Measurement and Outcomes Workgroup:
Considerations for Minimizing Respondent Burden in Collecting Data for Patient-Centered Clinical Decision Support

Agency for Healthcare Research and Quality
5600 Fishers Lane
Rockville, MD 20857
www.ahrq.gov

Contract No: 75Q80120D00018

Prepared by:
Rachel T. Kurtzman, Ph.D., and Polina Kukhareva, Ph.D., M.P.H.
Mustafa Ozkaynak, Ph.D., M.S.
Ruth Nwefo, M.P.H.
Frances Jiménez, M.P.H.
Priyanka J. Desai, Ph.D., M.S.P.H.
CDSiC Measurement and Outcomes Workgroup
Prashila M. Dullabh, M.D., FAMIA

AHRQ Publication No. 25-0074
September 2025

AHRQ Agency for Healthcare Research and Quality

Clinical Decision Support Innovation Collaborative

PURPOSE

The Clinical Decision Support Innovation Collaborative (CDSiC) aims to advance the design, development, dissemination, implementation, use, measurement, and evaluation of evidence-based, shareable, interoperable, and publicly available patient-centered clinical decision support (PC CDS) to improve health outcomes of all patients by creating a proving ground of innovation. The Measurement and Outcomes Workgroup supports the measurement of PC CDS implementation and effectiveness to ensure that PC CDS works as intended. The Workgroup is comprised of eight experts representing varied perspectives related to CDS. This report is intended to be used by those interested in collecting data from patients for PC CDS. All qualitative research activities conducted by the CDSiC are reviewed by the NORC at the University of Chicago Institutional Review Board (FWA00000142).

FUNDING STATEMENT

This project was funded under contract number 75Q80120D00018 from the Agency for Healthcare Research and Quality (AHRQ), U.S. Department of Health and Human Services (HHS). The opinions expressed in this document are those of the authors and do not reflect the official position of AHRQ or HHS.

PUBLIC DOMAIN NOTICE

SUGGESTED CITATION

Kurtzman RT & Kukhareva P, Ozkaynak M, Nwefo R, Jiménez F, Desai PJ, CDSiC Measurement and Outcomes Workgroup, and Dullabh PM. Considerations for Minimizing Respondent Burden in Collecting Data for Patient-Centered Clinical Decision Support. Prepared under Contract No. 75Q80120D00018. AHRQ Publication No. 25-0074. Rockville, MD: Agency for Healthcare Research and Quality; September 2025.

Contributors: CDSiC Measurement and Outcomes Workgroup

Members of the Measurement and Outcomes Workgroup who contributed to this report are listed below.

Name	Affiliation
Ben Hamlin, DrPH	Island Peer Review Organization (IPRO)
Richard Schreiber, MD, FACP, FAMIA, ABPM-CI	Pennsylvania State University
Dean Sittig, PhD	University of Texas
Quinn Nelson, MD, MPhil	Oregon Health & Science University
Jasvinder Singh, MD, MPH	Veterans Affairs Medical Center, University of Alabama at Birmingham
Swaminathan Kandaswamy, PhD, FAMIA	Emory University School of Medicine
Arthur H. Owora, PhD, MPH	Indiana University School of Medicine
Tiffany Peterson	LupusChat

Table of Contents

Executive Summary

Personalized healthcare can ensure that medical treatments and care are tailored to an individual's characteristics, needs, and preferences. This personalization often requires collecting data directly from the patient to incorporate their information into evidence-driven, patient-specific recommendations. Patients can provide patient-generated health data (PGHD) and other data (e.g., patient preferences, health-related social needs) to personalize their clinical care and inform decision making.

Digital health tools like patient-centered clinical decision support (PC CDS) are used to collect PGHD and other patient-provided data. However, collecting these data can place a burden on patients, often referred to as respondent burden. Caregivers can also experience this burden if they are providing data on behalf of a patient or helping a patient provide data. Respondent burden reduces response rates and data accuracy and can negatively impact the patient-clinician relationship. Understanding of what causes respondent burden for patients and how to address respondent burden in the context of PC CDS is still developing.

This report explores contributors to, and mitigation strategies for, respondent burden associated with data collection for PC CDS. Given that PGHD and other patient-provided data are collected through a range of mechanisms, we focus on respondent burden associated with:

- **Collecting data using patient-facing PC CDS:** Data may be collected directly from patients through patient-facing PC CDS (i.e., questions or requests received from apps, text messages, and patient portals). For example, a PC CDS tool may collect patient-reported blood pressure measurements to inform care decisions about hypertension management.
- **Collecting data via assessments or surveys:** Patients may provide data through assessments and surveys (e.g., quality of life and pain assessments) designed to collect information such as patient-reported outcomes (PROs), patient preferences, and health-related social needs. These assessments and surveys can be administered during clinical visits or outside the clinical setting through patient portals and smart phone apps. These data are then used to inform PC CDS recommendations. For example, a patient may respond to a survey during a clinical encounter, and this information is used by decision support tools to inform recommendations about patient care.

Methods

We conducted a targeted review of peer-reviewed and grey literature. We identified 160 unique articles and then performed two levels of screening: a title/abstract and full-text review. Following title/abstract and full-text review, 25 articles were deemed eligible for inclusion. An additional five articles were identified as eligible for inclusion through the snowball search method and targeted searches.

Findings were then abstracted into five domains aligned with the Unified Theory of Acceptance and Use of Technology (UTAUT) framework, adapted for the PC CDS context (Exhibit E1). Literature review findings were augmented by qualitative interviews with four key informants and discussions with eight members of the Clinical Decision Support Innovation Collaborative (CDSiC) Measurement and Outcomes Workgroup.

Exhibit E1. Respondent Burden Domains Based on the Adapted UTAUT Framework

Domain	Definition
Performance Expectancy	What a patient expects to gain from providing data
Social Influence	Interaction with clinicians and/or caregivers
Effort Expectancy	Ease of use/complexity of the tool or instrument
Facilitating Conditions	Conditions to support the collection of data from patients (health system, conditions when completing a measure)
Personal Factors	Factors specific to the characteristics, preferences, and needs of an individual

Contributors to and Mitigation Strategies for Respondent Burden When Providing Data

The different ways patients and caregivers provide data for healthcare decision making raise important considerations about respondent burden, especially when these data are collected outside of the clinical setting.

The literature review and qualitative discussions identified 13 contributors and 16 mitigation strategies for respondent burden. Caregivers may also experience this burden if they are helping to provide data on behalf of a patient. Exhibit E2 organizes these findings across the five UTAUT domains. We stratified contributors and mitigation strategies to distinguish those most relevant to:

- Data collected directly by patient-facing PC CDS
- Data collected by assessments and surveys

We recognize that some contributors and mitigation strategies may be relevant to both data collected through patient-facing PC CDS and data collected through assessments and surveys. However, we have grouped contributors and mitigation strategies in the context that they were raised by key informants and Workgroup members.

