

Advancing Standardization and Interoperability of Disability-Related Data in Electronic Health Records: A Qualitative Study

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Advancing Standardization and Interoperability of Disability-Related Data in Electronic Health Records: A Qualitative Study

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Abstract

Background: Approximately 27% of United States adults live with a disability, yet they face persistent disparities in health outcomes and access to care. The systematic collection of disability status and accommodation needs data in electronic health records (EHRs) can support more equitable access to care, help ensure that patients with disabilities receive appropriate, person-centered care, and bolster efforts to monitor and address health disparities for people with disabilities. However, data collection remains limited in the health care setting.

Objective: This qualitative study aimed to examine current practices for collecting, documenting, and exchanging disability-related data in EHRs. This study identifies the current state of disability-related data collection by health care organizations; describes how these data are used by health care organizations and researchers; presents challenges to data collection; and offers opportunities to advance the standardized collection and use of disability-related data.

Methods: A qualitative, two-pronged approach was employed, consisting of a literature scan and 13 key informant interviews with stakeholders from health systems, research institutions, and policymaking and advocacy organizations. Data were analyzed using a structured abstraction matrix to identify themes related to data collection practices, use cases, challenges, and opportunities to improve standardization and interoperability.

Results: We identified three use cases for collecting, documenting, and exchanging disability-related data: (1) preparing for patient visits, (2) improving care quality, (3) facilitating care transitions, and (4) advancing equity research. However, findings from the literature scan and key informant interviews revealed that most health care organizations do not routinely collect disability status or accommodation needs data. Among those that do, they employ varied and non-standardized approaches, hindering the ability of health care organizations to provide legally mandated accommodations and deliver equitable, patient-centered care.

Conclusions: Standardized and systematic collection of disability status and accommodation needs data is critical to advancing health equity, improving care quality, and supporting patient-centered care for people with disabilities. The inclusion of “disability status” as a requirement for certified health information technology, including electronic health records (EHR), beginning in 2026 represents a critical step toward more standardized data collection. Efforts to strengthen data collection practices should include workflows for documenting a patient’s self-reported disability and requested accommodations, enhancing health information technology systems, engaging stakeholders across health care settings, and promoting adoption of national standards to ensure disability-related data are accurate, actionable, and interoperable.

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Key Words: Persons with disabilities, disability accommodations, accessibility, electronic health records, documentation, patient-centered care

Introduction

Approximately 27% of adults in the United States live with some form of disability, with cognitive and mobility impairments being most prevalent [1]. Adults with disabilities experience significant disparities in health outcomes and access to care compared to adults without a disability [2] [3] [4] [5]. One in four adults with disabilities do not have a usual health care clinician and have unmet health needs in the past year due to health care costs [1].

Lack of accessible health care facilities, including medical and diagnostic equipment, and ineffective communication, particularly for patients with communication disabilities, are persistent barriers that contribute to poor access and lower quality of care for individuals with disabilities [6] [7]. Despite longstanding civil rights legislation, such as the Americans with Disabilities Act (ADA) [8] and Section 504 of the Rehabilitation Act of 1973 [9], many health care environments remain ill-equipped to accommodate patients with disabilities. For example, examination rooms may lack height-adjustable exam tables and accessible weight scales [10] [11], and staff may not be adequately trained in communicating with patients who are deaf, hard of hearing, or have intellectual and developmental disabilities [12] [13]. These gaps in accessible health care can lead to unmet medical needs [14], failure to receive clinical preventive services [15], and inappropriate treatment plans [16], thus contributing to existing health disparities among this population.

Barriers to accessing health care for individuals with disabilities include (1) insufficient knowledge and workforce training within health care organizations around providing accommodations for people with disabilities, (2) access to appropriate medical and diagnostic equipment (i.e., accommodations), (3) clinician's unconscious biases about the health and quality of life of persons with disabilities, and (4) physical barriers within a health care facility [17].

