Supportive Care in Cancer (2025) 33:810
https://doi.org/10.1007/s00520-025-09865-0

RESEARCH

# Development of an electronic system for self/proxy symptom tracking alongside children with cancer and their caregivers: a co-design exemplar

**Stacey Crane[1] · Aaron Ganci[2] · Sheri L. Robb[3] · Karen DiValerio Gibbs[1] · Rebecca Nosich[4] · Andrew D. Miller[5]**

Received: 28 February 2025 / Accepted: 13 August 2025 / Published online: 26 August 2025


## Abstract

**Purpose** Symptom tracking systems are essential for identifying symptoms in patients, prompting timely clinical intervention to reduce suffering and improve outcomes for children with cancer. Electronic patient-reported outcome tools have been designed to assess the presence and severity of symptoms and notify clinicians of the patient's condition, facilitating quick and effective symptom management. Utilizing co-design methods allows end user input in the tool development process. This manuscript describes how we used a co-design process to develop an electronic system for tracking the symptoms of children with cancer and their caregivers.

**Methods** Collaborative co-design sessions were conducted using a Future Workshop format. Participants were six children with cancer and seven caregivers. Co-design activities were used to gather insights into current symptom reporting practices and to envision an ideal system. Data from these sessions were analyzed using Braun and Clark's method for descriptive thematic analysis.

**Results** Key themes identified during data analysis included the importance of relationships and interactions with the health care team, miscommunication in symptom reporting, and the need for centralized information storage and timely clinician response. Children in particular indicated challenges with finding the words to share how they are feeling, while caregivers expressed constant worry and the burden of advocating on their child's behalf.

**Conclusions** Co-design is a powerful method for envisioning solutions to clinical problems. By involving end users in key stages of the creative process, it is possible to develop solutions that better address underlying challenges and are more enticing for users to adopt. In this study, we successfully used co-design to identify key features for an electronic system intended to improve symptom tracking, facilitate communication with clinicians, and allow for better symptom management. Barriers to consistent electronic system use were also identified, emphasizing the need for simplicity in system design, an engaging interface, and a clear benefit for users.

**Keywords** Pediatric · Oncology · Co-design · System design · Symptom assessment

✉ Stacey Crane
stacey.crane@uth.tmc.edu

Aaron Ganci
aganci@iu.edu

Sheri L. Robb
shrobb@iu.edu

Karen DiValerio Gibbs
Karen.D.Gibbs@uth.tmc.edu

Rebecca Nosich
rxnosich@texaschildrens.org

Andrew D. Miller
andrewm@iu.edu

[1] Cizik School of Nursing, University of Texas Health Science Center at Houston, Houston, TX, USA

[2] Herron School of Art and Design, Indiana University, Indianapolis, IN, USA

[3] School of Nursing, Indiana University, Indianapolis, IN, USA

[4] Texas Children's Hospital, Houston, TX, USA

[5] Luddy School of Informatics, Computing, and Engineering, Indiana University Indianapolis, Indianapolis, IN, USA

## Introduction

Direct patient report is considered the gold standard for assessing subjective symptoms. Systematic use and documentation of patient report provides data that is easily tracked and analyzed [1, 2]. Emerging evidence indicates that collecting patient-reported data can improve quality of life in adult patients with cancer [3]. Additionally, patient-reported data can prevent inaccuracies in symptoms recorded in the electronic health record (EHR) [1, 4–6]. In pediatric oncology, patient-report involves both child self-reporting (primary method) and separate proxy-reporting by parents or caregivers (secondary method) for children unable to self-report (i.e., due to developmental level). There are currently a wide variety of patient-reported outcome measures available that allow children with cancer and/or their caregivers to directly report symptoms to clinicians, including tools that evaluate specific concerns such as depression (Beck Depression Inventory), quality of life (PedsQL), or cancer-specific measures such as the Symptom Screening in Pediatrics Tool (SSPedi) [7–9]. While these tools are increasingly used in research, they have not been widely integrated into pediatric oncology clinical practice [10, 11].

Electronic patient-reported outcome (ePRO) systems facilitate the collection of data from patients and their caregivers. These systems allow children and parents or caregivers to report symptoms using tablets, computers, and/or smartphones in a variety of settings. They negate the need for transcribing information, allow data to be securely stored and integrated into EHRs, and can produce reports highlighting trends in symptoms over time as well as trends in symptoms of children with similar characteristics (e.g. children receiving the same treatment or sharing the same diagnosis) [12, 13]. However, the benefits of ePRO systems and self or proxy symptom assessments are only realized when they are successfully implemented and routinely used by patients, families, and clinicians [12, 13]. Barriers to the implementation of electronic systems for self/proxy symptom assessments include poor system usability (i.e., systems that are difficult to use, confusing, or do not seem useful), difficulty timing completion with clinical processes, patient/family discomfort with the system, and lack of system use by patients/families [14–16]. Barriers can also occur at the institutional level, including regulatory or data security concerns, the need for ongoing technical support, the cost of hiring additional staff or training existing staff, and the cost of new electronic equipment (as reviewed in [17]).