Exhibit E2. Respondent Burden Contributors and Mitigation Strategies

Domain	Contributors	Mitigation Strategies
Performance Expectancy	*Patient-facing PC CDS:* - Value for providing data is unclear *Assessments & Surveys:* - Lack of interest in providing data	*Patient-facing PC CDS:* - With patient input, identify and remove non-relevant questions *Assessments & Surveys:* - Allow patients flexibility and customization regarding what information they provide
Social Influence	*Patient-facing PC CDS:* - Lack of messaging from clinicians and health systems about why data should be provided *Assessments & Surveys:* - Lack of clinician response to data shared during clinical encounters	*Patient-facing PC CDS:* - Inform participants why data are being collected *Assessments & Surveys:* - Review data with patients and act based on it
Effort Expectancy	*Patient-facing PC CDS:* - Data collection that is distracting, time-consuming, or inconvenient *Assessments & Surveys:* - Data collection that takes too long or is too complex - Questions that are non-specific or too general	*Patient-facing PC CDS:* - Increase readability and accessibility - Inform individuals ahead of time when data collection may occur - Allow patients to choose the timing and frequency of data collection *Assessments & Surveys:* - Use short-form versions of surveys or shorten surveys when available and appropriate - Use Computerized Adaptive Testing (CAT) when available and appropriate - Include graphics in surveys - Provide sample questions
Facilitating Conditions	*Patient-facing PC CDS:* - Confidentiality concerns reporting data due to the platform or the type of data being collected *Assessments & Surveys:* - Technical issues when providing data - Too many data collection requests	*Patient-facing PC CDS:* - Use apps that are integrated into existing infrastructure - Be transparent about how data will be used and stored *Assessments & Surveys:* - Offer in-person assistance when collecting data to resolve questions or help individuals who cannot enter their own data - Decrease frequency of repeated measurement when possible

Domain	Contributors	Mitigation Strategies
Personal Factors	*Patient-facing PC CDS:* - Personal characteristics including age, comfort with technology, and memory issues - Patients who are in poorer health may experience more data requests - Health anxiety and stress caused by reporting data	*Patient-facing PC CDS:* - Codesign interventions or data collection tools with patients

Discussion

As PC CDS tools become more prevalent, it is essential that data collection methods are designed to be both practical and sustainable. Informants and Workgroup members identified codesign of data collection tools with patients and content experts as a critical strategy for addressing multiple contributors to respondent burden. While the causes of respondent burden and mitigation strategies focused primarily on patient-facing PC CDS and other data collection instruments (i.e., assessments and surveys), it is important to take a holistic view of the collective burden patients may experience from engaging with multiple digital or paper-based tools to manage their health. Informants and Workgroup members discussed the potential for artificial intelligence to both lessen and contribute to respondent burden, and noted further research is needed as this area continues to develop. Additional research is also needed to understand patients' perspectives on these issues.

Conclusion

This report details factors that contribute to and mitigate respondent burden when collecting data through patient-facing PC CDS tools or other data collection mechanisms. The identified factors span the five UTAUT domains including performance expectancy, social influence, facilitating conditions, effort expectancy, and personal factors. As digital health tools and PC CDS continue to evolve, researchers and clinicians must continue to evaluate the response burden of these tools and apply mitigation strategies as needed to reduce burden placed on respondents.

1. Introduction

The delivery of personalized healthcare is important to achieving patient-centered care. Personalized healthcare can ensure that medical treatments and care are tailored to an individual patient's characteristics, needs, and preferences, which can lead to more appropriate health-related decision making.[1] Personalizing care recommendations often requires collecting data directly from patients and then incorporating this information into evidence-driven, patient-specific recommendations.[2,3] Recent technological advances in patient-facing digital health tools are making the collection of data needed to deliver personalized healthcare more accessible.

Patients can provide a range of patient-generated health data (PGHD) including patient-reported outcomes (PROs) and data from wearables and devices, as well as other types of data (e.g., patient preferences, health-related social needs) to personalize their clinical care and inform decision making. Incorporating data provided by patients into healthcare decision making offers promising benefits in the customization of care, but can increase burden for patients.[6–8] This is often referred to as respondent burden, which is defined as the degree to which participation or providing data is perceived as difficult, time-consuming, or emotionally stressful.[9] Patients can also report fatigue, a component of burden, that occurs when participants become overwhelmed with providing data.[9] Caregivers can also experience this burden if they are providing data on behalf of a patient or helping a patient provide data. Respondent burden can reduce response rates and data accuracy, and negatively impact the patient-clinician relationship.[7,10–12]

PC CDS encompasses a spectrum of decision making tools that significantly incorporate patient-centered factors related to knowledge, data, delivery, and use.[4]

- *Knowledge* refers to the use of comparative effectiveness research or patient-centered outcomes research (PCOR) findings.
- *Data* focuses on the incorporation of PGHD, patient preferences, social determinants of health (SDOH), and other patient-specific information.
- *Delivery* refers to directly engaging patients and/or caregivers across different settings.
- *Use* focuses on facilitating bi-directional information exchange in support of patient-centered care, including shared decision making.

However, our understanding of what causes burden for patients, or how to address it in the context of patient-centered clinical decision support (PC CDS), is still developing. Moreover, there is limited evidence exploring the patient perspective on respondent burden associated with patient-facing digital health tools.[13,14]

To address this gap, this report explores contributors to and mitigation strategies for respondent burden associated with data collection for PC CDS. Given that PGHD and other patient-provided data can be collected through a range of mechanisms, we focus on respondent burden associated with:

- **Collecting data using patient-facing PC CDS:** Data may be collected directly from patients through patient-facing PC CDS tools via questions or requests received from apps, text messages, and patient portals. For example, a PC CDS tool may collect patient-reported blood pressure measurements to inform care decisions about hypertension management.

- **Collecting patient-provided data via assessments or surveys:** Patients may provide data through assessments and surveys designed to collect information such as PROs, patient preferences, and health-related social needs. For example, the Vanderbilt Patient-Reported Outcomes Measurement System (VPROMS) collects information from patients on their health, mood, pain, and ability to complete daily activities.[17] These assessments and surveys can be administered during clinical visits or outside the clinical setting through patient portals and smart phone applications. These data can be used to inform PC CDS recommendations.[2,3] For example, a patient may respond to a survey during a clinical encounter and their answers can then be used to inform recommendations from a decision support tool.

1.1 Roadmap of the Report

This report describes the methods and findings of an environmental scan to identify respondent burden determinants and ways to alleviate respondent burden. The report includes the following sections:

- *Methods.* This section summarizes our approach to conducting an environmental scan and qualitative interviews to identify contributors to and mitigation strategies for respondent burden.
- *Contributors to and Mitigation Strategies for Respondent Burden.* This section presents the identified contributors and mitigation strategies of respondent burden associated with collecting data from both patient-facing CDS and patient-completed assessments or surveys.
- *Discussion.* This section discusses the identified contributors and mitigation strategies of respondent burden, highlighting the importance of acknowledging burden as new digital health tools emerge.
- *Conclusions.* This section summarizes the conclusions from the identified contributors to and mitigation strategies of respondent burden.