In 2022, the National Council on Disability, released its *Health Equity Framework for People with Disabilities*, which outlines five core components to advance equity [18]. One of these components emphasizes the importance of integrating disability-related data (i.e., disability status and accommodation needs) into electronic health record systems (EHRs). The framework urges health care organizations to systematically collect this information to ensure that patients with disabilities receive appropriate, person-centered care, and to support broader efforts in monitoring and addressing health disparities.

Collecting and documenting a patient's disability status in the EHR can help health care organizations prepare for an upcoming visit by notifying the clinical care team and staff to address any barriers to accessible medical and diagnostic equipment. To make this information more actionable, health care organizations can also document disability-specific accommodation needs in the EHR, facilitating person-centered care based on an individual's identified disability.

The United States Core Data for Interoperability (USCDI) represents a set of health data used to standardize electronic health information and support data interoperability. USCDI is also part of the requirements of the Assistant Secretary for Technology Policy/Office of the National Coordinator for Health IT (ASTP/ONC) Health Information Technology (IT) Certification. This Certification Program supports the availability of health IT, including certified EHRs, that meet established certification criteria, and is required for use by

clinicians and health care organizations participating in certain Centers for Medicare & Medicaid Services (CMS) programs [19]. However, while data standards for documenting and exchanging information on disability status are specified in USCDI Version 3 [20], adoption of this certification criteria does not take effect until January 2026 [21]. Additionally, an equivalent data element for accommodations needs is not included in USCDI, which may slow the adoption of standardized EHR data capture of this information.

The growing attention on disability-inclusive care, and the forthcoming implementation of USCDI Version 3, presents a timely opportunity to assess the current landscape and readiness of health care organizations to collect, document, and exchange standardized disability-related information in the EHR. Examining these practices is essential to identifying gaps and opportunities for standardization and interoperability, ensuring that health systems are equipped to meet the diverse needs of patients with disabilities and advance health equity.

Objectives

This paper examines current practices for collecting, documenting, and exchanging disability-related data in EHRs. We highlight the current state of disability status and accommodation needs data collection in health care organizations; benefits of collecting disability-related data and how these data are used by health care organizations and researchers; challenges to data collection and use; and opportunities to advance the standardized collection and use of disability-related data.

Methods

To assess the current landscape of disability-related data collection in EHRs, we employed a two-pronged qualitative approach that involved (1) a literature scan and (2) key informant interviews. This methodology was designed to capture both documented practices and real-world experiences from a diverse set of stakeholders.

Literature Scan

The literature scan was conducted in November 2024 and included a systematic search of both peer-reviewed and grey literature using Google and PubMed. In addition, we reviewed content from key websites, including Health Level Seven International (HL7), ONC, and the CMS Data Element Library. Our review followed a structured process: we first compiled all identified literature sources, screened titles and abstracts to assess relevance, and then conducted full-text reviews of those that met the inclusion criteria. Eligible sources addressed one or more of the following topics: (1) practices for collecting, documenting, or exchanging disability-related data elements in the EHR and (2) challenges or opportunities related to the collection, use, or standardization of disability-related data. Sources were included if they addressed any disability defined by CMS (hearing, vision, cognition, ambulatory, self-care, or independent living), were based in the United States, published within the last 10 years, and written in English. The search yielded a total of 202 peer-reviewed sources and 66 grey literature sources. After applying our inclusion criteria, we identified 29 relevant peer-reviewed sources and 25 grey literature sources for inclusion in our analysis.

Textbox 1. Example search terms.

PubMed Search Terms

(disability OR disab*) AND ("electronic health record" OR EHR)
((disability OR disab*) AND ("electronic health record" or EHR)) AND (accommodation or accomod*)

Grey Literature Search Terms

intitle:disability intext:accommodation intext:("electronic health record" OR "electronic health records" OR EHR) -job -student -benefit

Key Informant Interviews

To complement the literature scan and gather insights into current practices and challenges not identified in the literature, we purposively sampled 13 key informants who represented health systems and clinicians (n = 4), researchers (n = 3), and policymaking and advocacy organizations (n = 6). Health system and clinician informants—including representatives from large private health systems and academic medical centers—provided insights on how health care organizations collect and use disability-related data in the EHR, specifically, when and how the data are collected, how the data are used, associated challenges, and interoperability gaps. Disability researchers and policymaking and advocacy organizations—including federal agency staff, members of a national data standards collaborative, and a nonprofit health IT organization—shared insights on disability-related data within broader data standardization efforts. AA, KHH, and PD performed the interviews. Each one-hour interview was conducted virtually and audio recorded. Transcript-style notes were produced for each interview to support analysis.