### Co-design

There are gaps in understanding the experiences of children with cancer and their caregivers regarding symptom reporting. In addition to examining the strengths and weaknesses of current methods, there is a need to explore the ideal process for reporting symptoms during treatment and how that system would function. By employing a participatory approach to the design of technologies, often referred to as user-centered design, *participatory design,* or *co-design*, end users of technologies are able to develop their own interfaces [18]. While end users sometimes participate as full collaborators (such as in Community-Based Participatory Research [19]), most co-design approaches involve users as *informants* by conducting co-design interviews, workshops, and feedback sessions throughout the design and development process. By collaborating closely with end users, designers can identify potential barriers, customize solutions, and ensure greater ecological validity of designs before they are deployed as fully-functional products [20, 21]. Whereas individual usability tests or focus groups ask for feedback on existing applications or prototypes, co-design methods involve users in the creation of new, speculative designs. Depending on the length of the co-design sessions, designs can take the form of anything from paper prototypes to semi-functional electronic systems. Co-design has been particularly influential in the development of interactive technologies for children, whose values and priorities might otherwise be ignored or misinterpreted [22]. In the area of child-computer interaction, a recent analysis found that in the last 20 years, over 60% of research papers at a prominent publication venue involved children as informants or design partners, with the remaining studies engaging children as testers throughout development [23]. Co-design techniques have been successfully used in medical settings, with research publications using the method dating back at least 20 years [24]. Participatory and co-design approaches have also been integrated in other pediatric contexts, such as positive psychology interventions, inpatient interfaces for children and their family caregivers [25], and patient-centered oncology care [26, 27].

The purpose of this manuscript is to describe how we used co-design in partnership with children with cancer and their caregivers to develop an ePRO system for tracking symptoms. Findings from these co-design sessions will guide larger studies in the future to validate results and further improve the system.

## Methods

Outside of clinic visits, children/caregivers at Riley Hospital for Children at Indiana University Health currently communicate with their health care team through a patient portal that functions like a basic email system, allowing asynchronous back-and-forth messaging. This co-design study

gathered perspectives from children with cancer and their caregivers on creating a novel electronic system for symptom reporting. Co-design sessions focused on developing an ideal system for self or proxy symptom assessment.

Session transcripts were analyzed using Braun and Clark's method for descriptive thematic analysis. Caregivers included parents, family members, or other adults providing regular care to the child with cancer. Indiana University Institutional Research Board approval was obtained prior to screening and enrolling participants.

## Sample

Purposive sampling was used to recruit children who were currently being treated through the pediatric oncology program at Riley Hospital for Children. We approached children and their caregivers at the clinic or inpatient to determine if they were willing and able to provide feedback on the design of a web-based interface. To be included in the study, children had to be between the ages of 7–17 years, diagnosed with cancer at least three months prior to recruitment, and either actively receiving cancer treatment or completed treatment within the past 18 months. Their caregivers had to be at least 18 years of age, and all children and their caregivers were required to be able to read and speak English. Children and their caregivers were recruited together and participated in the study at the same time.

## Procedures

Following informed consent, caregivers completed a study-specific demographic form and were scheduled to participate in a single co-design session that involved the consenting caregiver, child, and members of the research team. Questions on the demographic form covered: caregiver and child age, gender, educational level, primary language, race, ethnicity, child's cancer diagnosis, family configuration, and household income.

### Co-design sessions

Co-design sessions were scheduled during a routine treatment visit or scheduled inpatient admission and were conducted in the clinic or in a hospital room. Sessions were audio-recorded, and photographs or scans were taken of all notes and drawings developed by participants and researchers during the sessions. The semi-structured interview guide used to direct the co-design sessions is presented in Table 1. Experts in co-design and pediatric oncology reviewed the interview guide prior to its use in this study. At the end of the co-design session, each child and caregiver participant received their own $75 gift card in recognition of their time and effort.

In this study, it was crucial that both children and caregivers felt empowered, creative, and equal in the process. Researchers employed Druin's techniques with participants, in order to strive for a neutral power structure: using first names, wearing informal clothing, avoiding hand-raising, and reimbursing both children and caregivers for their time [28]. The interviewers who conducted the focus groups included the principal investigator (SC), either a member of the research team from the school of art and design (AG) or an expert in informatics who specializes in interfaces for children (AM), and another research team member with training in qualitative interviewing. The principal investigator (SC) is a pediatric oncology nurse, while another member of the research team (SR) has extensive experience working with pediatric oncology patients and possesses training in qualitative data collection and analysis.

Sessions began with an ice-breaking activity called "Silly Scribble". Everyone in the room (researchers, children, and caregivers) was given a blank template and asked to draw a big scribble on the page (Fig. 1). Then everyone passed their scribble to the person on their right. The second person was asked to turn the scribble into a monster. Finally, they passed again to a third person who named the monster and made up a story about it. Each step of this activity was intentional and important to setting a collaborative and creative tone for the session. The Silly Scribble established the following necessary foundations for a co-design activity: (1) it is okay to express ideas visually in any fidelity (drawing, in our case), (2) it is okay to be silly and fantastical, (3) everyone can develop an engaging a story, and (4) everyone's creativity is valid and equal.

With these foundations in place, we proceeded using a Future Workshop format [28–30]. This format involves critiquing the past, dreaming about a better future, and implementing something in the present that can help us move to that ideal future state [29–31]. Co-design sessions initiated a critique of the past through semi-structured discussion about the children's personal experiences, using an activity called "Sharing Your Story". The next activity, "The Good and The Bad," is where insights from the shared stories were listed and characterized by children and caregivers as either positive or negative aspects of managing and communicating symptoms (Fig. 2). This activity facilitated identification of the most pressing problems that need addressing. We then moved into the future state with the "Your Magic Idea" activity, by asking children and caregivers to develop a fantastical solution that they felt would solve all the identified problems (Fig. 3). This activity empowered participants to dream about an ideal solution without constraint, to visualize the ideas, and to tell a story about how a new solution could work.