2. Methods

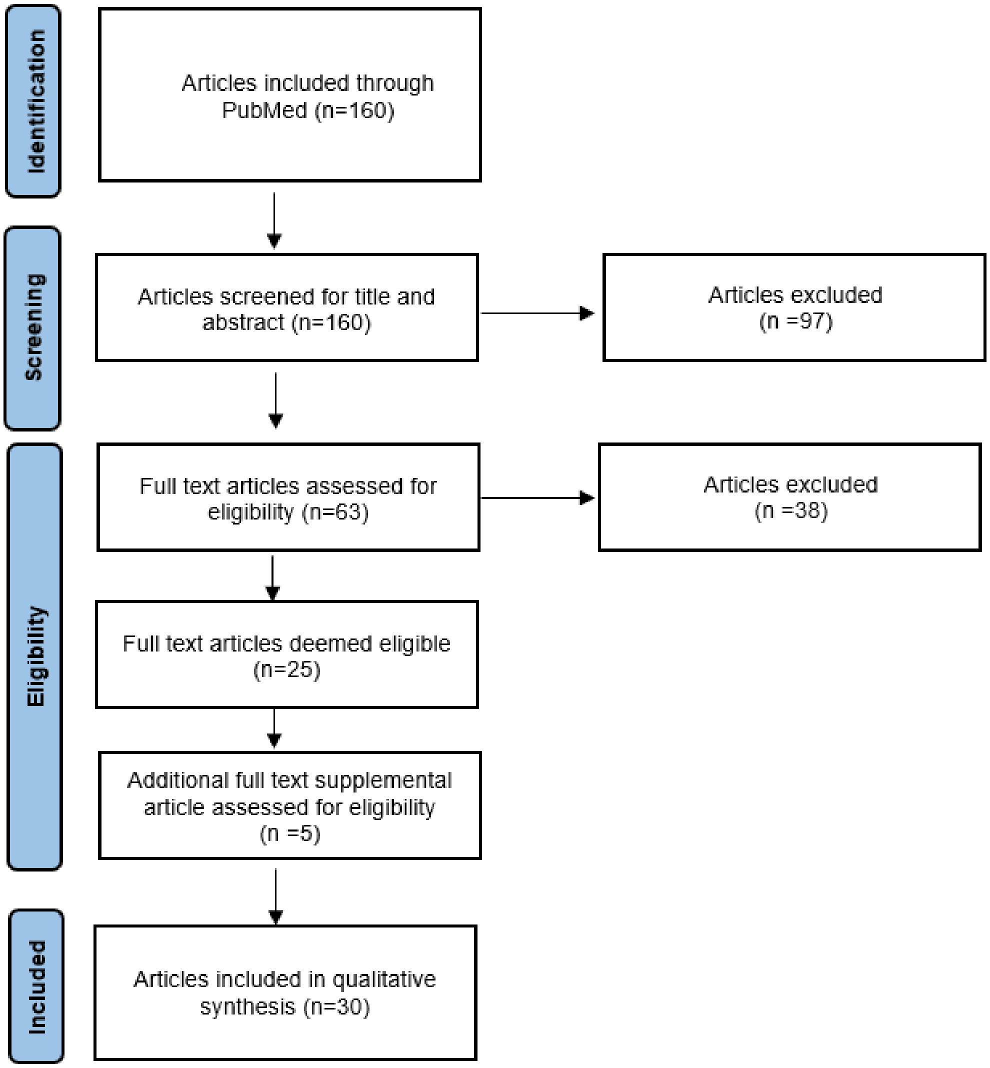
To identify potential contributions and mitigation strategies of respondent burden associated with data collection for PC CDS, we conducted a targeted literature review and qualitative interviews.

2.1 Literature Review

We conducted a targeted review of peer-reviewed and grey literature to identify publications related to respondent burden. We focused our review on papers that discussed patient respondent burden and burden related to collection of patient-provided data (e.g., PGHD, patient preferences), or papers that explored considerations around patient burden for PC CDS developers and implementers. As this is a developing area, we used a variety of search terms to identify articles related to respondent burden, respondent fatigue, survey burden, and survey fatigue (Appendix A1). Eligibility criteria used to screen the literature are detailed in Appendix A2.

We identified 160 unique articles and then performed a title/abstract screening followed by full-text review. At each level, we assessed whether the article met the eligibility criteria. Sixty-three articles were included after title/abstract screening, and 25 articles were included after full-text review (Exhibit 1). We also identified five additional articles through the snowball search method and targeted searches related to digital health and gamification.

Exhibit 1. Literature Scan PRISMA Diagram



We abstracted factors that contribute to respondent burden or potentially mitigate respondent burden into Microsoft Excel for analysis. We extracted findings into five domains aligned with the Unified Theory of Acceptance and Use of Technology (UTAUT) framework (see 2.3 Analysis and Synthesis for additional information).

2.2 Qualitative Discussions

To refine and augment findings from the literature, we conducted 60-minute key informant interviews with three PC CDS researchers and one patient advocate. Interviews were conducted using a semi-structured interview guide that focused on understanding interviewees' thoughts on the areas identified from the literature and additional factors not captured in the literature. Each interview was conducted via Zoom and recorded.

We also discussed our findings with eight members of the Clinical Decision Support Innovation Collaborative (CDSiC) Measurement and Outcomes Workgroup, which includes clinicians, researchers, and patient advocates, during Workgroup meetings. These iterative discussions with the Workgroup were guided by targeted questions drawn from the interview guide and conducted and recorded via Zoom. A CDSiC team member took notes during each interview and during Workgroup meetings, which were verified for accuracy against the Zoom recordings.

2.3 Analysis and Synthesis

Factors identified from the literature were organized into five domains aligned with the UTAUT, a widely used informatics framework that provides a holistic understanding of acceptance of technology.[15] The model is rooted in the belief that the use of technology is determined by behavioral intention and the likelihood of technology adoption is based on five domains.[16] Definitions for the domains of the UTAUT were adapted to the PC CDS context (Exhibit 2).

Exhibit 2. Respondent Burden Domains Based on the Adapted UTAUT Framework

Domain	Definition
Performance Expectancy	What a patient expects to gain from providing data
Social Influence	Interaction with clinicians and/or caregivers
Effort Expectancy	Ease of use/complexity of the tool or instrument
Facilitating Conditions	Conditions to support the collection of data from patients (health system, conditions when completing a measure)
Personal Factors	Factors specific to the characteristics, preferences, and needs of an individual

To derive qualitative findings from the interviews and Workgroup discussions, notes and transcripts were analyzed using rapid qualitative content analysis aligned with the domain structure of the UTAUT.[15] Analysis focused on identifying additional factors that may contribute to or mitigate respondent burden that were not identified based on the literature, and contextual factors that may impact the feasibility and acceptability of the mitigation strategies.

3. Contributors to and Mitigation Strategies for Respondent Burden

The different ways patients and caregivers provide data for healthcare decision making raise important considerations about respondent burden, especially when these data are collected outside of the clinical setting.

We identified 13 contributors and 16 mitigation strategies for respondent burden and organized them by the five UTAUT domains: performance expectancy, social influence, effort expectancy, facilitating conditions, and personal factors. In the sections that follow, we discuss factors relevant to:

1) Data collected through patient-facing PC CDS
2) Data collected from patients through assessments or surveys that inform PC CDS recommendations

We recognize that some contributors and mitigation strategies may be relevant to both categories. However, we have grouped contributors and mitigation strategies in the context that they were raised by key informants and Workgroup members.

3.1 Performance Expectancy

Performance expectancy is what a patient expects to gain from providing data. Contributors to burden in this domain may vary based on how data are collected. For instance, patient-facing PC CDS may ask patients to provide data at various timepoints within their daily lives, but patients may not understand why they are being asked to share these data outside of clinical encounters. Alternatively, patients may provide data through online forms, mobile applications, portals, kiosks, or personal health devices before, during, or after a clinical visit. Patients may lack interest in providing this data due to factors such as questionnaire length.

Mitigation strategies to address these contributors may include removing questions that seem less relevant or useful and providing patients with flexibility regarding what data they provide (e.g., what symptoms they report on) (Exhibit 3).

Exhibit 3. Performance Expectancy Contributors to and Mitigators of Respondent Burden

Domain	Contributors	Mitigation Strategies
Performance Expectancy	*Patient-facing PC CDS:* - Value for providing data is unclear *Assessments & Surveys:* - Lack of interest in providing data	*Patient-facing PC CDS:* - With patient input, identify and remove non-relevant questions *Assessments & Surveys:* - Allow patients flexibility and customization about what information they provide

Patient-Facing PC CDS. Patients may experience burden if the benefits from providing data or the value of the time and effort they spend providing data are unclear.[10,21] For example, in a study where patients reported daily symptom data through a smartwatch app, patients expressed frustration about completing tasks they thought were not relevant or useful.[18] Across the literature, studies found that patients reported that it is not useful to provide data that does not seem relevant to their care.[12,18]

To address this, PC CDS developers can consider removing questions that may seem less useful or less meaningful to patients. This can reduce the number of questions, thus reducing the time and cognitive burden to complete data collection. Additionally, removing questions that patients find less relevant or meaningful can help clarify why the questions asked are important.[7,18,22] Patients' views on questions that are relevant or meaningful may differ from what researchers or clinicians consider relevant or important to measure. To understand which questions or outcomes are most meaningful to patients, PC CDS developers can consult patients for their perspectives during PC CDS development through qualitative data collection or using methods such as codesign. Patients may also find generic validated measures that include a wide range of questions less useful or meaningful, and developers can consider if more specific measures are more appropriate.

