing errands. It is important to note that these categories of disability types, as well as the ones represented in the question sets below are not inclusive of all disabilities. Your organization might decide to expand the disability questions, especially if your community has a high prevalence of other disabilities not represented in these questions. We highly recommend including patient response options of “none”, “decline to answer” and “other disability”. When an “other” disability is indicated, there should be an option for a comment field to write in the disability.

- American Community Survey (ACS) Disability Questions: Following the passage of Section 4302 of the ACA, HHS recommended the use of the ACS Disability Questions.<sup>23</sup> The original intent of the questions was to provide population-level prevalence estimates of disability in the United States.
  - Benefits of using these questions:
    - i. These are standard questions in disability population surveys in the United States. This allows for interoperability of the data across the health care system and population surveys.
    - ii. The questions are endorsed by HHS.
  - Potential drawbacks:
    - i. The questions have only been tested in the United States.
    - ii. There is no communication disability question.
    - iii. Several of the questions have long preambles, which might make implementation more challenging.
    - iv. The “doing errands” question does not assist in identifying patients who require health care accommodations. It is hard to conceptualize what disabilities these patients might represent.
    - v. The questions differ slightly from the Washington Group questions which does not allow for interoperability and sharing of the data between health care systems and public health data.
    - vi. These questions have not been tested in a health care setting.
    - vii. The questions are not inclusive of all disability types.
- Washington Group: The United Nations Washington Group on Disability Statistics developed a set of 6 disability status questions. The original intent of the questions was to provide population-level prevalence estimates of disability throughout the world. As such, these questions have been implemented in countries all over the world.<sup>24</sup>
  - Benefits of using these questions:
    - i. The questions have been internationally tested and implemented with linguistically and culturally diverse groups.
    - ii. The questions include a communication disability question.
    - iii. Several of the question wordings are more concise than the ACS questions.



- Potential drawbacks:
  - i. The questions differ slightly from the ACS questions which does not allow for interoperability and sharing of the data between health care systems and public health data.
  - ii. The questions have not been tested in the health care setting.
  - iii. The questions are not inclusive of all disability types.
- Patient-Centered Disability Questionnaire: Our study team embarked on a series of studies to identify disability status questions to be used in health care organizations for the purposes of identifying patients who require disability accommodations and tracking quality of care at an organization-level.<sup>25</sup> These studies included a survey, qualitative focus groups and interviews, a national Delphi panel and cognitive interviews.
  - Benefits of using these questions:
    - i. The questions incorporate both the ACS and the Washington Group questions.
    - ii. The questions have been tested in the health care setting.<sup>26</sup>
    - iii. The questions include a communication disability question.
  - Potential drawbacks:
    - i. Since the questions are not identical to either the ACS or Washington Group questions, it is not possible to compare the full disability question set to public health data gathered using either of the two other sets of questions.
    - ii. The questions are not inclusive of all disability types.

Disability Category	ACS Questions	Washington Group Questions	Patient-Centered Disability Questionnaire
Hearing	Are you deaf or having serious difficulty hearing?	Do you have difficulty hearing, even if using a hearing aid(s)?	Are you deaf, or do you have serious difficulty hearing?
Vision	Are you blind or having serious difficulty seeing, even when wearing glasses?	Do you have difficulty seeing, even if wearing glasses?	Are you blind, or do you have serious difficulty seeing, even when wearing glasses?
Cognition	Because of a physical, mental, or emotional problem, do you have difficulty remembering, concentrating, or making decisions?	Do you have difficulty remembering or concentrating?	Do you have difficulty remembering or concentrating?
Mobility	Do you have serious difficulty walking or climbing stairs?	Do you have difficulty walking or climbing steps?	Do you have serious difficulty walking or climbing stairs?
Activities of Daily Living (ADL) /Fine Motor	Do you have difficulty bathing or dressing?	Do you have difficulty with self-care, such as washing all over or dressing?	Do you have difficulty dressing or bathing?

<b>Instrumental Activities of Daily Living (IADL)</b>	Because of a physical, mental, or emotional problem, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?		**Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a physician's office or shopping?
<b>Communication</b>		In your usual language, do you have difficulty communicating, for example understanding or being understood?	Using your usual language, do you have difficulty communicating (for example, understanding or being understood)?
<b>General</b>			**Due to a disability, do you need any additional assistance or accommodations during your visit?