**Table 1** Co-design session interview guide

**Welcome (5 min)**

- I am _____ from _____, these are [other research team members]
- Thanks for coming today!
- The goal of this project is to understand how to support kids and teens in keeping track of their symptoms and in communicating that information to doctors and nurses

**Icebreaker (10 min): Silly Scribble**

- Draw a silly scribble, then pass to the person on your right (Starting with the child)
- Turn the scribble into a friendly monster, then pass to the person to your right
- Name the monster, and tell a silly story

**Your story (10 min)**

- Tell us what having cancer is like for you/your child.
- What would you (the child) say has been the hardest part? What do you (caregiver) think has been the hardest part for your child?
- What has been the best part?
- If <13 years old: What does the word "symptom" mean to you?
- What are the symptoms that you/your child experience?
- How do you currently track, manage, or share these symptoms?

**Good and bad experiences (20 min)**

- Now they are given the "Good and Bad Canvas" and a list of words which could potentially describe their feelings about sharing their symptoms (5 min)
- In the bad section place words that describe the bad parts about how you manage and share your/your child's symptoms currently
- In the good section place words that describe the good parts about how you manage and share your/your child's symptoms currently
- Tell us any incident or story related to the words that you have chosen

**Your ideal experience (20 min)**

- Tell us a story about how you want to track your symptoms
- Think about these questions:
  a. How do you share your/your child's symptoms?
  b. With whom do you share your/your child's symptoms?
  c. How can we make sharing your/your child's symptoms easy?
- You can either draw or choose pictures from the ones given to you
  a. Describe the thing
  b. How do you use it
  c. How does it make you feel?

## Analysis

Data analysis was conducted by the study team using inductive semantic thematic analysis per Braun and colleagues' phases of qualitative analysis [32]: becoming familiar with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing design ideas. A professional transcriptionist transcribed the recordings of the co-design sessions. A study team member (SC, AG, SR, RN, or AM) verified the transcripts for accuracy, made corrections as needed, and de-identified the transcripts. Each transcript was then reviewed and important themes were coded individually using ATLAS.ti (https://atlasti.com). Study team members also independently reviewed drawings and came to a consensus regarding the important themes depicted. Field notes collected during sessions were used during analysis to help provide context. The identified themes were discussed during study team meetings until a final consensus was reached and a codebook was created. During recruitment, data saturation was discussed and the team determined that sufficient saturation was reached at six participants for this pilot qualitative work. Transcripts and results were not reviewed with the participants in this study, as this was part of an iterative process and future studies were planned that included refinement to the system with user feedback.

## Results

Recruitment occurred between November 2018 and April 2019 at a pediatric academic medical center in the Midwest United States. A total of 11 children and caregivers


**Fig. 1** Silly Scribble


**Fig. 2** The Good and The Bad


**Fig. 3** Your Magic Idea

were approached, but four families were unavailable and one declined participation. Ultimately, six school-aged children and adolescents with cancer, along with seven caregivers, consented to participate. Demographic information for the recruited sample is provided in Table 2. Six design sessions were conducted and averaged 53 min each (range: 35–70 min). Analysis of the transcribed design session recordings revealed several themes, which are outlined in Table 3.

## "Sharing Your Story"

Children and caregivers reported a range of symptoms throughout treatment, varying in severity, from fatigue and memory issues to joint pain, neuropathy, jaundice, fever, and anemia. Along with physical symptoms, major themes that emerged were feelings of worry, loss of control, and the impact of community support during treatment. Caregivers highlighted feeling panic and hyperfocus in response to even minor changes in their child's condition. Participants noted the profound loss of control that cancer imposed, providing crucial context for understanding their experiences with symptom reporting.

## "The Good": positive experiences of current symptom reporting

Design sessions revealed several positive themes regarding their current symptom reporting system, which is conducted through an electronic medical record patient portal. These positive themes included relationships with health care staff, personal interactions, and the creation of a record of the experience. Children and caregivers clearly valued their relationships with the treatment team, noting the personal connection, consistency, and connection that emerges during cancer treatment. With respect to symptom reporting, caregivers discussed how the treatment team's familiarity with their children was helpful in recognizing small signs of concern or unusual patterns during the treatment process. Participants reported using journals and other written notes to record their experiences. They described that they liked having the ability to review that information for trends or for a deeper understanding of their condition.

## "The Bad": negative experiences of current symptom reporting

Participants highlighted several challenges with their current symptom reporting system, including difficulties with

**Table 2** Characteristics of the sample

| Item | *n* (%) |
|---|---|
| Total annual household income (*n* = 7 caregivers) | |
| < US$40,000 | 0(0) |
| > US$40–US$59,999 | 0(0) |
| > US$60–US$99,999 | 5(71.4) |
| > US$100,000 | 1(14.3) |
| Preferred not to answer | 1(14.3) |
| Parent's highest level of education (*n* = 7 caregivers) | |
| Less than 12th grade | 0(0) |
| High school graduate | 0(0) |
| Some college or professional training | 1(14.3) |
| College graduate | 6(85.7) |
| Graduate or professional degree | 0(0) |
| Parent's gender (*n* = 7 caregivers) | |
| Female | 6(85.7) |
| Male | 1(14.3) |
| Parent's race/ethnicity (*n* = 7 caregivers) | |
| Non-Hispanic white | 7(100) |
| Parent's primary language (*n* = 7 caregivers) | |
| English | 7(100) |
| Parent's number of other children (*n* = caregivers) | |
| 1 | 1(14.3) |
| 2 | 5(71.4) |
| 3 | 1(14.3) |
| Child's gender (*n* = 6) | |
| Female | 2(33.3) |
| Male | 4(66.7) |
| Child's race/ethnicity (*n* = 6) | |
| Non-Hispanic white | 6(100) |
| Child's primary language (*n* = 6) | |
| English | 6(100) |
| Child's current age (*n* = 6) | |
| 11 | 2(33.3) |
| 13 | 1(16.7) |
| 14 | 1(16.7) |
| 15 | 1(16.7) |
| 16 | 1(16.7) |
| Child's primary cancer (*n* = 6) | |
| AML relapse | 1(16.7) |
| B-ALL | 2(33.3) |
| Brain cancer | 1(16.7) |
| Leukemia | 1(16.7) |
| Osteosarcoma | 1(16.7) |