Analytic Approach

For the literature scan, we extracted relevant information from each source using a structured data abstraction matrix. The matrix included domains related to: (1) current practices for collecting, documenting, and exchanging disability-related data, (2) use cases for these data, (3) implementation challenges, (4) data standardization and interoperability, and (5) barriers to collecting, documenting, and using disability information. Data from the key informant interview transcripts were organized in an abstraction matrix using the same domains applied in the literature scan. Drawing on insights across these domains, we identified key themes, which were iteratively refined to ensure consistency and comprehensiveness. We also used findings from both the literature scan and key informant interviews to identify opportunities to strengthen the collection, documentation, use, and exchange of disability-related data.

Ethical Considerations

This study was reviewed by the NORC at the University of Chicago Institutional Review Board and was determined non-human subjects research, as set forth in Federal Regulations 45 CFR 46.102.

Results

The findings from the literature scan and key informant interviews reveal a fragmented and inconsistent approach to collecting and using disability-related data among health care organizations. While a few institutions have begun to implement structured processes, most lack standardized practices, interoperable systems, or the organizational readiness necessary to support standardized data collection and use.

Use Cases

We identified four use cases that describe how disability-related data can be used by health care organizations to enhance person-centered care and reduce health inequities: (1) preparing for patient visits, (2) tracking quality of care, (3) facilitating care transitions, and (4) research. However, the degree to which these data are currently collected for these purposes varies by organization.

Use Case 1: Preparing for patient visits. Documentation of a patient's disability status can prompt questions to identify any accommodations (such as assistive communication devices, mobility aids, ADA accessible rooms, and access to specialized diagnostic

equipment, lifts, bed transfers etc.) the patient may need during the health care encounter. By understanding a patient's disability status, health care organizations can plan to make requested accommodations available before a care visit, thereby minimizing potential inefficiencies that may occur if staff are unaware of these needs ahead of time [22].

To prepare for patient visits, health care organizations use different approaches for sharing disability-related data among administrative staff and clinicians. For example, one of the organizations interviewed, an academic medical center, had a process for using disability status documented in specific fields in the EHR to identify potentially suitable accommodations based on a pre-defined list based on the disability. Dedicated staff members then share a twice-daily report containing these data across the health care system to ensure appropriate care for patients with disabilities.

"When somebody is coming in and scheduling an outpatient appointment, [disability] will be part of the screening that they're asked when they're scheduling their appointment so that we can collect that information and make it present in the person's chart, so that then the clinic is prepared to accommodate the disability even before the person arrives."

A different informant shared that their health care system integrates disability-related data from daily reports into a real-time Power BI dashboard to assist in managing resources to meet a patient's accommodation needs.

Use Case 2: Improving quality of care. Disability-related data can contribute to improvements in care quality by facilitating individualized treatment plans that align with patient goals. When clinicians consistently and longitudinally collect disability status, clinicians are better able to track a patient's disability over time and to promptly address any changes.

Health care organizations can also use disability-related data to enhance understanding of health outcomes and health care utilization of people with disabilities. One informant shared that their health care organization hopes to one day extract disability status data from the EHR to quantify disability disparities within the community, develop strategies to address them, and improve patient care experiences.

Use Case 3: Facilitating care transitions. Key informants noted that sharing disability-related data among health care organizations and in-home health care teams supports discharge planning, referrals, and identification of appropriate community-based services by helping to ensure safe, and patient-centered transitions of care. A key informant emphasized the clinical relevance of sharing these data across health and social services providers:

"When we fail to fully describe the context and need of an individual when they're moving through different health care delivery systems, the risk is higher that the experience and actually, maybe the effectiveness of care, is compromised because we're not meeting the full need of the person."

