

## STEP 5 | Selecting or Creating an Assessment Instrument

**Assessment instruments** are tools used to collect, measure, and analyze data of interest. Assessments for health equity can take many different forms, and there is currently no standardized instrument for assessing health equity among children with medical complexity (CMC).

Regardless of methodology, any tool or process for assessing health equity should be co-designed with key partners who can speak to the needs of the CMC population. Their input should directly inform the content and measures included in an assessment as well as the approaches to asking questions.<sup>1</sup>

The following considerations and linked resources in this document can support efforts to select or craft questions for a health equity assessment, with engagement and input from these partners.

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## Engaging Key Collaborators in Design

### ***Who should be involved while designing and validating your assessment?***

Whether adopting an existing tool or creating a new assessment, it is crucial to ask questions in ways that build trust and foster mutual respect. Inviting input from key collaborators (e.g., patients, caregivers, families, providers, and community partners) throughout design can yield assessments that accurately gauge the target population's needs and experiences. This involvement helps to:

- shape question framing so that people feel comfortable responding completely and candidly, even to personal or sensitive questions.
- reinforce trust and build rapport by demonstrating respect for key partners' priorities, perspectives, and preferences for the types or depths of information they share. This can honor respondents' agency and balance power dynamics between patients, families, and providers.

Key collaborators can help shape the design of your assessment by providing feedback on what questions to ask and how to ask them. In planning and conducting activities to engage key collaborators, consider having them answer the following questions:

#### **Patients, Caregivers, Families**

- Do the questions center the needs, priorities, and preferences of patients, caregivers, or other family partners?
- Is the assessment clear and easy to understand?
- Are there concerns with including any questions or should sensitive questions be rephrased?

#### **Providers**

- Do the questions elicit information that is useful to inform providers' decision-making or care delivery?
- Can the data collected be acted upon in any way?
- If assessing social needs: does the provider feel confident communicating about the need or directing patients and families to available resources?

#### **Community Partners**

- If assessing social needs: what community resources are available that patients and families may be referred to?

## Data Collection Strategy

### *What depth and type of information is needed?*

The format and phrasing of assessment questions is informed by the types of data needed.

- **Closed-ended questions** present respondents with a constrained, pre-defined list of options to choose from (e.g., yes/no, multiple choice options, ratings). These are useful for collecting precise information that can be easier to analyze. This format may be more appropriate for more straightforward questions about health equity.
- **Open-ended questions** allow respondents to provide more detail about their experience in their own words and allow for individualized responses that generate more meaningful insights about one's attitudes, needs, preferences, etc. This type of question allows families to provide a more comprehensive description of the complexity of their situation and may elicit nuances that may otherwise be overlooked in closed-ended questions.

More information on **quantitative and qualitative question design:**

- Quantitative: [Questionnaire Design Tip Sheet](#) (Harvard University)
- Qualitative: [Designing Semi-Structured Interview Guides for Rapid Turnaround Qualitative Work](#) (VA QUERI)

## Mode of Delivery

### *Who will complete the assessment, and how will they access it?*

Consider the needs of the person who will directly interact with the tool.

- If a **patient or caregiver** will independently complete a questionnaire: include clear instructions, define key terms, and provide supporting examples when possible.
- If a **provider or staff member** will complete the assessment on behalf of a patient or caregiver (e.g., by soliciting information from them via communication): include additional directions or guiding prompts that might support them in posing questions and documenting responses.

More information on **designing questions for different modes of administration:**

- Questionnaires: [Self-Administered-Surveys](#) (University of Michigan)
- Qualitative interviewing: [Strategies for Qualitative Interviews](#) (Harvard University)
- Empathic Inquiry: [Social Needs Conversation Guides](#) (Oregon Primary Care Association)

## Accessible Instrument Design

### *Does the assessment accommodate various communication styles and needs?*

**Accessibility** includes the practice of ensuring all people regardless of ability are afforded the same opportunities to obtain information, engage in interactions, and enjoy services.<sup>1</sup>

Considering accessibility is important in designing any instrument, and it is especially critical for the design of tools to be used by the CMC population. When designing assessments, consider how to accommodate the varying learning styles and communication needs of people with vision, hearing, speech, or intellectual, cognitive, or developmental disabilities.