communication and concerns regarding how symptoms were interpreted by the health care team. Some children discussed barriers to reporting symptoms in outpatient settings, as opposed to hospital settings, where the proximity of medical staff made it easier to raise concerns. Although this study did not specifically recruit patients with advanced cancer, some children had cancer that was at a more advanced stage. Caregivers of these participants noted that the stage of cancer could affect symptom reporting, with children in advanced or terminal stages, and their caregivers, less likely to report symptoms compared to those earlier in treatment, due to an increased feeling of burden/sadness regarding the child's health status. Caregivers emphasized the importance of monitoring their child's mental health and noted challenges with remembering and tracking symptoms if they did not document them right away. Participants also found it difficult to remember instructions from the care team, with one participant voicing a preference for written communication to review and confirm later.

Children often struggled to describe their symptoms, particularly with finding the right words to explain how they are feeling. For children, barriers to reporting included fear of being a burden, shyness, competing opinions from caregivers, and potential communication limitations (depending on the developmental stage of the child), which can influence symptom reporting. Some caregivers noted that teenagers may be more likely to confide in friends than caregivers and family, adding further complexity to reporting for this age group. Caregivers sometimes hesitated to report symptoms on behalf of their child, concerned that they might overstep or misinterpret the child's experience.

Caregivers described how being the "middleman" that connects the patient, other caregivers, and the health care team added stress. Participants also noted that a challenging part of the current system was delays in responses to symptoms reported in the patient portal. While caregivers communicated that relationships with the care team were important, they also noted a disparity in focused attention, such that they themselves were focused solely on their own child while the care team had multiple children to monitor. With respect to symptom reporting, caregivers and children noted that sometimes their concerns were pushed aside. Caregivers commented that what was recorded in the child's medical record often did not accurately reflect their experiences or was not fully appreciated by the medical team and discussed frustration with reporting symptoms multiple times before concerns were addressed.

## "Your Magic Idea": ideal symptom assessment system features

During the co-design sessions, participating children and caregivers identified several key features that should be included in an ideal system for symptom assessment. These key features include (1) the ability to track the child's medical history over time, (2) having a central place to keep records and store data (such as a log of medications and treatments, and the child's response to each), (3) a calendar feature for tracking appointments,

**Table 3** Themes identified during qualitative analysis

| Activity | Theme | Exemplar |
|---|---|---|
| **"Sharing Your Story"** | Constant worry | "The bad stuff is like just the fear of it, whether you're here or in remission or out at home. You just constantly worry. It's just constant anxiety. A lot of, like, similar to PTSD type things. We have nightmares or just a lot of anxiety-type. I work over at [name of company], and I'll see something, and it'll be a trigger to an anxiety episode, and you're just, with him, I'm like on edge and at high alert all of the time. So, if I even think he has an eye twitch, I'm just like focused in on it." (Caregiver) |
| | Loss of control | "The things that are bad about the whole thing are all the things that you can't control." (Caregiver)<br>"There are things that you can't control, and you just miss people, but you can still stay connected. That's one of them over here. So, I'm not alone, which is good. I've got them and grandparents and friends who I can talk to, and uhh I know what I'm in for because I did this once already. [tapping noises] So, I kind of know what to expect which is nice." (Child) |
| | Community Support | "We got a lot of community support in our neighborhood as well too from the school systems and a lot of people in our community that did … donate to local businesses and things like that, fundraisers and stuff like that." (Caregiver) |
| **"The Good"** | Relationships with the staff, nurses, and doctors | "When you make a lot of relationships here with the staff and the nurses and the doctors, and they follow you when you're outside of here, when you're not or when you're in, and they get to know you and get to know your kids. Then they can tell by the look on your face when you come around the corner like if you've had a good day or not." (Caregiver) |
| | Positive interactions | "Because I feel [Children's hospital] is so focused on young kids. And finding the doctors or particular nurse or particular tech that he can have fun with and he jokes and he laughs and that makes his day better. When someone walking up with a toy. Or will I get a sucker for you today. I mean, that has been our benefit is the personal interaction." (Caregiver) |
| | Record of experience | "I guess what I'm saying is if we mention something in clinic, I don't know for sure if she [the clinician] has put it in her notes, but I've got it in mine, and it may come up three or four times for me, whereas she puts it in her notes in clinic, and she doesn't see this as something that is … a problem that isn't necessarily unique to [Child's name]." (Caregiver)<br>"I have a binder full of lab results just so I know where he's at. …Mostly that. I have a journal that I write when we come in what's going on and that's mostly to keep it straight in my head and have a record of our experience in my eyes, you know." (Caregiver) |
| **"The Bad"** | Accessibility | "Using my notebook paper. Problem with paper is it rips out of my book. Storage. So, I have file folders full. I have a big tub full of all of his stuff I've kept." (Caregiver)<br>"I prefer email because then I have it to reference back and forth, and I'll be like did I read that right, and is that really what they said? Like I need to go back and read that again" (Caregiver) |
| | Communication between different providers | "My problem was being the middle person to connect several professionals" (Caregiver) |
| | Problems remembering symptoms | "I keep forgetting things as I, so have to think like five times." (Child)<br>"Normally I just complain about things, and I don't really remember them, and she [mother] writes them down so that we can talk to the doctor about them." (Child) |
| | Trouble describing symptoms | "So, it's just kind of like explaining how you feel sometimes because sometimes I don't know if what I have counts as nausea or not or like if what I have is like allergies, I guess. So, it's kind of hard." (Child)<br>"I know I feel crappy, but how do I feel crappy" (Child)<br>"It's hard to explain things. I don't know. I think there needs to be more, like, words invented, maybe. I don't know." (Child) |