*\*\*Optional, but highly recommended question*

## 7. Are all 6 questions necessary?

Currently, regardless of which set of questions is used, the recommendations are to ask all 6 questions listed in the table above. Using the Patient-Centered Disability Questionnaire, our study team tested asking one screener question versus all 6 disability questions.<sup>26</sup> In the case of the screener question, if a patient answered the question affirmatively, then the staff was instructed to ask the full set of 6 questions. We found that staff were more likely to ask the screener question than the full set of 6 questions. We found no difference in the percentage of those who reported a disability between asking only the screener question or the full set. Despite these findings, we highly recommend more research in this area.

## 8. Do we need to ask all patients about their disability status?

Some patients might have non-apparent disabilities and so it is important that all patients are asked about their disability status.

## 9. Are the questions coded within a standardized system?

Yes. All of the questions are already coded and included in the latest version of LOINC. See Appendix A for a list of the LOINC codes.

## 10. Is there a place to report these questions in my organization's electronic health record (EHR)?

This will depend on your EHR vendor and whether your organization has opted to have these questions available. It is possible that you will need to build these questions into your EHR. Efforts are underway to develop EHR tools and support for the disability questions. Please email Dr. Megan Morris ([megan.a.morris@cuanschutz.edu](mailto:megan.a.morris@cuanschutz.edu)) for additional information.

### 11. Could we ask only about accommodation needs rather than the disability status questions?

It is important to ask about disability status *and* accommodation needs. Not all persons with disabilities will require accommodations. Conversely, not all persons who have accommodation needs will self-identify as having a disability. As with other demographic characteristics that are routinely collected, it is important to track who has a disability in order to ensure you are providing equitable care to all patients with disabilities.

### 12. What about caregivers?

Health care organizations are required to provide accommodations to caregivers who have disabilities. For example, if a caregiver is Deaf and their primary language is American Sign Language, health care organizations must provide an ASL interpreter for the caregiver. As such, you should collect disability status and accommodation needs from caregivers as well and store it in the patient's medical chart.

### 13. How and when should we collect disability status and accommodation needs?

There are no specific standards for how disability status and accommodation needs should be collected. How it is collected will be likely influenced by the setting in which the information is collected. It should be noted again, that the questions need to be patient-reported. Collection should occur in the emergency department, outpatient, and inpatient settings, as well as telehealth and home care. It is recommended to have multiple options and settings in which disability status and accommodation needs are asked. Having multiple points will allow patients to disclose in the setting they are most comfortable. One option is to have patients input their disability status and accommodation needs via the patient portal. It is important to note that this requires that the patient portal also be accessible, including usable for patients with low vision who use a screen reader.

Disability status and accommodation needs should be collected ***either prior to or at the beginning*** of a patient's appointment. This will allow you to identify their accommodation needs and provide the accommodations at the time of the appointment.

Who should collect?	When should it be collected?	How should it be collected?
Registrars Schedulers Medical Assistants Clinicians Patients	New patient registration Scheduling Check-in Intake In exam or patient room	Patient Portal Intake forms Verbally asked by staff or providers Patient kiosks

## 14. How often should we collect disability status and accommodation needs?

Generally, the agreed upon timeframe is every 6-12 months, though no concrete standard exists. Patients with either progressing conditions such as Parkinson's Disease, or patients who are recovering from an injury might need to be asked about their disability status and accommodation needs more frequently.

## 15. How much work is it to ask patients about their disability status?

The time it takes to inquire about disability status depends on the method used. In a study we conducted, we trained registration staff to ask disability status questions as part of the new patient registration process. The main performance metric for these staff was the length of calls. Consequently, time to ask the questions was important to leadership. During the study time frame, the disability status questions were asked approximately 1,682 times during recorded calls. Asking the full set of 6 disability status questions lengthened the call time by an average of 62 seconds. Asking a screener question then the full set of questions lengthened the call time by an average of 18 seconds. Other methods such as collecting disability status through intake forms or the patient portal are likely more time efficient collection methods for staff.