#### More information on **accessible communication**:

- [Communicating with People with Disabilities](#) (National League for Nursing)
- [Communicating Effectively with People with Disabilities](#) (ADA)

### *Can individuals with disabilities readily access and interact with the assessment?*

An assessment should be designed to be accessible to a diverse audience with varying physical and mental abilities. Whether you are administering your assessment on paper or electronically, be sure to adhere to accessibility guidelines. Consider the following examples:

- Use visual depictions for people who are non-verbal.
- Provide descriptive alt text for all images and videos for people with visual impairment.
- Ensure there is sufficient color contrast between the background and foreground and do not rely solely on color for emphasis.
- Use proper headers to organize your assessment.
- Ensure digital assessments are keyboard accessible and do not rely on clicking a mouse.
- Limit questions that ask people with cognitive disabilities to recall old information.
- Offer the ability to request alternative formats of the assessment.

#### More information on **inclusive and accessible design**:

- [A Step-by-Step Guide to Creating More Accessible Surveys](#) (SurveyGizmo)
- [Inclusive Design Toolkit](#) (University of Cambridge)
- [Accessible Survey Design Checklist](#) (Virginia Board for People with Disabilities)

## Plain Language

### *Is the assessment clear and easy to understand?*

Assessment design should consider varying levels of health and general literacy across the intended audience. **Plain language** is clear, concise, and well-organized to help an audience understand a message the first time they read or hear it.<sup>2</sup> Using plain language often involves avoiding industry jargon or other technical terms.

#### More information on **using plain language**:

- [Plain Language Materials & Resources](#) (CDC)
- [Plain Language Checklist](#) (Family Voices)

## Patient, Caregiver, and Family-Centered Language

### *Do the questions use non-stigmatizing, person-centered language?*

**Person-centered language** acknowledges the individual as the expert in their own lived experience and emphasizes that people are not defined or created by their conditions, situations, or contexts.<sup>3</sup> Taking a person-centered approach can support interactions with historically stigmatized populations by recognizing that people's unique combination of identities and experiences impacts their individual needs and priorities.

Person-first and identity-first language are both ways to refer to someone's identity or experience. **Person-first language** emphasizes the individual over the disability, disease, or condition (e.g., person with a cognitive disability, person who uses a wheelchair, etc.). However, some disability communities prefer **identity-first language** that prioritizes a person's right to self-define and place the disability first (e.g., deaf person).<sup>4</sup> This linguistic choice is more commonly preferred in blind, deaf, and autistic communities. Lead with asking about a patient or family's preferences first, and consult with your key collaborators (e.g., patients, caregivers, families) to understand your populations' preferences for describing disabilities.

#### More information on **person-centered language and disability language**:

- [Using Person-Centered Language](#) (Resources for Integrated Care)
- [Disability Language Guide](#) (The Independence Center)
- [Glossary: Disability Language Style Guide](#) (National Center on Disability and Journalism)

## Designing with Cultural Humility

### ***Did assessment design account for the cultures of individuals who will use the tool?***

When designing an instrument, it is important to consider the multiple identities held by those providing information. Practicing **cultural humility**—the process of self-reflecting that informs a deeper understanding of cultural differences and how to honor others' identities, customs, and beliefs<sup>5</sup>—should inform assessment design. While interrelated concepts, cultural humility differs from cultural competence in that cultural humility recognizes power dynamics and a desire to improve these imbalances. For the CMC population, practicing cultural humility in assessment design should additionally account for reflection on how sense of identity develops in relationship to disability.

Instrument design and delivery should account for levels of mistrust experienced by some who identify with cultural or other groups that have historically been mistreated by research and/or medical professionals.<sup>6,7</sup> It is, however, important not to make assumptions about patients' attitudes or behaviors based on their perceived culture to avoid stereotyping or perpetuating implicit biases.

More information on **cultural humility** and **communicating across cultures**:

- [What is Cultural Humility? The Basics](#) (University of Oregon)
- [Think Cultural Health](#) (Office of Minority Health)
- [Cultural Humility Guidelines for Interactions with People with Disabilities](#) (Florida Rural Health)

## Sensitivity, Safety, and Compassion

### ***Do your questions acknowledge the sensitivity of information being requested?***

Assessing health equity often involves discussing highly sensitive social needs or psychosocial factors. Patients or caregivers may hesitate to disclose this information due to discomfort or concerns about judgment, confidentiality, or relevance to care. Consider whether assessment language directly acknowledges the sensitivity of the topic and clearly explains how collected information will be used. Clearly communicating that respondents can choose to not answer any question helps build trust and respects people's autonomy to disclose only the information they feel comfortable sharing.