**Table 3** (continued)

| Activity | Theme | Exemplar |
|---|---|---|
| | Communication between child and caregiver | "He doesn't like to be the center of attention. He doesn't like to get embarrassed. If I tell the nurse something that he doesn't want me to tell the nurse, he's irritated. He's annoyed." (Caregiver)<br>"When I get home at the end of the night and I say how was your day. Did you have any issues? No, I was fine. Two days later – oh, I did have a headache. If there was a way at that moment he could put it somewhere and it got to me at some point in time where I knew, yes, that would be beneficial." (Caregiver) |
| | Advocating for child | "Yeah, it would be nice to have as much information as possible. I trust the doctors and nurses to be able to track these, but I'm [Child's name]'s only mom, whereas the doctors, [Child's name] is not their only patient, so it would be nice to have that information and be able to see the trends." (Caregiver)<br>"She notices things at home, but if we mention it in clinic, if it didn't meet a certain standard in clinic, it kind of just got pushed aside and not recognized, whereas I knew that it was significant, and to have to keep bringing it up, that's where the annoying part comes in." (Caregiver) |
| | Needing current information | "The only problem I have with the patient portal is it's delayed two days. So, when you're in an inpatient like this and you're wanting to know daily what's happening, you're on a two-day delay." (Caregiver) |
| | Problems with technology | "The younger kids, the moms are probably more actively using the phones. I'm not. I don't call myself old. I'm 41 and that's what I grew up with in school. We didn't have the technology like a 30-year-old might that has a kid." (Caregiver)<br>"I know that I can get online and look up all his blood results and test results. Have I? I haven't. And maybe that's just me not wanting to remember another password." (Caregiver)<br>"Then your battery dies. Where is my notebook and paper?" (Caregiver) |
| **"Your Magic Idea"** | Star Trek-like scanner | In the form of furniture, suit, and smart watch. Smart watch monitors vitals 24/7 and chair and/or furniture scans child and gives instant updates/results. Updates would be instantly sent to parents' phone |
| | Reset button | Scans patients and automatically fixes patients symptoms, keeps a log of what was fixed and sends report to health care provider. Physician could pop out in form of hologram and talk to patient |
| | Bedside assistance popup | Patient taps on certain areas of tablet/tv screen to notify computer what is wrong. Symptoms would then be color coded based on urgency. Computer would then notify physician/nurse on urgency of symptoms and the physician/nurse would be able to see a pop up visual on the patient. Patients questions could be answered instantly |
| | Monitor assistance | Patient information is stored within a monitor that displays vitals, stores all appointments, and lists patients' physicians/nurses. There is a button on the monitor that can answer parents' questions about anything at any time of day. Monitor would serve as middleman instead of parents to get ahold of several health care professionals to answer questions and update physicians/nurses on patients' status |
| | Magical note scanner | Automatically scans parents journaling notes into a technological device after they finish a page |
| | Magic boogie board | Parents could write journaling notes on board, push the button and it goes straight to their phone or computer and saves it in a file. Once button is pushed, a new clear screen pops up to write again |

treatments, and chemotherapy cycles, and (4) a communication feature that facilitates information sharing with the treatment team. Many caregivers kept journals of their child's cancer experience and felt that they were likely to keep their journal and use it in addition to any new system, in order to provide context and better understand the connection between treatment and symptoms.

Participants discussed how in their ideal system a clinician would be available to answer questions via telehealth visit, phone call, chat function, or some other interface

that allows for timely and direct contact. It was clear that coordination and communication were key, and that the ideal system should facilitate communication across inpatient and outpatient health care teams to ensure continuity of care. Both caregiver and child participants wanted feedback on symptoms from their clinical team, focused on providing relief from those symptoms. While both children and caregivers expressed anxiety about the child's cancer journey, caregivers emphasized the importance of receiving immediate feedback on the child's symptoms to reduce their child's suffering. They also highlighted the need to expand current symptom assessments to include mental, emotional, and social health for both the child and caregiver, along with access to appropriate support and interventions.

Families also placed high value on the relationship between the patient and clinicians. Caregivers stressed the importance of understanding their child as an individual, and that interpretation of symptom reports relied on the clinicians' understanding of each patient's unique experience. Toward this, one caregiver suggested that numeric graph scales in the ideal system should be adaptable to highlight variations in their child's data. Tracking the timing and severity of symptoms in relation to events like medication changes or clinical activities was thought to be particularly helpful to identify triggers and inform necessary adjustments to care plans.

Participants shared a wide variety of preferences and customization ideas for what they considered the ideal system. Participants noted that additional features like character customization or visual incentives may improve their use. Some of the examples they suggested included methods they currently use for offline symptom tracking, such as journaling. Integration with commonly used devices (such as cell phones), reminders through pop-up notifications, and "gamification" of the system with visuals like badges or awards were also suggested by participants.

During data analysis, some differing perspectives emerged between caregivers and children regarding their priorities in symptom reporting. Both groups valued having a summary of data trends and ways to intervene to alleviate symptoms and improve communication with the health care team. They also emphasized the emotional impact of cancer treatment on mental health. However, unlike adult caregivers, adolescents stressed the importance of privacy and confidentiality in symptom reporting. An emphasis on maintaining control of their information was clear from both the child's and the caregiver's perspective.