## 16. Where should disability status and accommodation needs be displayed in the electronic health record?

Disability status and accommodation needs should be prominently displayed in a patient's medical record. Typical locations include the top or sidebar of the patient's medical record. The information should be located in a similar place as the patient's primary language, age, gender identity, allergies, etc.

### 17. Who should have access to view the patient's disability status?

Anyone who will be interacting with the patient in-person, virtually, over the phone, or by mail should be able to view the patient's disability status. This could include staff in the following areas:

- Billing
- Risk Management/Claims
- Patient Experience
- Patient Safety
- Quality Improvement
- Health Equity
- Scheduling
- Interpretation
- Clinical teams

### 18. Will we offend patients by asking about their disability status?

In research we have conducted, including a survey of patients with and without disabilities, participants report a high level of comfort with healthcare systems collecting the information.<sup>27</sup> In another study in which we implemented collection of disability status for >3,000 patients, we had no patient complaints about collection of patients' disability status.<sup>26</sup> When we conducted follow-up interviews with patients who completed the questions, they reported not even remembering that they were asked the questions. Additionally, they reported that they expected their health care organization to collect disability status, as disability information was less sensitive than other information that is routinely collected by their health care team.

To be prepared to address patients' concerns, we recommend providing a short prompt prior to the disability questions in case the patient questions why the questions are being asked. (See Appendix B for an example prompt). Additionally, we suggest preparing staff with a list of answers to common questions the patient might ask. (See Appendix C for example questions and responses).

### 19. Will collecting disability status lead to greater stigma and discrimination?

It is always possible that a staff member will identify that a patient has a disability and then treat the patient differently. However, we believe the benefits greatly outweigh the risks. Patients with disabilities already report being treated differently and being discriminated against in health care settings. We cannot begin to address this discrimination until we collect patients' disability status. Collection of disability status allows organizations to measure the extent of the problems and to develop and implement interventions to ameliorate the disparities. Additionally, the health care system has collected demographic characteristics such as race and ethnicity from patients for decades, without an increase in discrimination.

### 20. What if a patient refuses to answer the questions?

Since the questions are patient-reported, it is completely within a patient's right to refuse to answer the questions. Even if you suspect a patient has a disability, only record what the patient reports.

### 21. What training do staff need to ask the questions?

Because this is not a clinical assessment, the staff asking the disability questions do not need any specialized clinical training. Staff should be trained on how to ask the questions and why the disability status questions are asked. Additionally, we suggest some basic disability etiquette so that staff know how to talk about disabilities in a patient-centered and respectful manner. See Appendix D for example trainings and training materials.

### 22. What if we ask patients about their disability status and accommodation needs and we do not have the accommodations they request?

You will not know what accommodations you need to have available in your clinic or hospital if you do not begin to ask patients about their disability and accommodation needs. Therefore, asking about disability status and accommodation needs is the first step in your organization's journey to providing equitable care. In qualitative work that we have conducted, patients with disabilities reported that they understood that an organization might not have an accommodation immediately available. They believed it was important to ask about their disability status anyway. Included in the Appendix B is a scripted response that staff can utilize to if they are unsure about the ability to offer an accommodation that is requested.

### 23. Our organization is interested in collecting patients' disability status and accommodation needs. Where do we start?

Leadership support is critical to success. Documenting patients' disability status and providing disability accommodations touches almost all units and departments within a health care organization, so it is important to engage leadership across departments. Examples of departments include but are not limited to: registration, scheduling, billing, IT, patient experience, emergency departments, and inpatient and outpatient clinics. Some organizations have convened cross-department committees on the topic to facilitate communication and to gain wide-spread support. Once you have leadership support and buy-in, you will need to work with your IT team to identify where disability status will exist in your EHR, what disability and accommodation options and questions you will include, and what additional functionalities you would like built into and connected to disability status. Finally, you would need to determine the workflow processes to integrate routine and systematic documentation into your routine operations. Again, this will likely require multiple stakeholders in your organization working together.

### 24. What are other considerations we should make when building the disability and accommodation fields within our EHR?