Use Case 4: Promoting equity research. Disability-related data serves multiple research purposes, including enhancing understanding of population health, health equity, and intersectionality of people with disabilities. Researchers utilize disability-related data to explore various health outcomes and conditions, such as neurologic outcomes in hospitalized adults [23], functional status among older adults in hospitals [24], and neurodevelopmental disorders in adults and children [25] [26] [27] [28]. Informants advocate using disability-related data to tackle health disparities and access issues, with a focus on marginalized groups such as racial minorities, low-income populations, and individuals developing functional limitations before age 65.

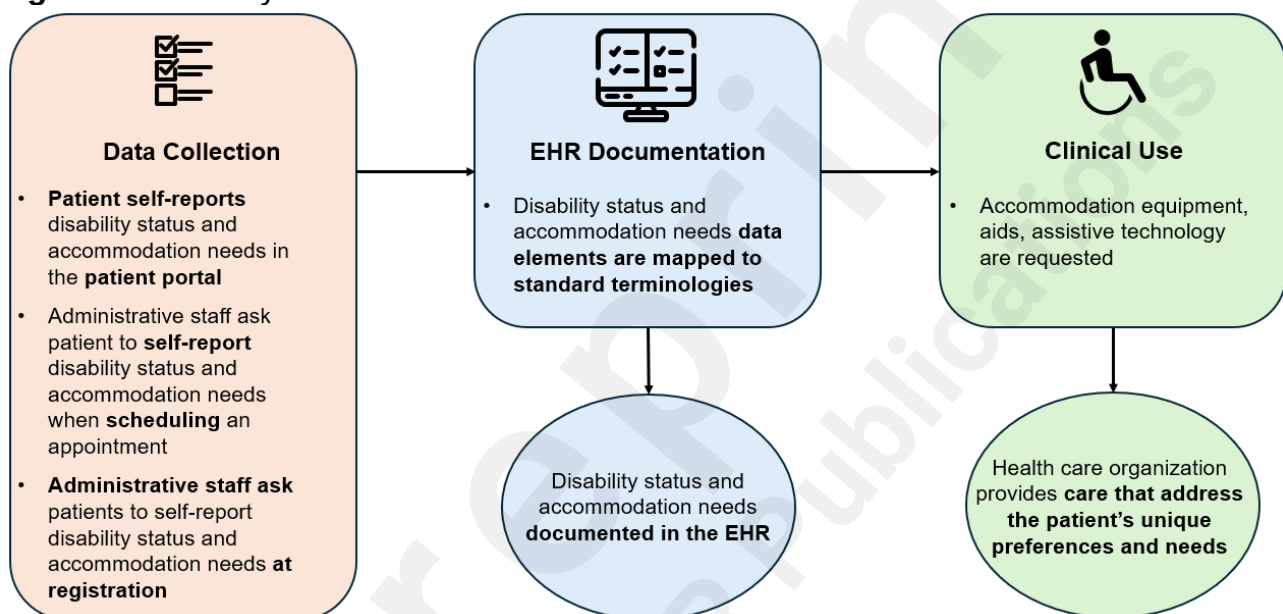
Current State of Disability-Related Data Collection in Health Care Organizations.

According to the literature [22] [24] [29] [30] [31] and key informant interviews, some health

care organizations collect disability status data. For health care organizations that do collect this information, there are differences in points in time when this information is collected, the types of questions asked, who collects the information, and whether it is mapped to standardized terminologies. Six themes emerged characterizing the current landscape for disability-related data collection by health care organizations.

Theme 1: Few health care organizations collect disability-related data. The literature and key informant interviews highlighted that few health care organizations collect disability status or accommodation needs data. Among the few health care organizations that do collect these data, they typically collected it prior to the patient's visit. Information is collected during one of three different events (1) at the point of scheduling an appointment, (2) collected from the patient during inpatient or outpatient registration [22] [29] [30], or (3) self-reported by the patient via a patient portal [30]. Figure 1 presents a model workflow for collecting disability-related information from patients.