Table 3 includes the technology "superpowers" that children and caregivers identified to incorporate into an ideal electronic system that facilitates symptom assessment and tracking. Although some of these ideas are beyond the current capabilities of technology, elements of these ideas are achievable and can be integrated into technological solutions.

### Barriers to electronic system use

During the co-design sessions, several barriers to using an electronic system were identified. A key challenge was ensuring consistent use. Participants suggested offering incentives beyond financial compensation, such as earning digital badges or awards for completing questionnaires. Notifications and reminders were also recommended to encourage ongoing engagement. Caregivers stressed the need for simplicity, noting that an overly complex system might lead them to revert to solely traditional journaling methods. Children and adolescents, however, expressed more comfort using tablets and phones due to their familiarity with technology. As previously mentioned, some participants noted that those with advanced or terminal cancer might avoid symptom reporting, as it could feel mentally burdensome. To overcome these barriers, participants suggested that if the system connected them with clinicians and addressed the child's and family's needs, they would be more likely to use it consistently, knowing it could positively impact care.

## Discussion

This co-design study elicited the perspectives of children with cancer and their caregivers on an ideal ePRO system for self and proxy symptom assessments, and the characteristics that should be instilled into this system. There are a number of ePRO systems currently available for symptom tracking in pediatric settings [33–39], and especially in pediatric cancer [36, 38, 40, 41], but few have been designed using input from children themselves [26, 27, 42]. For the successful implementation of a novel electronic system, it is essential that end users are meaningfully integrated into the design and evaluation process [26, 43–48]. Using participatory or co-design methods, children and caregivers can have a hand in designing their own electronic systems and can provide valuable real-world feedback throughout the development process [18].

Through interviews with six children and seven caregivers, several key concepts emerged with respect to both positive and negative aspects of the current state of symptom reporting as well as co-design features of an ideal ePRO system. Overall, children and caregivers provided many more negative experiences than positive when describing their current methods for symptom reporting. Describing symptoms with written or spoken language is challenging, particularly for children who are in different developmental stages or who have family dynamics that may inhibit their ability to report their symptoms [49].

Participants' preferences for features to include in the ideal system, like character customization and gamification, are found in many health-related applications [50, 51]. Studies show these features might be helpful to keep children engaged, as they can enhance the user experience and make symptom reporting feel more familiar, interactive, and rewarding [40, 52]. By integrating these elements, ePRO systems can better support sustained engagement, especially during prolonged treatment periods when motivation may fluctuate.

An added challenge in working with children with cancer is that output reports from ePRO systems must integrate multiple perspectives, encompassing reports from the child, the caregiver, and potentially the health care team, and address cases in which these reports are discordant. Maintaining privacy and confidentiality is incredibly important for adolescents and young adult users [53, 54]. Failure to do so may lead to distrust in the health care team and limit future reporting [55–58]. To respect participants' privacy while still facilitating communication between children, caregivers, and the health care team, developers may need to create separate accounts for caregivers and children, and to carefully consider what aspects of the child's reported information are visible to caregivers. Balancing a caregiver's responsibility to monitor and support their child's health with the child's right to privacy is a difficult challenge, and one that becomes more complex as the child matures and seeks independence [53, 54]. At the same time, integrating data from all perspectives into a unified report is essential to provide context and a comprehensive view of the child's health status.

In addition to privacy concerns, symptom reporting systems should also accommodate developmental changes, as the ability to report symptoms may evolve with treatment intensity or end-of-life care. Younger children may enter their symptoms with their caregivers' assistance, while older children and adolescents may prefer to engage in shared decision-making and take on primary reporting responsibilities. Systems should be flexible enough to adapt to each child's cognitive and emotional maturity, as well as to the shifting roles between children and caregivers over the course of their illness. Incorporating customizable interfaces and age-appropriate features may help ensure that symptom reporting remains accurate, meaningful, and empowering for all users.

To respond to caregivers' needs, ePRO systems will need to lighten the burden for caregivers who serve as the middlemen between the child and their health care team. Developers should consider integrating information from the electronic medical record into ePRO systems, to enhance transparency and improve communication with clinicians. More so than child participants, adult caregivers stressed the importance of immediate feedback, particularly regarding the recognition of potentially serious symptoms, since there is already so much anxiety and fear surrounding the cancer experience. A centralized ePRO system that combines timely and accurate symptom tracking, provides reports reflecting symptom data from children and caregivers, includes customizable settings adjustable to the patient's privacy preferences and developmental stage, and facilitates communication with clinicians could help reduce delays in symptom management.

### Limitations and future directions

This study has several important limitations that affect the generalizability of the findings. The small number of participants resulted in a narrow age range of child participants and limited representation of cancer diagnoses, which restricts the applicability of the results to a broader pediatric oncology population. Although we identified that an ideal ePRO system would be able to adjust for developmental changes, our sample did not include any participants under the age of 11 to confirm these findings in younger children.

Despite efforts to include a diverse sample, participants were recruited from a single institution, were predominantly non-Hispanic white, highly educated, and had an income above the national average. Additionally, recruitment ended when the principal investigator changed institutions. Nonetheless, we are confident that the qualitative analysis captured key themes in symptom reporting.

Future research will build on these co-design insights to develop a more inclusive and relevant symptom-reporting system. Recruitment for future studies will focus on a larger, more diverse sample, and will consider equity, health literacy, and technology access in system development and implementation.

## Conclusions

This co-design study explored pediatric cancer patients' and caregivers' experiences with symptom reporting and their preferences for an ideal ePRO system to support cancer care. Partnering with families when developing electronic health systems provides valuable insights and helps to ensure the system is user-friendly, addresses families' needs, and collects information that is meaningful and accurate. Our future research will use further co-design strategies to develop a preliminary prototype for the ePRO symptom tracking system and focus on enhancing collaboration between children, caregivers, and clinicians. Enhancing the integration of technology with health care relationships can deepen our understanding of childhood cancer, improve communication between families and clinicians, and hopefully set the stage to more effectively meet children's needs throughout cancer treatment.