When building the disability status and accommodation fields within your EHR, consider adding a timestamp of when the field is completed, the source and method used to collect disability status, and who completed the field. Since a person's disability status could change over time, having the historical record of their disability status is important. For the accommodation fields, consider building in the ability to document when an accommodation was provided and used, as well as if a patient declined an accommodation. Finally, consider what additional functionalities you would like

to build into the fields. For example, if a patient has a documented visual disability and need large print materials, their After-Visit Summaries could automatically print in large print. Or, if a patient has a documented mobility disability, the scheduling application will automatically schedule the patient in an examination room with a height adjustable examination table. Organizations have also found it helpful to be able to generate reports of upcoming accommodation needs by clinic.

### 25. We have begun to collect patients' disability status and accommodation needs. Now what do we do?

Disability status information can be used in any quality improvement work you conduct in your organization, such as stratifying patient process and outcome measures, patient experience, access to care, etc. by disability status. For example, if you have a project on Social Determinants of Health, you could use collected disability status to identify if there are certain disability groups that are at risk for the disparate impact of social determinants of health. Additionally, be prepared if your state or local public health department might request that the information about patients' disability status be shared. For example, they could request COVID-19 cases, deaths, and immunizations by disability status. For patients with an identified disability accommodation need, workflow processes need to be established to ensure that accommodations are provided in a timely and efficient manner. Finally, some organizations have stated that they use reports of the accommodation needs field to assist with planning for purchasing accessible equipment and other accommodations.

### 26. How do I connect with others about documenting patients' disability status and providing equitable healthcare to patients with disabilities?

The Disability Equity Collaborative (<https://www.disabilityequitycollaborative.org/>) has learning communities for health care organizations and clinics on providing equitable healthcare to patients with disabilities. Additionally, we host a library of resources, publish a quarterly newsletter, and convene multiple workgroups. Contact us for more information or to get connected.

### 27. What research exists on documenting patients' disability status and accommodation needs?

Below is a list of references of existing research on the topic of documenting patients disability status and accommodation needs:

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# APPENDIX A

## *LOINC Codes*

## Appendix A: LOINC Codes

LOINC Number	Method and Type	Class	Question Description	Status	ACS <sup>a</sup>	WG <sup>b</sup>	PCDQ <sup>c</sup>	Disability Type
69860-5		SURVEY.HHS	Do you have difficulty dressing or bathing	ACTIVE	x		x	Activities of Daily Living
69858-9		SURVEY.HHS	Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions	ACTIVE	x		x	Cognition
75254-3	HHS.ACA Section 4302.ONC	SURVEY.HHS	Do you have difficulty communicating, reading, or do you have limited proficiency in English [HHS.ACA Section 4302.ONC]	TRIAL				Communication
98068-0		SURVEY.GNHLTH	Difficulty communicating in usual language	ACTIVE			x	Communication
75255-0	HHS.ACA Section 4302.ONC	SURVEY.HHS	Assistance needed [HHS.ACA Section 4302.ONC]	TRIAL				General
98079-7		SURVEY.GNHLTH	Do you need any additional assistance or accommodations during your visit	ACTIVE			x	General
69856-3		SURVEY.HHS	Are you deaf or do you have serious difficulty hearing	ACTIVE	x		x	Hearing
75250-1	HHS.ACA Section 4302.ONC	SURVEY.HHS	Are you deaf or do you have difficulty hearing [HHS.ACA Section 4302.ONC]	TRIAL				Hearing
69861-3		SURVEY.HHS	Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a physician's office or shopping	ACTIVE	x		x	Instrumental Activities of Daily Living
75253-5	HHS.ACA Section 4302.ONC	SURVEY.HHS	Because of a physical, mental, or emotional condition, do you have difficulty doing errands such as visiting a doctor's office or shopping [HHS.ACA Section 4302.ONC]	TRIAL	x		x	Instrumental Activities of Daily Living
98078-9		SURVEY.GNHLTH	Difficulty reading or writing	ACTIVE			x	Learning
69859-7		SURVEY.HHS	Do you have serious difficulty walking or climbing stairs	ACTIVE	x	x	x	Mobility
75252-7	HHS.ACA Section 4302.ONC	SURVEY.HHS	Do you have difficulty walking or climbing stairs [HHS.ACA Section 4302.ONC]	TRIAL				Mobility
69919-9	HHS.ACA Section 4302	PANEL.SURVEY.HHS	Race, ethnicity, sex, primary language, disability - Health and Human Services (HHS) panel [HHS.ACA Section 4302]	TRIAL				Title of questionnaire
75256-8	HHS.ACA Section 4302.ONC	PANEL.SURVEY.HHS	Disability information and assistance needed panel [HHS.ACA Section 4302.ONC]	TRIAL				Title of questionnaire