Figure 1. Disability status data collection workflow.



However, health care organizations lack standardized workflows for collecting disability-related data, which is a challenge to routine collection and documentation. While some resources are available to assist with workflow integration, such as the toolkit developed by The Disability Equity Collaborative [32], overall, resources appear limited and not widely disseminated. Without a standardized workflow, disability-related data are unlikely to be collected on a routine basis and with varying degrees of quality. One informant highlighted the potential value of standardized workflows:

"The fact is, we could absolutely benefit from a more systematic way of allowing people to not only disclose that they have a disability for purposes of them explaining to us what disability related accommodations they need but also making it part of the routine of preparing for appointments."

Theme 2: Health care organizations adapt standardized disability status questionnaires and assessment tools to meet their organizational needs. Findings from the literature and key informant interviews reveal a range of data collection approaches. When collecting information about disability status for a general patient population, health care organizations primarily (1) adapt validated question sets collected as part of population-level surveys, such as those developed by the American Community Survey (ACS) [33] or the Washington Group [34] or (2) collect information on what patients and clinicians view to be the main disability categories.

Health care organizations that rely on input from patients and clinicians to identify primary disability categories may employ various methods to pinpoint this information. For example, Michigan Medicine elicited feedback from people with disabilities and disability advocacy groups when developing their disability categories [30]. Some organizations focus on disabilities associated with specific conditions or procedures, and in these cases health care organizations appear to utilize standardized disability question sets, such as those for migraines [35] [36], chronic pain [37], activities of daily living [24], and spinal disease [31]. Several informants expressed that the lack of an agreed upon definition for disability status contributed to heterogeneity in the types of disabilities that are collected across health care organizations. Further, informants flagged that the lack of an agreed upon set of disability status questions limits the quality and comparability of the disability data that are collected.

Theme 3: Disability status data are generally not mapped to available standard terminologies. Key informants stated that most EHRs currently do not include structured data fields to document a patient's self-reported disability status. The literature underscored this EHR system limitation citing that few health care organizations use Logical Observation Identifiers Names and Codes (LOINC®) for disability status. The Interoperability Standards Advisory interoperability standard "Representing Patient Functional Status and/or Disability," which integrates disability and functional status, shows moderate to low adoption rates for corresponding LOINC and Systematized Medical Nomenclature for Medicine-Clinical Terminology (SNOMED) standards [38]. While USCDI references LOINC version 2.77 for disability status terminology standards [39], because adoption of USCDI Version 3 is voluntary until January 2026, many health care organizations are likely using EHRs that have not mitigated to the Version 3 standard.

The lack of standardization is notable given that LOINC codes are available to document six common patient-centered disability status questions used by the U.S. Department of Health and Human Services, including CMS, to characterize disability along the following domains—vision, hearing, communication, memory/concentration, self-care, and physical ability [40] [41]. These questions also align with the disability questions used to assess disability status in the ACS and the Washington Group survey. One informant from a large health care organization, which collects disability status data extensively, described the lack of standardization as:

"That data is not routinely captured in a structured way across [our] health IT systems [I] think we're seeing a lot of variances in workflow and data element level information that's captured."

Organizations without structured data fields built into their EHR may record disability status in free-text clinical notes or may forego collecting disability status [22]. In situations where these data are documented, the data are not easily visible or may be difficult to locate within the patients record, limiting the utility of the data to clinical care teams. An informant noted that some EHRs may be able to place the data element where it can be easily integrated into the health care organization's workflow while other EHR developers have less flexibility to meet the organization's needs.

Theme 4: Disability status data are rarely exchanged outside of an individual health care organization. Although sharing disability status and disability-related data can facilitate person-centered transitions of care, the key informants representing health care organizations indicated that their organization rarely share a patient's disability status with other organizations.