**Acknowledgements** The authors thank Drs. Emily Mueller, Siddhant Bhandari, Kaylee Green, Jessica West, and Jessica Wooden for their support and efforts towards the conduct and publication of this research.

**Author contributions** SC, AG, SR, and AM contributed to the study conception and design. Material preparation and data collection were performed by SC, AG, and AM. Data analysis was performed by all authors. The initial drafts of the manuscript were written by SC, AG, KDG, and AM. All authors commented on versions of the manuscript. All authors read and approved the final manuscript.

**Funding** This research study was generously funded through the Interdisciplinary Training in Behavioral Oncology Grant (T32 CA117865) from the National Cancer Institute, the UTHealth Innovation for Cancer Prevention Research Summer Undergraduate Fellowship from the Cancer Prevention and Research Institute of Texas, and a St. Baldrick's Foundation Scholar Award (712343). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health, the Cancer Prevention and Research Institute of Texas, or St. Baldrick's Foundation.

**Data availability** The data generated and/or analyzed in this study are available from the corresponding author on reasonable request.

## Declarations

**Ethics approval** This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Indiana University Institutional Review Board (Date: November 8, 2018, Number: 1810896595).

**Consent to participate** Informed consent was obtained from parents/legal guardians. Assent was obtained from all participants less than 18 years of age.

**Consent for publication** The authors affirm that the informed consent and assent obtained from participants included an agreement for publication of the de-identified data they provided.

**Competing interests** The authors declare no competing interests.

## References

1. Pinheiro LC et al (2018) Child and adolescent self-report symptom measurement in pediatric oncology research: a systematic literature review. Qual Life Res 27:291–319. https://doi.org/10.1007/s11136-017-1692-4
2. Leahy AB, Feudtner C, Basch E (2017) Symptom monitoring in pediatric oncology using patient-reported outcomes: why, how, and where next. Patient 11(2):147–153
3. Fiteni F et al (2019) Clinical relevance of routine monitoring of patient-reported outcomes versus clinician-reported outcomes in oncology. In Vivo 33(1):17–21
4. O'Donnell HC et al (2009) Physicians' attitudes towards copy and pasting in electronic note writing. J Gen Intern Med 24(1):63–68
5. Weis JM, Levy PC (2014) Copy, paste, and cloned notes in electronic health records. Chest 145(3):632–638
6. Yadav S et al (2016) Comparison of accuracy of physical examination findings in initial progress notes between paper charts and a newly implemented electronic health record. J Am Med Inform Assoc 24(1):140–144
7. Beck AT et al (1961) An inventory for measuring depression. Arch Gen Psychiatry 4:561–571
8. Varni JW, Burwinkle TM, Seid M (2005) The PedsQL(TM) as a pediatric patient-reported outcome: reliability and validity of the PedsQL(TM) measurement model in 25,000 children. Expert Rev Pharmacoecon Outcomes Res 5(6):705–719
9. Dupuis LL et al (2017) Validation of the symptom screening in pediatrics tool in children receiving cancer treatments. J Natl Cancer Inst. https://doi.org/10.1093/jnci/djx250
10. Meryk A et al (2021) Implementation of daily patient-reported outcome measurements to support children with cancer. Pediatr Blood Cancer 68(11):e29279
11. Meryk A et al (2022) Use of daily patient-reported outcome measurements in pediatric cancer care. JAMA Netw Open 5(7):e2223701
12. Crane S et al (2022) Challenges in the implementation of electronic systems for patient report of symptoms in oncology: a scoping review. J Hosp Manag Health Policy 5:31
13. Basch E et al (2022) Effect of electronic symptom monitoring on patient-reported outcomes among patients with metastatic cancer: a randomized clinical trial. JAMA 327(24):2413–2422
14. Garcia Farina E et al (2022) Barriers to electronic patient-reported outcome measurement among patients with cancer and limited English proficiency. JAMA Netw Open 5(7):e2223898
15. Lutz AT et al (2022) Patient reported outcomes in the daily practice in clinical oncology: a systematic review. Crit Rev Oncol Hematol 173:103658
16. Meirte J et al (2020) Benefits and disadvantages of electronic patient-reported outcome measures: systematic review. JMIR Perioper Med 3(1):e15588
17. Büttner M et al (2017) Quality of life measurements: any value for clinical practice? Curr Treat Options Oncol 18(5):30
18. Kuhn S, Muller MJ (1993) Participatory design. Commun ACM 36(6):24–29
19. Unertl KM et al (2016) Integrating community-based participatory research and informatics approaches to improve the engagement and health of underserved populations. J Am Med Inform Assoc 23(1):60–73
20. Mueller EL et al (2018) A survey of mobile technology usage and desires by caregivers of children with cancer. Pediatr Blood Cancer 65(11):e27359
21. Mueller EL et al (2022) An mHealth app to support caregivers in the medical management of their child with cancer: co-design and user testing study. JMIR Cancer 8(1):e33152
22. Druin A (2002) The role of children in the design of new technology. Behav Inform Technol 21(1):1–25
23. Kawas S et al (2020) Another decade of IDC research: examining and reflecting on values and ethics. In Proceedings of the Interaction Design and Children Conference 2020:205–215
24. Gennari JH, Reddy M (2000) Participatory design and an eligibility screening tool. Proceedings of the AMIA Symposium 2000:290–294
25. Miller AD, Pollack AH, Pratt W (2016) Bursting the information bubble: identifying opportunities for pediatric patient-centered technology. AMIA Annu Symp Proc 2016:894–903
26. Marchak JG et al (2020) User-centered design and enhancement of an electronic personal health record to support survivors of pediatric cancers. Support Care Cancer 28(8):3905–3914
27. Vaughn J et al (2020) Mobile health technology for pediatric symptom monitoring: a feasibility study. Nurs Res 69(2):142–148
28. Druin A (2002) The role of children in the design technology. Behav Inf Technol 21(1):1–25
29. Muller MJ (2003) Participatory design: the third space in HCI. In: Sears A, Jacko JA (eds) human-computer interaction: development process. CRC Press, Boca Raton, FL, pp 165–185