Assessments and Surveys. For questionnaires and other assessment forms, patients may not be interested in providing data for a number of reasons, such as survey length, and motivation can wane over time if the benefits of providing data are unclear or unrealized.[23–25] For example, in a survey that assessed individuals' willingness to share data from their smartphone sensors and wearables, nearly 10 percent of participants reported not wanting to provide data.[26]

Allowing patients the flexibility to choose what data they provide (e.g., what symptoms they report on) can help patients feel that the data provided are important and reduce unnecessary reporting. One study that included patients with various cancers treated with concurrent chemoradiation suggested that patients should be able to select the symptoms that are of greatest concern to them at each timepoint when reporting data, rather than having to report on all possible symptoms.[12] In another study, patients suggested it would be useful to be able to skip specific questions that did not apply to their health condition or symptoms experienced (e.g., not asking questions about itching if that was not a symptom they experienced).[18]

3.2 Social Influence

Social influence represents factors related to interaction with clinicians and/or caregivers. Interaction with care teams is a critical component of PC CDS, as PC CDS should ultimately enhance patient-clinician communication to be effective.[4] However, respondent burden can increase when the benefit of using PC CDS is unclear. Clinical encounters can also provide an opportunity for patients to share data directly with their care teams through assessments or surveys that then inform PC CDS recommendations. Providing data through these assessments or surveys may be associated with additional contributors and mitigators to respondent burden.

Key contributors to respondent burden in this area include a lack of communication from care teams regarding the purpose of data collection, as well as failure to utilize a patient's data to make recommendations or inform their care. Mitigation strategies to address these factors can include informing patients why data are being collected and taking action based on patient-provided data (Exhibit 4).

Exhibit 4. Social Influence Contributors to and Mitigators of Respondent Burden

Domain	Contributors	Mitigation Strategies
Social Influence	*Patient-facing PC CDS:* - Lack of messaging from clinicians and health systems about why data should be provided *Assessments & Surveys:* - Lack of clinician response to data shared during clinical encounters	*Patient-facing PC CDS:* - Inform participants why data are being collected *Assessments & Surveys:* - Review data with patients and act based on it

Patient-Facing PC CDS. Patients may feel burdened during or after data collection if their clinician or healthcare system messaging does not clearly explain why data are being collected through patient-facing PC CDS.[10,23,27,28] This can include lack of communication from a clinician about the purpose of data collection as it relates to their treatment or care and how data will be used or shared.

> "In my experience, I don't think I've ever had any of my clinicians mention anything about [the value of] questionnaires or surveys that I would have filled out beforehand. So that definitely [would be] super helpful."
> —Key Informant

To mitigate this burden, clinicians and PC CDS implementers should ensure patients are informed why their data are being collected through PC CDS. A few informants noted that having clinicians explicitly explain the purpose and relevance of data requests to patients can reduce the burden associated with collecting data. This communication can help patients contextualize the data requests in relation to their own health, and clarify why they are being asked to provide data.[29] Informants and Workgroup members emphasized that it is particularly important to clarify why questions that may seem unrelated to a main concern are being asked, as well as explaining the rationale for collecting data outside of clinical encounters.

Assessments and Surveys. Patients may experience response burden when data shared during clinical encounters are not used to inform their care. For patients interested in contributing data, a lack of clinician responsiveness to that data can reduce motivation. In a study that examined sustained engagement in an electrocardiogram (ECG) self-monitoring program, some patients who reported receiving little to no guidance from their clinicians about abnormal readings ultimately opted to stop using the device.[11] Patients may also provide data about their treatment preferences, but if their clinician does not discuss these as part of a shared decision making conversation, this may cause burden for patients. Failing to discuss patient-provided data can also hinder development of collaborative patient-clinician relationships by creating situations in which patients do not feel listened to or heard.[11,23,30]

> "Make clear how it [data] is going to be used when it's been provided. Make sure that it is addressed, acknowledged, [Say] thank you for providing this. …. in the visit referencing what they entered… so the fact that your provider acknowledges, thanks you, use it, like sending a clear message that they value it, and they want you to do it right."
> —Key Informant

To address this concern, PC CDS implementers and health systems should encourage clinicians to review data with patients and take action based on it, creating feedback loops between patients and clinicians.[31] Taking time to review data with patients helps reinforce why reporting data is important, clarifies how a patient's data are being used, and can strengthen the patient-clinician relationship.[11,21,25,26,32] A few studies noted that explaining how patient data are used helps patients know that providing data is not a waste of time.[21,25,33]

3.3 Effort Expectancy

Effort expectancy reflects the ease or complexity of the tool or instrument used to capture patient-provided data. Patient-facing PC CDS may collect data from patients through targeted questions delivered via text messaging, mobile applications, and patient portals. Data can also be captured from patients in other ways, such as through paper surveys, online forms, and at kiosks when attending clinical visits. These assessments and surveys may be lengthy and prior studies have found that the collection of PROs often relies on time-consuming questionnaires.[7]

Key contributors to respondent burden in this area include data collection that is distracting, time-consuming, or inconvenient, and questions that are too general or difficult to answer. Mitigation strategies to address these contributors include increasing readability and accessibility of data collection tools, letting patients know the schedule for data collection ahead of time, shortening data collection tools, and using methods that can improve understanding of questions, such as graphics (Exhibit 5).

Exhibit 5. Effort Expectancy Contributors to and Mitigators of Respondent Burden

Domain	Contributors	Mitigation Strategies
Effort Expectancy	*Patient-facing PC CDS:* - Data collection that is distracting, time-consuming, or inconvenient *Assessments & Surveys:* - Data collection processes that take too long or are too complex - Questions that are non-specific or too general	*Patient-facing PC CDS:* - Increase readability and accessibility of data collection tools - Inform individuals ahead of time when data collection may occur - Allow patients to choose the timing and frequency of data collection *Assessments & Surveys:* - Use short form versions of surveys or shorten surveys when available and appropriate - Use Computerized Adaptive Testing (CAT) when available and appropriate - Include graphics in surveys - Provide sample questions

Patient-Facing PC CDS. Patients may experience burden if they find providing data for PC CDS to be distracting, time-consuming, or inconvenient.[10,23] Some PC CDS tools prompt patients to provide data when a clinician triggers a notification, which may not always align with patients' daily routines or preferred timing.[34] It is important that PC CDS balance integration with clinical workflows and triggering notifications in alignment with patient availability to ensure sustained patient engagement.[35] Furthermore, data collection may be inconvenient or distracting if it occurs at times individuals do not expect it such as data requests patients were not previously aware of, or requests that come at an unexpected or unpredictable time.[18,21]

To mitigate the burden related to effort expectancy, PC CDS developers can consider increasing readability/accessibility of data collection tools. This can reduce the time it takes a patient to comprehend and respond to a data collection request and ensure participants are able to respond appropriately. For example, it is recommended that data collection instruments be written at a 6th grade reading level.[28,36,37] Additionally, it is important to consider other characteristics that can increase readability and accessibility of written information such as making sure items are left indented, are of an appropriate font size, have clear instructions, and have adequate white space.[27,28,37]

Furthermore, when possible, letting participants know the schedule for data collection ahead of time can help reduce respondent burden.[7] For patient-facing PC CDS, this may include informing patients when they will be asked to provide data or when they will receive communication from their clinician. To further limit disrupting patients with unexpected prompts, PC CDS implementers can ask patients to indicate their preferred timing (i.e., time of day, day of week) and frequency (i.e., number of messages in a given period) for receiving PC CDS data collection prompts.[38,39] This allows patients to customize the PC CDS message delivery based on their preferences and can prevent message fatigue.[39] PC CDS implementers may also consider tool functionalities that allow patients to change their notification or message preference settings to reflect changes in their schedule or preferences over time.[38]

Assessments and Surveys. A common issue with surveys and questionnaires is that they are too long or too complex. This may contribute to respondent fatigue. Researchers and health systems should consider the minimum number of questions needed to collect data and the context in which data are being collected (e.g., number of instruments a patient is given, amount of data requested), as what patients find burdensome may change by location, disease state, and other factors.[7,12,25,28] For example, patients who are extremely ill or experiencing fatigue or side effects from a treatment may be more burdened by lengthy data collection than others.[7] Patients may find it takes more time to provide data in a busy outpatient waiting room and be less tolerant of lengthy measures in these settings.[28]

> "We are sometimes asking for too much, especially now with the tendency to use all these digital technologies, wearables, mobile. We tend to add as many devices as we can to come out with the best algorithm. And patients can be a little overwhelmed with this."
> —Key Informant

In addition, questions that are non-specific or too general were identified as contributing to respondent burden. Questions with vague wording can be difficult for patients to interpret and respond to.[20,40] This can be particularly frustrating for patients if no one is available to explain what is being asked.