We identified an HL7 Fast Healthcare Interoperability Resources (FHIR®) profile [42] for exchanging disability status data that corresponds to the six-item set of questions used on the ACS and Washington Group survey in a standard way. Additionally, the FHIR Implementation Guide for functional status is currently published as a Standard for Trial Use

[43]. However, only one informant identified an instance when disability status data is exchanged outside of the health care organization, and this exchange did not leverage the available FHIR standard. In this instance, Oregon legislature passed a law that requires health care organizations to collect race, ethnicity, language, and disability data at health care encounters related to COVID-19 and to share this information with the Oregon Health Authority [44]. According to the key informant, the process for exchanging data to the Oregon Health Authority is manual and cumbersome.

Theme 5: Programmatic, regulatory, and legal requirements appear to be primary organizational motivators for collecting disability status data. Multiple informants stated that absent federal and state requirements, the collection of disability status is likely to remain low, highlighting the role of governmental entities in encouraging collection of disability data. One informant summarized this perception as:

"Because [data collection] doesn't relate to payment it's not integrated into care systems or some incentive as a quality measure, it's not really going to happen."

Certified EHR technology is a requirement of participation for several CMS value-based payment models and quality improvement programs, such as the Promoting Interoperability, Merit-based Incentive Payment System (MIPS) and the Medicare Shared Savings Program (MSSP) [45].

At the state level, some states have passed legislation that requires health care organizations to collect disability data (e.g., Oregon [44] and Washington [46]). Key informants highlighted the need for continued coordination across federal and state agencies for data standards and implementation guidance regarding disability data.

Theme 6. Disability status data alone is insufficient for health care organizations to plan for and provide mandated accommodation. While the literature indicates that health care organizations are striving to collect and use accommodations data to prepare for patient visit [22], the majority of organizations in our sample reported they lack systematic workflows for data collection and documenting these data in the EHR. Furthermore, because a data element for accommodations needs is not included in USCDI, health care organizations must rely on the functionality (e.g., structured fields, mapping to standard terminologies) offered by their EHR developer to store this information, which may limit standardization and interoperability in the short term.

Without appropriate accommodations, patients experience lower rates of preventative screenings [15] [47] and are less likely to report positive experiences of care [34]. However, despite requirements for health care organizations to provide accommodations, patient's needs often go unmet [14] [48] [49]. Many informants perceived that their health care organization is not sufficiently prepared to meet the accommodation needs of patients, due to organization capacity to provide requested accommodations. Several key informants stated that clinicians may not be familiar with the accommodation equipment or devices which can add time burdens to existing clinical workflows. Some health care organizations may also lack the resources for accommodations training and may face obstacles planning for and coordinating across different accommodation needs.

Discussion

Findings from this landscape assessment highlight a growing recognition of the importance of collecting disability-related data to improve quality and equity of care. Despite this recognition barriers remain to the consistent collection and use of disability-related data including limited use of available standard terminologies, lack of clinical workflows, and insufficient standardization for capturing patient accommodation needs. To advance the

systematic collection and use of standardized disability-related data, proactive implementation efforts may address both identified technical and organizational barriers thus improving interoperability and use of these data to improve quality of care.

Engage health system leadership to foster organizational commitment to identify and support effective disability-related data collection and use workflows. Findings from the literature scan and key informant interviews highlighted that many health care organizations lack workflows for disability-related data, which can lead to fragmented data collection. Health care organizations that successfully implemented disability-related data collection workflows cited strong support from care teams and senior leadership as a key factor to implementation success [22]. Cultivating this support is vital to sustaining meaningful, system-wide change that promotes equitable care for patients with disabilities.

Develop practical implementation resources. Workflow templates, data collection toolkits, and role-specific job aids can support organizations in integrating these data collection processes into clinical workflows and daily operations. These resources can offer clear, step-by-step strategies for incorporating disability-related fields into EHR templates, triage processes, and patient intake workflows without significantly increasing staff workload. By equipping care teams with both the knowledge and the tools to act, health systems can more effectively build capacity for sustained, high-quality data collection. Ultimately, this dual approach supports not only compliance with policy and civil rights mandates but also meaningful improvements in care accessibility, coordination, and outcomes for patients with disabilities.