30. Jungk R, Müllert N (1996) Future workshops: how to create desirable futures, 2cd edn. Institute for Social Inventions, London
31. Kensing F, Madsen KH (1991) Generating visions: future workshops and metaphorical. In Design at work. CRC Press, pp 155–168
32. Braun V, Clarke V (2006) Using thematic analysis in psychology. Qual Res Psychol 3(2):77–101
33. Arbuckle R et al (2023) Psychometric validation and testing of the 10-item pediatric daily chest-related electronic patient reported outcome (ePRO) diary. Journal of Patient-Reported Outcomes 7(1):6
34. Yamaguchi R, Nicholson Perry K, Hines M (2014) Pain, pain anxiety and emotional and behavioural problems in children with cerebral palsy. Disabil Rehabil 36(2):125–130
35. Heath LE et al (2017) Successful utilization of an electronic pain diary in a multinational phase 3 interventional study of pediatric sickle cell anemia. Clin Trials 14(6):563–571
36. Reeve BB et al (2020) Validity and reliability of the pediatric patient-reported outcomes common terminology criteria for adverse events. J Natl Cancer Inst. https://doi.org/10.1093/jnci/djaa016
37. Cella D et al (2010) The patient-reported outcomes measurement information system (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005–2008. J Clin Epidemiol 63(11):1179–1194
38. Montgomery KE et al (2020) Using patient-reported outcomes to measure symptoms in children with advanced cancer. Cancer Nurs 43(4):281–289
39. Dussel V et al (2022) A multisite randomized controlled trial of an early palliative care intervention in children with advanced cancer: the PediQUEST response study protocol. PLoS One 17(11):e0277212
40. Bernier Carney KM et al (2021) Communication of pain by school-age children with cancer using a game-based symptom assessment app: a secondary analysis. Eur J Oncol Nurs 52:101949
41. Wolfe J et al (2015) Symptoms and distress in children with advanced cancer: prospective patient-reported outcomes from the PediQUEST study. J Clin Oncol 33(17):1928–1935
42. O'Sullivan C et al (2016) Evaluation of the electronic self-report symptom screening in Pediatrics tool (SSPedi). BMJ Support Palliat Care 8(1):110–116
43. Greenhalgh T et al (2019) Frameworks for supporting patient and public involvement in research: systematic review and co-design pilot. Health Expect 22(4):785–801
44. Jibb LA et al (2018) Perceptions of adolescents with cancer related to a pain management app and its evaluation: qualitative study nested within a multicenter pilot feasibility study. JMIR Mhealth Uhealth 6(4):e80
45. Jibb LA et al (2023) Parent and clinician perceptions and recommendations on a pediatric cancer pain management app: a qualitative co-design study. PLoS Digit Health 2(11):e0000169
46. Lai-Kwon J et al (2024) Co-design of an electronic patient-reported outcome symptom monitoring system for immunotherapy toxicities. Support Care Cancer 32(12):843
47. Bonotis P, Angelidis P, Natsiavas P (2025) Usability and user experience testing of a co-designed electronic patient-reported outcomes app ("MyPal for Adults") for palliative cancer care: mixed methods study. JMIR Hum Factors 12:e57342
48. Lai-Kwon J et al (2024) Using implementation science frameworks to guide the use of electronic patient-reported outcome symptom monitoring in routine cancer care. JCO Oncol Pract 20(3):335–349
49. Cheng L et al (2019) Symptom experience of children with cancer younger than eight years of age: an integrative review. J Pain Symptom Manage 58(1):157–166
50. Desai AD et al (2020) User-centered design of a longitudinal care plan for children with medical complexity. J Am Med Inform Assoc 27(12):1860–1870
51. Schwarz A et al (2023) Design features associated with engagement in mobile health physical activity interventions among youth: systematic review of qualitative and quantitative studies. JMIR Mhealth Uhealth 11:e40898
52. Linder LA et al (2021) Feasibility and acceptability of a game-based symptom-reporting app for children with cancer: perspectives of children and parents. Support Care Cancer 29(1):301–310
53. Hagström J et al (2022) Views, use, and experiences of web-based access to pediatric electronic health records for children, adolescents, and parents: scoping review. J Med Internet Res 24(11):e40328
54. Silva M et al (2021) Adolescents with cancer on privacy: fact-finding survey on the need for confidentiality and space. Tumori J 107(5):452–457
55. Baldridge S, Symes L (2018) Just between us: an integrative review of confidential care for adolescents. J Pediatr Health Care 32(2):e45–e58
56. Lehrer JASD et al (2007) Forgone health care among U.S. adolescents: associations between risk characteristics and confidentiality concern. J Adolesc Health 40(3):218–226
57. Rubin SE et al (2010) Delivery of confidential care to adolescent males. J Am Board Fam Med 23(6):728–735
58. Williams RL, Taylor JF (2016) Four steps to preserving adolescent confidentiality in an electronic health environment. Curr Opin Obstet Gynecol 28(5):393–398