To mitigate these contributors, researchers, clinicians, and PC CDS implementers can consider several strategies. For example, using short form versions of surveys or shortening existing surveys can reduce respondent burden from lengthy data collection.[7,19,20,24,25,28,36,40] Computerized Adaptive Testing (CAT), a type of measurement in which the questions an individual is asked are tailored based on their responses to past questions, can also reduce the number of questions asked overall and irrelevant questions.[7,12,19,41,42]

Using graphics or pictures in data collection tools can also help patients better understand questions and make data collection easier to complete. For example, if the questions are about skin reactions, showing pictures of what those can look like on different skin tones may help patients recognize their symptoms and report more accurately.[12]

> "Across settings, across languages, pediatrics, adults… graphics can go a long way in helping people to understand the question and kind of overcoming those barriers … of the questions being a bit general or hard to interpret."
> —Key Informant

Finally, researchers and health systems may consider adding sample questions that can help familiarize patients who are new to data collection procedures or response methods.[37] Sample questions can help reduce issues patients have when providing data and increase comfort with data collection processes. There is precedent for providing sample questions in patient measurement tools; examples of tools that provide practice items include the American Speech-Language-Hearing Association Quality of Communication Life (ASHA-QCL) Scale and the Stroke and Quality of Life (SAQOL) Scale.[37] This could potentially be a model for a range of data collection mechanisms that ultimately inform PC CDS.

3.4 Facilitating Conditions

Facilitating conditions are factors that support the collection of data from patients. For patient-facing PC CDS, facilitating conditions may be related to the healthcare system as well as how patients enter data (e.g., the data collection platform). Facilitating conditions for data provided through other mechanisms such as surveys or online assessments may depend on the conditions a patient experiences when completing an instrument.

Key contributors to respondent burden in this area include patients' privacy concerns, technical issues, and asking patients to provide data too frequently. Mitigation strategies include using secure apps that are integrated into existing health information technology (IT) infrastructure, being transparent about how data will be used and stored, asking patients to provide data less frequently, and providing support for in-person data collection (Exhibit 6).

Exhibit 6. Facilitating Conditions Contributors to and Mitigators of Respondent Burden

Domain	Contributors	Mitigation Strategies
Facilitating Conditions	*Patient-facing PC CDS:* - Confidentiality concerns reporting data due to the platform or the type of data being collected *Assessments & Surveys:* - Technical issues when providing data - Too many data collection requests	*Patient-facing PC CDS:* - Use apps that are integrated into existing infrastructure - Be transparent about how data will be used and stored *Assessments & Surveys:* - Offer in-person assistance when collecting data to resolve questions or help individuals who cannot enter their own data - Decrease frequency of repeated measurement when possible

Patient-Facing PC CDS. Patients may experience cognitive or emotional burden if they are concerned about how their data will be stored and used. Data privacy can be a significant issue for patients who may be concerned that their personal health information will be leaked or inappropriately accessed. Patients may not understand how a PC CDS tool protects data if this is not adequately explained before or at the time of data collection. Patients concerned about potential data privacy concerns may be less forthcoming when providing data or chose to opt out entirely.[21,23,30,32]

To reduce these concerns, PC CDS developers may consider using apps that are integrated into existing health IT infrastructure, such as those integrated into the electronic health record (EHR) patient portal. In addition to decreasing privacy and security concerns, collecting data through apps integrated into EHR infrastructure can reduce burden for patients by facilitating seamless data collection and reducing the number of platforms they need to access.[30,43] EHR-integrated apps can also reduce patient burden by providing the opportunity to view and review existing data prepopulated into fields This can save patients from needing to provide data they have previously entered. Several informants and Workgroup members highlight that use of EHR-integrated apps may not be feasible in all contexts and depends on resources within a healthcare system, such as the availability of existing EHR-integrated patient-facing PC CDS tools within a given healthcare system.

Additionally, PC CDS developers should be transparent about how data collected through patient-facing PC CDS will be used and stored. Patients should be informed about how their data will be used and be able to make choices related to use and storage of their data.[32] A few informants and Workgroup members noted the importance of informing patients about data security protections and risks, as a patient may be uncomfortable providing data if they are uncertain how it will be used, managed, or stored.

Assessments and Surveys. Technical issues faced by patients when reporting data (e.g., an app not loading correctly, devices not syncing) can be frustrating and prevent them from reporting data.[11,24] In a study where patients were tasked with self-monitoring their rheumatoid arthritis using a smartphone app, technical issues using the app was one of the most cited barriers to reporting data and several patients reported that technical barriers led them to stop using the app.[24,30]

Patients can also experience burden when they receive too many data requests or are asked to report data too frequently. This can occur several ways, such as data collection that is duplicated due to lack of coordination between different providers in a health system (e.g., being asked to complete the same survey multiple times for different providers).[22,42] In a study examining the use of PROs during treatment for head and neck cancers, the authors highlighted provider coordination of data collection to reduce duplication as a benefit of electronic PRO collection.[42] Patients may also experience burden when they are asked to provide too much data at once (e.g., asked to answer multiple surveys at one timepoint, asked to provide a large variety of data at once).[7,20,25,33] Finally, patients may experience burden if they are frequently asked to provide the same data multiple times (e.g., asked to answer the same survey every few days). In these situations, patients may become concerned about the value of time and effort required to report data, how that data will be used, or the value of continuing to provide data.[21,25]

Providing patients with in-person assistance during data collection may help mitigate some of these issues.[11,21] Research staff, clinical support staff, or care navigators can help patients who have difficulty providing data, are experiencing technical issues, or have questions about why data is being collected.[33,44] For example, having someone read questions aloud and mark answers could help individuals who are otherwise not capable of providing data alone.[33] Having in-person assistance can also help patients understand why they are being asked to respond to data requests that may seem repetitive.

Asking patients to provide data less frequently is also an important consideration for reducing burden.[7,12,18,25,28,33] The optimal frequency of data collection depends on the clinical context or disease area, with further variation due to individual preferences. In a study collecting PROs from radiation oncology patients via their patient portal, researchers found asking patients to complete symptom questionnaires weekly between visits with their radiation oncologist—rather than twice a week—increased response rates. This frequency may not be appropriate for other patient populations.[12] Informants and Workgroup members emphasized the importance of reducing data collection timepoints, and one researcher informant noted that they tend to combine data collection requests to reduce the number of times a patient is asked to provide data.

3.5 Personal Factors

Personal factors are specific to an individual's characteristics, preferences, and needs. Patient-facing PC CDS may ask patients to provide data using electronic tools outside of the clinical setting, which may be more challenging for certain patients. These factors may also create challenges for patients providing data through other mechanisms such as surveys.

Key contributors to respondent burden in this area include individual characteristics as well as health anxiety or stress. Mitigation strategies can include codesign of data collection tools with patients and aligning data collection with healthcare visits (Exhibit 7).