## Documenting Disability Status in Electronic Health Records

98067-2		PANEL. SURVEY. GNHLTH	Patient-centered disability questionnaire	ACTIVE				Title of questionnaire
69857-1		SURVEY.HHS	Are you blind, or do you have serious difficulty seeing, even when wearing glasses	ACTIVE	x		x	Vision
75251-9	HHS.ACA Section 4302.ONC	SURVEY.HHS	Are you blind or do you have difficulty seeing [HHS.ACA Section 4302.ONC]	TRIAL				Vision

<sup>a</sup>American Community Survey Questions

<sup>b</sup>Washington Group Questions

<sup>c</sup>Patient-Centered Disability Questionnaire

# APPENDIX B

## *Example Prompt and Disability Questions*



### Example Prompt and Disability Questions

**Prompt:** “The next question asks about whether or not you have a disability, in order to help us train our staff and figure out how to be most helpful to our patients.”

**Screener question:** “Due to a disability, do you need any additional assistance or accommodations during your visit?”

If NO, do not ask any additional disability questions and move to next section.

**Only if YES:** “Thank you, now I’m going to ask you a few more questions about your needs.”

1. Are you deaf or have serious difficulty hearing? (**deaf/hard of hearing**)
  2. Are you blind or do you have difficulty seeing, even when wearing glasses?  
(**blind/visually impaired**)
  3. Do you have serious difficulty walking or climbing stairs? (**mobility disability**)
  4. Do you have difficulty remembering or concentrating? (**cognitive disability**)
  5. Do you have difficulty dressing or bathing? (**manual dexterity disability**)
  6. Using your usual language, do you have difficulty communicating (for example, understanding or being understood)? (**communication disability**)
- 

*Scripted responses if a patient asks why this information is being collected, has concerns about answering the prompt or receiving accommodations.*

**Q: Why is this information being collected?**

A: “We ask this question to all new patients at the clinic in order to learn more about our patient population and the accommodations that our patients with disabilities might need, such as large print documents for patients with visual impairment, or height-adjustable exam tables for patients with physical disabilities. This allows us to identify ways to best meet the needs of all of our patients. However, you can choose not to answer this question if you prefer.”

**Q: Will you provide my requested accommodation?**

A: “At this time, we cannot guarantee that a specific clinic or facility will have your requested accommodation. However, I will make a note about your accommodation request in your chart so that the clinic staff is aware of your needs.”

# APPENDIX C

## *Collecting Disability Status FAQs for Clinics*

### Collection of Patients' Disability Status: Frequently Asked Questions

#### 1. Why is disability status being collected?

To provide equitable, patient-centered care that responds to the needs of its patient population, consistent collection of patients' disability status data need collected. Also, it's also the law! As part of the Affordable Care Act, healthcare organizations must now document patients' disability status in order to track the quality of care delivered to patients with disabilities and to identify patients who require healthcare accommodations.

#### 2. Why is disability status being collected at registration?

All of the healthcare team members need to be aware if a patient has a disability so that everyone from the person registering and scheduling the patient to the doctor to the phlebotomist can accommodate the patient.

#### 3. How do patients feel about being asked to disclose their disability status?

In surveys, 94% of all patients with and without disabilities report being comfortable with healthcare organizations collecting their disability status.

#### 4. How should I respond if someone refuses to answer the question?

Patients are not required to provide a response to the disability status questions. Registration staff should mark "Prefer not to answer" in Epic and proceed to the next question.

#### 5. What do I do if a patient requests a specific accommodation?

At this time, we cannot guarantee that a specific clinic or facility will have the requested accommodation. However, let the patient know that you will make a note about this in their chart so that the clinic staff is aware of their needs.