### ***Might any of the questions cause harm or undue fear?***

If a priority domain of interest for your assessment is highly sensitive (e.g., child abuse or neglect, physical or sexual violence, substance use, suicidal ideation, immigration status),

think carefully about how these questions are asked and how answers are documented.

Consider the following:

- Phrasing questions indirectly (e.g., whether a respondent has concerns about a specific topic they want to discuss with their medical team) can encourage self-reporting.
- Considering confidentiality (e.g., avoiding questions about domestic violence when other family members are present) can avoid endangering people or putting them in an uncomfortable position.
- Understanding patient privacy laws and regulations (e.g., rights to privacy regarding immigration status) should inform how patient-provided information gets documented and retained.

More information on **communication and screening techniques for sensitive topics**:

- [Talking to Patients About Sensitive Topics](#) (Association of American Medical Colleges)

## Pilot Testing

***Will the instrument feasibly provide valid, reliable results? What changes need to be made based on stakeholder feedback?***

Once you have considered the guidance listed above and selected your questions, you will want to know if your instrument is going to yield valid, reliable results. Conducting a small-scale, pilot test before full implementation of your assessment can help evaluate (1) the experiences of individuals completing the assessment, and (2) the feasibility of implementing it at scale.

Engaging your key collaborators in a pilot test (e.g., patients, caregivers, families, providers) will help you identify what changes need to be made to your instrument. For example, pilot testing an assessment with caregivers may uncover that a question is confusing or does not elicit the depth of type of information you hoped to collect. Use feedback provided by those involved in the pilot test to inform necessary adaptations to your instrument.

More information on **pilot testing**:

- [How to pretest and pilot a survey questionnaire](#) (tools4dev)
- [Making the Most of Parent Involvement Data: Pilot the Survey](#) (Idea Data Center)

## Key Considerations for Screening for Social Needs and Determinants

While there are several strategies for assessing health equity, one common method involves screening for patients' **health-related social needs (HSRN)**: the immediate needs affecting one's ability to maintain their health and well-being.<sup>9,6</sup> These factors may be thought of as existing immediately downstream from **social determinants of health (SDOH)**: the conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.<sup>8</sup> SDOH represent the broader social conditions that shape communities and often serve as drivers of social needs.

Screening for social needs driven by SDOH involves:

- understanding patients' or families' social concerns, needs, and priorities;
- identifying risk and protective factors;
- assessing social issues; and
- referring people to appropriate support and/or services (when possible).<sup>10</sup>

Growing recognition of social drivers' impact on health outcomes has prompted development of general screening instruments, but no standardized CMC-specific screening tool exists. While not designed for CMC, several assessments developed by the Robert Wood Johnson Foundation's *Transforming Complex Care* initiative account for factors common among patients with complex needs.<sup>11</sup>

Population	Examples of Screening Instruments	Source
General	<a href="#">Accountable Health Communities Health-Related Social Needs Screening Tool</a>	Centers for Medicare and Medicaid Services (CMS)
General	<a href="#">The EveryONE Project</a>	American Academy of Family Physicians (AAFP)
General	<a href="#">PRAPARE: Protocol for Responding to &amp; Assessing Patients' Assets, Risks &amp; Experiences</a>	National Association of Community Health Centers (NACHC)
General	<a href="#">Social Needs Screening Tool</a>	Health Leads
General	<a href="#">Upstream Risks Screening Tool</a>	HealthBegins
Complex Care	<a href="#">Social Determinants Screening Tool</a>	AccessHealth Spartanburg
Complex Care	<a href="#">Self-Sufficiency Outcomes Matrix</a>	OneCare Vermont



Population	Examples of Screening Instruments	Source
Complex Care	<a href="#">Redwood Community Health Coalition PRAPARE Tool</a>	Redwood Community Health Coalition
Complex Care	<a href="#">Community Paramedicine Pilot Health Assessment</a>	ThedaCare
Complex Care	<a href="#">Social Needs Assessment</a>	Virginia Commonwealth University Health System

To explore questions focused on specific SDOH from a variety of screening instruments, visit our **SDOH Item Bank**: [https://academyhealth.sharepoint.com/:x/s/HRSA/CMC/Item Bank](https://academyhealth.sharepoint.com/:x/s/HRSA/CMC/Item%20Bank)

Information provided for each question includes:

- tags indicating relevance to specific SDOH topics,
- the instrument from which the question was sourced, and
- any applicable implementation considerations.

## References

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