Exhibit 7. Personal Factors Contributors to and Mitigators of Respondent Burden

Domain	Contributors	Mitigation Strategies
Personal Factors	*Patient-facing PC CDS:* - Personal characteristics including age, comfort with technology, and memory issues - Patients who are in poorer health may experience more data requests - Health anxiety and stress caused by reporting data	*Patient-facing PC CDS:* - Codesign interventions or data collection tools with patients

Patient-Facing PC CDS. Personal factors that may contribute to respondent burden include characteristics such as age or familiarity with technology that may impact individuals' ability and comfort with providing data through patient-facing PC CDS. Other personal factors including declining capabilities in memory, attention, reasoning, and problem solving, as well as literacy, numeracy, and health literacy may influence how individuals are able to read or interpret questions or engage with patient-facing PC CDS.[28,33,36,37,45] Patients in poorer health or those who have multiple medical issues may receive more data requests than others, leading to greater respondent burden.[18,20,46]

Reporting data for PC CDS may also cause patients stress and anxiety and increase negative feelings about their health, leading to feelings of inadequacy or failure.[43] For example, negative attitudes and judgement surrounding stigmatized conditions, such as diabetes, can discourage some individuals from seeking care or taking steps to manage their condition; prompting patients to track data related to managing a condition may routinely remind them about their condition or reinforce negative perceptions associated with it.[47,48] Patients may worry about how their clinicians view their data and judgements that may be made about them based on their responses.[49] Additionally, patients may misinterpret data or information related to PC CDS, leading to anxiety or stress.[23]

To mitigate respondent burden related to personal factors, PC CDS developers should consider codesigning data collection tools with patients. Codesigning interventions or data collection tools can help researchers understand the personal factors associated with potential barriers that their target population may experience. For example, CDS developers have used surveys to assess the knowledge and information needs of their patient population as well as patient preferences for information display and formatting when developing a CDS tool.[50] In a multi-phased codesign approach, CDS developers can then use the information gathered via surveys and/or conduct focus groups with patients to co-create the content and visual layout for a prototype of the tool. Patients can then review and provide feedback on the prototype for further refinement, ensuring that the tool is readable, usable, and easy to navigate for patients.[51]

Codesign may also be able to help address digital and health literacy needs when patients with varying levels of digital and health literacy are engaged in codesigning a PC CDS tool.[50] PC CDS developers and implementers should consider following best practices to develop PC CDS that accommodates the needs of individuals with low digital or health literacy. Effective strategies include assuming all patients find it difficult to understand health information, avoiding jargon, utilizing best practices for low reading literacy as described above, using numerical odds (e.g., 1 in 100) to express risk, and providing technical training.[52,53]

4. Discussion

Respondent burden is a multifaceted issue that can occur throughout the PC CDS lifecycle.[2] Previous work from the CDSiC outlined how patients and caregivers interact with PC CDS tools to provide data and identified the many interactions and steps in these workflows.[34] This report outlines contributors to and mitigators of respondent burden that may arise for patients providing data via patient-facing PC CDS as well as through assessments and surveys that inform PC CDS recommendations. These contributors and mitigators include a range of factors related to individuals, data collection tools, systems, and the relationships individuals engage in when seeking care. Researchers, clinicians, and health systems should be aware that contributors to respondent burden may arise at many points along the data collection workflow and are not instrument or tool specific.

Documentation burden among clinicians—the time and effort associated with clinical documentation tasks—has been an increasingly important area of research.[13,54,55] As the use of PC CDS continues to expand, researchers and clinicians should also carefully consider the potential impacts of patient respondent burden on response rates, data accuracy and the patient-clinician relationship.[7,10–12] Patient-provided data are vital to PC CDS, whether collected through a patient-facing tool or other method, and data collection methods must be designed in a pragmatic way that is also sustainable. The factors discussed in this report can directly impact the use of PC CDS tools and should be considered in the design, planning, and real-world implementation of PC CDS.

A critical strategy for addressing multiple contributors to respondent burden is codesign of data collection tools, including patient-facing PC CDS and assessments and surveys that inform PC CDS recommendations. This collaborative approach was identified as an effective method to mitigate challenges associated with facilitating conditions and effort expectancy. Codesign with patients or content experts should be used at several points in the design, development, and implementation of PC CDS, and can take many forms including interviews, synchronous design, prototype testing, and iterative feedback/revision cycles.[56,57] Informants and Workgroup members underscored that codesign processes contribute to the development of data collection methods that are not only appropriate but also feasible and realistic, enhancing the overall quality and usability of tools.

As patient-facing digital health tools, including PC CDS, become more readily available, it is also important to consider the overall burden being placed on patients to provide information. While the causes of respondent burden and mitigation strategies included in this report primarily focus on impacts from individual PC CDS tools or other data collection instruments, it is important to take a holistic view about the collective burden patients may experience from engaging with multiple digital tools to manage their health. Digital health tools can support disease monitoring, treatment, and management, but most are designed to support a single condition. Fewer than 3 percent of available apps and wearable devices are intended for two or more conditions.[46] However, 42 percent of the U.S. population has more than one chronic condition.[58] As a result, patients may be engaging with multiple apps and devices to manage their health, navigating and managing different platforms and potentially receiving redundant or contradictory information and data requests from different tools, especially if their healthcare providers use different EHRs. The respondent burden associated with the use of digital health tools should be carefully considered within the context of their use.

4.1 Areas for Future Research

Respondent burden is an area of growing interest, and further work is needed to understand patients' perspectives on the impact of the strategies identified in this report to reduce burden. Continued research is particularly needed to assess the implications of artificial intelligence (AI) on respondent burden. Informants and Workgroup members highlighted that the impact of AI on this topic is currently unclear. While the integration of large language models into EHRs and the use of ambient AI to gather data during clinical encounters could potentially decrease burden, they also raise potential concerns related to patient safety, data privacy, and confidentiality.[59–61]

4.2 Limitations

There are several limitations to this study. While respondent burden is not a new concept, there were challenges in the literature review due to the variety of ways that respondent burden is described in the literature. We aimed to account for potential variety by searching various search terms (e.g., survey burden, respondent burden, patient burden, survey fatigue) and conducting additional supplemental searches. However, we may not have accounted for all the variations in terminology used. Additionally, while we completed interviews with multiple stakeholder groups, we were unable to engage a wide sample of patients who may have offered differing perspectives.

5. Conclusion

This report details factors that may contribute to and mitigate respondent burden when collecting data through patient-facing PC CDS tools or other data collection mechanisms. These factors span multiple domains, including performance expectancy, social influence, facilitating conditions, effort expectancy, and personal factors. Given the multifaceted nature of respondent burden, researchers, clinicians, and PC CDS developers should employ comprehensive mitigation strategies across these domains to ensure that patient-provided data are effectively captured and integrated into PC CDS recommendations.