#### 6. What if someone says they do not have a disability, but I think they might?

Disability status is a patient-reported field, just like race and ethnicity. Providers and staff should not assume or record a disability in the disability status field if the patient does not report having one. Patients who report a disability may receive accommodations from the healthcare system. Accommodations will be made for those patients identifying a need.

# APPENDIX D

## *Collecting Disability Status Training Slide Deck and Table Tent*

## Collecting Patients' Disability Status

Training materials developed at the University of Colorado,  
School of Medicine

1



### Documenting Patients' Disability Status- Learning Objectives

- Define disability and identify types of disabilities
  - Identify accommodations for common disabilities
- Identify appropriate language to use when talking to someone with a disability
- Describe why we need to collect disability status from patients
- Practice asking disability questions

2

## What is a disability?

- According to the American's with Disabilities Act (ADA), a person with a disability is an individual with a “**physical or mental impairment that substantially limits one or more major life activities**”.
  - Includes people who have an impairment but do not identify as disabled, but are regarded as having a disability (such as people who are Deaf who don't identify as having a disability).
- 1 in 5 people in the US lives with a disability, which includes physical, cognitive, hearing, visual, mental health, and communication disabilities
- Disabilities can be present from birth (e.g., cerebral palsy) or acquired later on in life (age-related hearing loss).

3

## Why collect disability status?

### To provide quality care to all patients

- The ADA requires healthcare organizations, hospitals, and clinics to provide disability accommodations so that patients with disabilities have equal access to healthcare services
- Despite this mandate, people with disabilities are at significant risk for **healthcare disparities**.
  - For example, patients with communication disabilities are 3x more likely to experience a preventable adverse medical event in the hospital as compared to patients without disabilities.
  - Women with physical disabilities are less likely to have preventative cancer screenings (e.g., mammograms and pap smears) due to inaccessible medical equipment
- To begin to provide equitable care, healthcare organizations need to consistently collect patients' disability status data.

4

### Why collect disability status?

#### **It's the law!**

- The Joint Commission and Section 4302 of the Affordable Care Act state that HCOs need to document patients' disability status in order to...
  - generate data for HCOs to use to track quality of care delivered to patients with disabilities
  - identify patients who require healthcare accommodations, such as height-adjustable examination tables.

5

### Example: Patient questions why disability status is being asked



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### We collect other demographic data, but not disability data

- Percent of hospitals that report collecting race and ethnicity data: **92%**
- Percent of hospitals that report collecting primary language data: **84%**
- HCOs **do not** systematically collect disability status.
  - Clinics may collect some information, such as use of a wheelchair, but these questions are often not inclusive of a range of disabilities and the data are not used to track or improve quality of care.
  - Using diagnosis codes is problematic as studies have found that providers infrequently and inconsistently use disability diagnosis codes.

7

### Why are the questions collected at registration?

- ALL of the healthcare team members need to be aware if a patient has a disability so that everyone from the person registering and scheduling the patient to the doctor to the phlebotomist can accommodate the patient
- These questions are self-reported and are not diagnosis code related
  - Patients are not required to disclose a disability if they don't want to
  - Please do not guess or assume that a patient has a disability

8

## Disability Questions

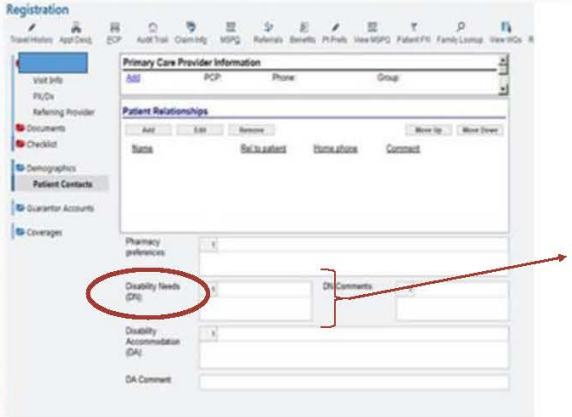


9

## Script

- **Prompt:** “The next questions ask about whether or not you have a disability, in order to help us train our staff and figure out how to be most helpful to our patients.”
  1. Are you deaf or have serious difficulty hearing? (deaf/hard of hearing)
  2. Are you blind or do you have difficulty seeing, even when wearing glasses? (blind/visually impaired)
  3. Do you have serious difficulty walking or climbing stairs? (physical/mobility disability)
  4. Do you have difficulty remembering or concentrating? (cognitive disability)
  5. Do you have difficulty dressing or bathing? (manual dexterity disability)
  6. Using your usual language, do you have difficulty communicating (for example, understanding or being understood)? (communication disability)
  7. Due to a disability, do you need any additional assistance or accommodations during your visit? (other disability)