Collaborate with EHR developers to understand how the disability status data element will be incorporated into developers' certified health IT. On January 1, 2026, USCDI Version 3, which includes disability status, will become the new baseline standard for certified health IT [21]. This forthcoming requirement presents a critical opportunity to work with EHR developers to improve the use of structured data fields for disability status. At the same time, health care organizations will need to carefully determine which disability status question sets to use and work with their EHR developer to ensure responses are mapped to available LOINC terms. Ensuring these data are mapped to standard terminologies will increase the interoperability of these data and the quality of data used for quality improvement and research.

Advance USCDI data standards for capturing accommodation needs data. To provide equitable access to care, health care organizations benefit from collecting information from patients on the accommodation they may need. However, few health care organizations collect this data, which can limit their ability to efficiently plan for and provide accessible medical and diagnostic equipment across all patient visits. This lack of planning can result in delays in care which can worsen disparities for people with disabilities. Unlike disability status, there is currently no data element for accommodation needs in the USCDI despite the availability of a standard terminology. The absence of a USCDI standard likely contributes to the wide variability in how, if at all, this information is collected, documented, and exchanged across systems. Recognizing this gap, the ASTP/ONC HITAC, has recommended the inclusion of a new accommodations data element in future versions of USCDI [50]. Similarly, groups such as the PACIO Project and the CMS Center for Clinical Standards and Quality have advocated for the addition of disability accommodations to USCDI Version 6 [51].

Limitations

This study has several limitations. The scope was limited to publicly available information and input from a targeted group of stakeholders, which may not represent the full range of current practices or perspectives within the health care ecosystem. Furthermore, while this research focused on health care system and policy perspectives, it did not include patient

perspectives—particularly from people with disabilities—an essential consideration for future research to ensure that solutions are responsive to the needs and preferences of the patient population they are intended to serve.

Conclusion

As identified through the literature scan and key informant interviews, systematically collecting both disability status and accommodation needs data can support whole-person, patient-centered care by enabling health care organizations to provide necessary accommodations, design treatment plans that align with patient goals, and ensure safer care transitions. Moreover, these data are critical to improving representation of people with disabilities in health research and identifying population-level disparities in access, outcomes, and quality of care.

While early progress is encouraging, significant gaps remain in availability of EHR functionality supporting standardized data documentation, organizational readiness, and workforce education for disability and accommodation needs information.

Future efforts should focus on expanding EHR capacity to collect and exchange disability data, fostering health system buy-in, and optimizing workflows for consistent and meaningful documentation. Additionally, the inclusion of more granular disability-related data elements—such as timing, duration, severity, and functional impact—could support more tailored and effective care. As national priorities around patient-centered care continue to grow, sustained collaboration among policymakers, health systems, developers, clinicians, and patients will be critical to ensure disability-related data are collected and used to drive improvements in care and outcomes.

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Author Contributions

All authors made substantial contributions to the conception and design of this research. KHH, AA and PD led data collection. All authors contributed to the analysis and interpretation of data. KHH, AA, AML, SS, and PD were involved in drafting the manuscript or revising it critically for important intellectual content and gave final approval of the version published.

Conflicts of Interest

None declared

Abbreviations

ACS: American Community Survey

ADA: Americans with Disabilities Act

CMS: Centers for Medicare & Medicaid Services

EHR: electronic health record

HL7: Health Level Seven

Interoperability Standards Advisory: Interoperability Standards Advisory

IT: information technology

LOINC: Logical Observation Identifiers Names and Codes

ONC: Office of the National Coordinator for Health Information Technology

PROMIS: Patient-Reported Outcomes Measurement Information System

SNOMED: Systematized Medical Nomenclature for Medicine-Clinical Terminology

USCDI: United States Core Data for Interoperability

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Supplementary Files

Figures

Disability status data collection workflow.