Appendix: Literature Review Methods

Exhibit A1. Search Strategy

("survey fatigue"[tiab] AND "patient"[tiab])
"Respondent burden"[tiab] AND "patient"[tiab] NOT (nurs*[tiab] OR clinician[tiab)
"Patient-generated health data"[Title/Abstract] AND "burden"[Title/Abstract]
"Respondent burden"[Title/Abstract] AND "patient"[Title/Abstract]

Exhibit A2. Literature Review Inclusion & Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
• Discuss patient or respondent fatigue or burden related to collecting patient-provided data • Highlight considerations to minimize fatigue or burden when collecting patient-provided data	• Focused on clinician burden or documentation fatigue • Do not discuss patient or respondent fatigue or burden related to collecting patient-provided data • Do not highlight considerations related to minimizing fatigue or burden when collecting patient-provided data • Not in English • Full-text not available

References

1. Nardini C, Osmani ,Venet, Cormio, Paola G, et al. The Evolution of Personalized Healthcare and the Pivotal Role of European Regions in its Implementation. *Pers Med*. 2021;18(3):283-294. doi:10.2217/pme-2020-0115
2. Sittig DF, Boxwala A, Wright A, et al. A lifecycle framework illustrates eight stages necessary for realizing the benefits of patient-centered clinical decision support. *J Am Med Inform Assoc JAMIA*. 2023;30(9):1583-1589. doi:10.1093/jamia/ocad122
3. Dullabh P, Leaphart D, Dhopeshwarkar R, Heaney-Huls K, Desai P. Patient-Centered Clinical Decision Support–Where Are We and Where to Next? In: Bichel-Findlay J, Otero P, Scott P, Huesing E, eds. *Studies in Health Technology and Informatics*. IOS Press; 2024. doi:10.3233/SHTI231004
4. Dullabh P, Sandberg SF, Heaney-Huls K, et al. Challenges and opportunities for advancing patient-centered clinical decision support: findings from a horizon scan. *JAMIA*. 2022;29(7):1233-1243. doi:10.1093/jamia/ocac059
5. Clinical Decision Support. Accessed March 18, 2024. https://www.ahrq.gov/cpi/about/otherwebsites/clinical-decision-support/index.html
6. Schöpf AC, Vach W, Jakob M, Saxer F. Routine patient surveys: Patients' preferences and information gained by healthcare providers. PLoS ONE. 2019;14(8):e0220495. doi:10.1371/journal.pone.0220495.
7. Aiyegbusi OL, Roydhouse J, Rivera SC, et al. Key considerations to reduce or address respondent burden in patient-reported outcome (PRO) data collection. *Nat Commun*. 2022;13(1):6026. doi:10.1038/s41467-022-33826-4
8. Atkinson TM, Schwartz CE, Goldstein L, et al. Perceptions of Response Burden Associated with Completion of Patient-Reported Outcome Assessments in Oncology. *Value Health J Int Soc Pharmacoeconomics Outcomes Res*. 2019;22(2):225-230. doi:10.1016/j.jval.2018.07.875
9. Sage Research Methods - Encyclopedia of Survey Research Methods - Respondent Burden. Accessed April 3, 2025. https://methods.sagepub.com/ency/edvol/encyclopedia-of-survey-research-methods/chpt/respondent-burden
10. Reading MJ, Merrill JA. Converging and diverging needs between patients and providers who are collecting and using patient-generated health data: an integrative review. *JAMIA*. 2018;25(6):759-771. doi:10.1093/jamia/ocy006
11. Reading M, Baik D, Beauchemin M, Hickey K, Merrill J. Factors Influencing Sustained Engagement with ECG Self-Monitoring: Perspectives from Patients and Health Care Providers. *Appl Clin Inform*. 2018;9(4). doi:10.1055/s-0038-1672138

12. Ma TM, Yang T, Philipson R, Kishan AU, Lee P, Raldow AC. Web-Based Symptom Monitoring With Patient-Reported Outcomes During Definitive Radiation Therapy With Chemotherapy (SYMPATHY): A Prospective Single-Center Phase 1 Study. *Adv Radiat Oncol*. 2023;8(3):101073. doi:10.1016/j.adro.2022.101073

13. 25x5 Documentation Burden Reduction Toolkit | AMIA - American Medical Informatics Association. Accessed March 25, 2025. https://amia.org/about-amia/amia-25x5/25x5-documentation-burden-reduction-toolkit

14. Fricker S, Yan T, Tsai S. Response Burden: What Predicts It and Who Is Burdened Out? Bureau of Labor Statistics; 2014. https://www.bls.gov/osmr/research-papers/2014/st140170.htm

15. Erlingsson C, Brysiewicz P. A hands-on guide to doing content analysis. *Afr J Emerg Med*. 2017;7(3):93-99. doi:10.1016/j.afjem.2017.08.001

16. Marikyan D. *Unified Theory of Acceptance and Use of Technology: A Review*.; 2023. https://open.ncl.ac.uk

17. Clendening J. Vanderbilt Patient-Reported Outcomes Measurement System collects millionth report. VUMC News. June 1, 2023. Accessed May 30, 2025. https://news.vumc.org/2023/06/01/vanderbilt-patient-reported-outcomes-measurement-system-collects-millionth-report/

18. Kenning C, Bower P, Small N, et al. Users' views on the use of a smartwatch app to collect daily symptom data in individuals with multiple long-term conditions (Multimorbidity): a qualitative study. *J Multimorb Comorbidity*. 2024;14:26335565231220202. doi:10.1177/26335565231220202

19. Plummer OR, Abboud JA, Bell JE, et al. A concise shoulder outcome measure: Application of computerized adaptive testing to the American Shoulder and Elbow Surgeons Shoulder Assessment. *J Shoulder Elbow Surg*. 2019;28(7):1273-1280. doi:10.1016/j.jse.2018.11.068

20. Tevis SE, James TA, Kuerer HM, et al. Patient-Reported Outcomes for Breast Cancer. *Ann Surg Oncol*. 2018;25(10):2839-2845. doi:10.1245/s10434-018-6616-1

21. Adler-Milstein J, Nong P. Early experiences with patient-generated health data: Health system and patient perspectives. *JAMIA*. 2019;26(10). doi:10.1093/jamia/ocz045

22. Schmidt T, Valuck T, Perkins B, et al. Improving patient-reported measures in oncology: a payer call to action. *J Manag Care Spec Pharm*. 2021;27(1):118-126. doi:10.18553/jmcp.2020.20313

23. Khatiwada P, Yang B, Lin JC, Blobel B. Patient-Generated Health Data (PGHD): Understanding, Requirements, Challenges, and Existing Techniques for Data Security and Privacy. *J Pers Med*. 2024;14(3):282. doi:10.3390/jpm14030282

24. Seppen BF, Wiegel J, L’ami MJ, et al. Feasibility of Self-Monitoring Rheumatoid Arthritis With a Smartphone App: Results of Two Mixed-Methods Pilot Studies. *JMIR Form Res*. 2020;4(9):e20165. doi:10.2196/20165

25. Young VN, Jordan KM, Schneider SL, Lazar A, Dwyer CD, Rosen CA. Laryngology Quality of Life Questionnaire Associations: Towards Reducing Survey Burden. *The Laryngoscope*. 2021;131(7):1561-1565. doi:10.1002/lary.29019

26. Struminskaya B, Toepoel V, Lugtig P, Haan M, Luiten A, Schouten B. Understanding Willingness to Share Smartphone-Sensor Data. *Public Opin Q*. 2020;84(3):725-759. doi:10.1093/poq/nfaa044

27. Guardado S, Karampela M, Isomursu M, Grundstrom C. Use of Patient-Generated Health Data From Consumer-Grade Devices by Health Care Professionals in the Clinic: Systematic Review. *J Med Internet Res*. 2024;26:e49320. doi:10.2196/49320

28. Aiyegbusi OL, Cruz Rivera S, Roydhouse J, et al. Recommendations to address respondent burden associated with patient-reported outcome assessment. *Nat Med*. 2024;30(3):650-659. doi:10.1038/s41591-024-02827-9

29. Turner RR, Quittner AL, Parasuraman BM, Kallich JD, Cleeland CS. Patient-Reported Outcomes: Instrument Development and Selection Issues. *Value Health*. 2007;10:S86-S93. doi:10.1111/j.1524-4733.2007.00271.x

30. Omoloja A, Vundavalli S. Patient generated health data: Benefits and challenges. *Curr Probl Pediatr Adolesc Health Care*. 2021;51(11):101103. doi:10.1016/j.cppeds.2021.101103

31. Dullabh P, Dhopeshwarkar R, Cope E, et al. Advancing patient-centered clinical decision support in today’s health care ecosystem: key themes from the Clinical Decision Support Innovation Collaborative’s 2023 Annual Meeting. *JAMIA Open*. 2024;7(4):ooae109. doi:10.1093/jamiaopen/ooae109

32. Chung AE, Basch EM. Potential and Challenges of Patient-Generated Health Data for High-Quality Cancer Care. *J Oncol Pract*. 2015;11(3):195-197. doi:10.1200/JOP.2015.003715

33. Wohlfahrt P, Zickmund SL, Slager S, et al. Provider Perspectives on the Feasibility and Utility of Routine Patient-Reported Outcomes Assessment in Heart Failure: A Qualitative Analysis. *J Am Heart Assoc*. 2020;9(2):e013047. doi:10.1161/JAHA.119.013047

34. Desai P, Osheroff J, Jimenez F, et al. *Scaling, Measurement, and Dissemination of CDS Workgroup: Approaches to Measuring Patient-Centered CDS Workflow and Lifeflow Impact*. Agency for Healthcare Research and Quality (AHRQ); 2023.