10

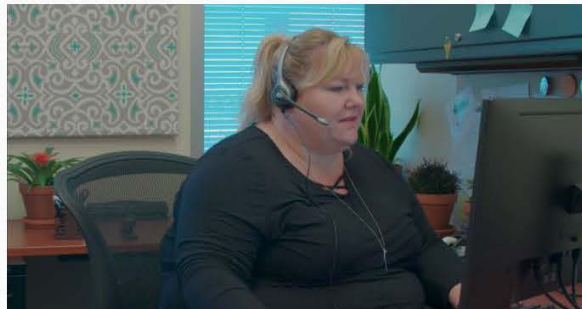


The screenshot shows a patient registration form in an EHR system. The form includes sections for Primary Care Provider Information, Patient Relationships, and various checkboxes for patient status. A red circle highlights the 'Disability Status (DS)' field, and a red arrow points to a dropdown menu. The dropdown menu lists the following options:

- Blind or Low Vision
- Cognitive/Intellectual Disability
- Deaf/Hard of Hearing
- Declined to Answer
- Manual Dexterity Disability
- Mobility Disability
- None
- Other Disability Requiring Accommodation
- Speech/Communication Disability

11

Example: Patient requests a specific accommodation



12

### How do patients feel about being asked to disclose their disability?

- **94% of patients** with and without disabilities reported **comfort** with disclosing their disability status
  - This is a higher percentage of patients who are comfortable disclosing race/ethnicity, which we routinely collect

13

### Example: Patient Refuses to Answer Question



14

## Disability Etiquette



15



### Disability Etiquette:

Use Person-First Language

**Person-First Language** = Refer to the person first, then the disability



Say:

“John is a person with autism”



Not:

“John is an autistic person”

16





### Disability Etiquette: Use value-neutral language

**Value-Neutral Language** = Language that doesn't have negative connotations



Say:

“She uses a wheelchair”



Not:

- “She is wheelchair-bound”
- “She is confined to a wheelchair”

17



### Disability Etiquette: Use value-neutral language

**Value-Neutral Language** = Language that doesn't have negative connotations; use neutral language

**Never Say:**

“handicapped”, “crippled”, “retarded”

18

Example: Scheduler asks all 6 questions, patient reports having a disability



19

### Types of Disabilities and Accommodations



20



## Disability Accommodations

- You are not expected to know all of the possible disability accommodations
- The following slides will give you examples so you are aware of what accommodations might exist

21



## Deaf and Hard of Hearing



- 15% of Americans report a hearing disability
- Not all patients who are deaf use American Sign Language (ASL)



### Common Accommodations:

- Qualified ASL interpreters
- Note takers
- Real-time captioning
- Written materials
- Assistive listening systems

22

## Blind or Visually Impaired



- Some patients are completely blind
- Others may have low vision



### Common Accommodations:

- Large-print materials
- Qualified readers
- Taped texts
- Braille materials (limited)

23

## Physical/Mobility Disabilities



- Limits an individual's...
  - physical functioning
  - mobility
  - stamina
- Patients with physical disabilities **may or may not use an assistive device** (e.g., wheelchair, scooter, crutches)

### Common Accommodations:

- Height adjustable exam tables
- Wheelchair accessible weight scale
- Exam room space to maneuver mobility device
- Additional time to travel between appointments
- Disability parking

24

## Manual Dexterity Disabilities



- **Manual dexterity** is defined as the coordination of small muscles to create movement, such as writing or buttoning



### Common Accommodations:

- Help dressing or undressing
- Assistance or alternative format to fill out written forms