35. Lobach D, Heaney-Huls K, Ryan S, et al. *Implementation, Adoption, and Scaling Workgroup: Exploring Challenges and Opportunities for Patient Engagement, Implementation, Adoption, and Scaling Through PC CDS Case Studies*. Agency for Healthcare Research and Quality; 2024.

36. Francis DO, McPheeters ML, Noud M, Penson DF, Feurer ID. Checklist to operationalize measurement characteristics of patient-reported outcome measures. *Syst Rev*. 2016;5(1):129. doi:10.1186/s13643-016-0307-4

37. Engelhoven AER, Bislick L, Gray S, Pompon RH. Respondent Burden and Readability of Patient-Reported Outcome Measures for People With Aphasia. *Top Lang Disord*. 2022;42(3):266-282. doi:10.1097/TLD.0000000000000288

38. Nelson LA, Spieker AJ, Kripalani S, et al. User preferences for and engagement with text messages to support antihypertensive medication adherence: Findings from a pilot study evaluating an emergency department-based behavioral intervention. *Patient Educ Couns*. 2022;105(6):1606-1613. doi:10.1016/j.pec.2021.10.011

39. Uhrig Castonguay BJ, Cressman AE, Kuo I, et al. The Implementation of a Text Messaging Intervention to Improve HIV Continuum of Care Outcomes Among Persons Recently Released From Correctional Facilities: Randomized Controlled Trial. *JMIR MHealth UHealth*. 2020;8(2):e16220. doi:10.2196/16220

40. Bäcker A, Forsström D, Hommerberg L, Johansson M, Hensler I, Lindner P. A novel self-rating instrument designed for long-term, app-based monitoring of ADHD symptoms: A mixed-methods development and validation study. *Digit Health*. 2024;10:20552076241280037. doi:10.1177/20552076241280037

41. Gausden EB, Levack A, Nwachukwu BU, Sin D, Wellman DS, Lorich DG. Computerized Adaptive Testing for Patient Reported Outcomes in Ankle Fracture Surgery. *Foot Ankle Int*. 2018;39(10):1192-1198. doi:10.1177/1071100718782487

42. Strachna O, Cohen MA, Allison MM, et al. Case study of the integration of electronic patient-reported outcomes as standard of care in a head and neck oncology practice: Obstacles and opportunities. *Cancer*. 2021;127(3):359-371. doi:10.1002/cncr.33272

43. Lavallee DC, Lee JR, Austin E, et al. mHealth and patient generated health data: stakeholder perspectives on opportunities and barriers for transforming healthcare. *mHealth*. 2020;6:8. doi:10.21037/mhealth.2019.09.17

44. Mercadal-Orfila G, Herrera-Pérez S, Piqué N, et al. Implementing Systematic Patient-Reported Measures for Chronic Conditions Through the Naveta Value-Based Telemedicine Initiative: Observational Retrospective Multicenter Study. *JMIR MHealth UHealth*. 2024;12:e56196. doi:10.2196/56196

45. NCI. Definition of cognitive impairment - NCI Dictionary of Cancer Terms - NCI. February 2, 2011. Accessed June 9, 2025. https://www.cancer.gov/publications/dictionaries/cancer-terms/def/cognitive-impairment

46. Phi NTT, Montori VM, Kunneman M, Ravaud P, Tran VT. Cumulative Burden of Digital Health Technologies for Patients With Multimorbidity: A Systematic Review. *JAMA Netw Open*. 2025;8(4):e257288. doi:10.1001/jamanetworkopen.2025.7288

47. CDC. Diabetes Stigma. Diabetes. June 10, 2024. Accessed June 9, 2025. https://www.cdc.gov/diabetes/articles/diabetes-stigma.html

48. Uchigata Y. The still persistent stigma around diabetes: is there something we can do to make it disappear? *Diabetol Int*. 2018;9(4):209-211. doi:10.1007/s13340-018-0373-z

49. Jo E, Zehrung R, Genuario K, Papoutsaki A, Epstein DA. Exploring Patient-Generated Annotations to Digital Clinical Symptom Measures for Patient-Centered Communication. *Proc ACM Hum-Comput Interact*. 2024;8(CSCW2):1-26. doi:10.1145/3686997

50. Dullabh P, Dungan R, Dungan R, et al. *Trust & Patient-Centeredness Workgroup: Methods for Involving End-Users in PC CDS Co-Design*. Agency for Healthcare Research and Quality; 2023.

51. van Gils AM, Viser LNC, Hendriksen HMA, Georges J, van der Flier WM, Rhodius-Meester, HFM. Development and design of a diagnostic report to support communication in dementia: Co-creation with patients and care partners. *Alzheimer's Dement.* 2022; 14:e12333. https://doi.org/10.1002/dad2.12333

52. Conrad S. Best practices in digital health literacy. *International Journal of Cardiology.* 2019; 292. https://doi.org/10.1016/j.ijcard.2019.05.070.

53. Turchioe MR, Mangal S. Health literacy, numeracy, graph literacy, and digital literacy: an overview of definitions, evaluation methods, and best practices. *European Journal of Cardiovascular Nursing.* 2024; 23(4). https://doi.org/10.1093/eurjcn/zvad085

54. Levy DR, Withall JB, Mishuris RG, et al. Defining Documentation Burden (DocBurden) and Excessive DocBurden for All Health Professionals: A Scoping Review. *Appl Clin Inform*. 2024;15(05):898-913. doi:10.1055/a-2385-1654

55. Wang Z, West CP, Vaa Stelling BE, et al. *Measuring Documentation Burden in Healthcare*. Agency for Healthcare Research and Quality (AHRQ); 2024. doi:10.23970/AHRQEPCTB47

56. Zogas A, Sitter KE, Barker AM, Fix GM, Khanna A, Herbst AN, Vimalanda VG. Strategies for engaging patients in co-design of an intervention. *Patient Educ Couns*. 2024;123:108191. doi:10.1016/j.pec.2024.108191

57. Slattery P, Saeri AK, Bragge P. Research co-design in health: a rapid overview of reviews. *Health Res Policy Syst*. 2020;18(1):17. doi:10.1186/s12961-020-0528-9

58. Multiple Chronic Conditions in the United States | RAND. Accessed June 10, 2025. https://www.rand.org/pubs/tools/TL221.html

59. Tierney AA, Gayre G, Hoberman B, Mattern B, Ballesca M, Kipnis P, Liu V, Lee K. Ambient Artificial Intelligence Scribes to Alleviate the Burden of Clinical Documentation. *NEJM Catal*. 2024;5(3):CAT.23.0404. doi:10.1056/CAT.23.0404.

60. Albrecht M, Shanks D, Shah T, et al. Enhancing clinical documentation with ambient artificial intelligence: a quality improvement survey assessing clinician perspectives on work burden, burnout, and job satisfaction. *JAMIA Open*. 2025;8(1):ooaf013. doi:10.1093/jamiaopen/ooaf013

61. Cohen I, Ritzman J, Cahill R. Ambient Listening—Legal and Ethical Issues. *JAMA Netw Open*. 8(2). Accessed June 23, 2025. https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2830390