25



## Cognitive Disabilities

- Impaired intellectual or adaptive functioning, such as...
  - Difficulties with memory
  - Problem-solving
  - Reading
  - Attention
- Examples include:
  - Down's Syndrome
  - Alzheimer's Disease

### Common Accommodations:

- Extra time during appointments
- Written summaries of appointments
- Assistance or alternative formats to fill out forms

26



## Communication Disabilities

- **10% of adults** report a speech, language, or voice disability
- People with communication disabilities can have difficulty understanding, speaking, reading or writing language
- Examples include:
  - Developmental delays that result in problems speaking
  - Stuttering
  - Voice disorders

### Common Accommodations:

- Extra time to ask and answer questions
- Written summaries
- Communication boards

**Note:** Patients with CD often experience being hung up on due to difficulties speaking—don't hang up!

**Note:** Communication disabilities do NOT include people for whom English is not their first language

27

## Example: Patient has impaired communication



28

**Only if YES:** "Thank you, now I'm going to ask you a few more questions about your needs."  
1. Are you deaf or have serious difficulty hearing? (**deaf/hard of hearing**)  
2. Are you blind or do you have difficulty seeing, even when wearing glasses? (**blind/visually impaired**)  
3. Do you have serious difficulty walking or climbing stairs? (**mobility disability**)  
4. Do you have difficulty remembering or concentrating? (**cognitive disability**)  
5. Do you have difficulty dressing or bathing? (**manual dexterity disability**)  
6. Using your usual language, do you have difficulty communicating (for example, understanding or being understood)? (**communication disability**)

---

**If NO,** do not ask any additional disability questions and move to next section.

**Prompt:** "The next question asks about whether or not you have a disability, in order to help us train our staff and figure out how to be most helpful to our patients."  
**Screeners:** "Due to a disability, do you need any additional assistance or accommodations during your visit?"

## Why is this information being collected?

**A:** "We ask this question to all new patients at the clinic in order to learn more about our patient population and the accommodations that our patients with disabilities might need, such as large print documents for patients with visual impairment, or height-adjustable exam tables for patients with physical disabilities. This allows us to identify ways to best meet the needs of all of our patients."

# APPENDIX E

## Overview:

### *Documenting Patients' Disability Status in the Electronic Health Record*



## Overview: Documenting Patients' Disability Status in the Electronic Health Record

### Why is it important to collect patients' disability status?

- (1) To identify and address potential disparities in care, patients' disability status needs to be systematically and accurately documented.
- (2) Health care organizations are required to provide patients with disabilities accommodations, auxiliary aids, and services. To provide these resources, health care organizations first need to ask patients if they have a disability.

### What are the requirements for documenting disability status?

Section 4302 of the ACA requires the collection of disability status by organizations that receive federal funding. The Department of Justice states that health care organizations need to collect disability status in order to identify patients who require accommodations.

### How does disability relate to other patient characteristics?

Disability is a patient-reported demographic characteristic like race, ethnicity, preferred language, gender identity, sexual orientation, etc. Processes for documenting other patient demographics should incorporate documentation of disability status.

### Can a clinician assess a patient's disability status?

Disability status must be patient-reported. Disability status is different than a clinical assessment that is used to inform care provision.

### Will we offend patients by asking about their disability status?

In multiple research studies, patients report little discomfort in disclosing a disability.

### How much work is it to ask patients about their disability status?

In a study in which a screener question followed by 6 disability status questions were asked during registration, call times increased by 18 seconds. Other methods for collection such as intake forms or the patient portal are potentially more time efficient for staff and providers.

### Sample questions:

Disability Category	Patient-Centered Disability Questionnaire
Hearing	Are you deaf, or do you have serious difficulty hearing?
Vision	Are you blind, or do you have serious difficulty seeing, even when wearing glasses?
Cognition	Do you have difficulty remembering or concentrating?
Mobility	Do you have serious difficulty walking or climbing stairs?
Activities of Daily Living (ADL)/Fine Motor	Do you have difficulty dressing or bathing?
Communication	Using your usual language, do you have difficulty communicating (for example, understanding or being understood)?
General screener	Due to a disability, do you need any additional assistance or accommodations during your visit?