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#### Document Version

Final published version

#### Citation (APA)

Verkijk, C., Tabeau, K., Ahaus, K., Gielen, M., de Wit, M. C., & van Veelen-Vincent, M. L. (2024). The challenges of involving child-patients in the development of a mobile application for their participation in pediatric brain care. In *Proceedings of DRS* (Proceedings of DRS; Vol. 2024). Design Research Society. <https://doi.org/10.21606/drs.2024.522>

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## The challenges of involving child-patients in the development of a mobile application for their participation in pediatric brain care

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# The challenges of involving child-patients in the development of a mobile application for their participation in pediatric brain care

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[doi.org/10.21606/drs.2024.522](https://doi.org/10.21606/drs.2024.522)

**Abstract:** Prior research shows that involving children in the development of technology is valuable, though challenging. Involving child-patients may come with additional difficulties, but as technology is gaining importance in (pediatric) care, it is important to uncover these difficulties. This paper identifies the difficulties of involving child-patients in the development of technology. We do so by reflecting on a project at the Sophia Children's Hospital, where we involved 17 children (of which 12 child-patients) in developing a mobile application for their participation in pediatric brain care. Our identified challenges are related to the recruitment of child-patients and the need to adapt the organization and content of our design research set-up, based on who we were able to recruit and how we recruited them. By identifying these challenges, we make designers and researchers aware of issues that may arise when involving child-patients in technology development and present guidelines to deal with them.

**Keywords:** healthcare technology; design research; child involvement; challenges

## 1. Introduction

Increasingly, a shift is evident in design research toward a collaborative approach in which designers and those served through the design work together as co-creators (Sanders & Stappers, 2012). Instead of designing for people, potential users are becoming more involved in the innovation process, so products and services can better match their needs and preferences (Jones et al., 2020; Sanders & Stappers, 2012). The involvement of children in the development of technology has been advocated for a considerable time (Druin, 2002; Fails et al., 2013). Not only does their involvement have value for the products or services



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being developed, but it also benefits children themselves. Indeed, children commonly enjoy participating in technology development (McNally et al., 2017; Nygren et al., 2017; Paracha et al., 2019), and their skills regarding creativity, collaboration, and communication can be enhanced by involving them (McNally et al., 2017).

However, involving children in co-creation, that is, the collective creativity throughout the entire innovation process (Sanders & Stappers, 2008; Vargas et al., 2022), requires a child-centered approach. In comparison to adults, children have different perceptions and competences, and should therefore be engaged in a way that suits their characteristics and needs (Gielen, 2013; Kinnula & Iivari, 2021; Markopoulos et al., 2021; Read et al., 2002). Although prior research shows multiple instances of involving child-patients in the development of technology (see e.g., Meulendijks et al., 2022; Stålberg et al., 2016; Wiljén et al., 2022), some studies reveal that difficulties may be encountered in this process (Lindberg, 2013; Lindberg et al., 2017; Nygren et al., 2017). For instance, authors encountered challenges with recruiting child-patients (Lindberg et al., 2017; Nygren et al., 2017) and with creating a suitable approach to consider child-patients' vulnerability and wellbeing (Lindberg, 2013). These studies, however, did not specifically aim to identify these difficulties, but focused on describing the technology development process and identified challenges as a "by product." Studies that did focus on exploring the challenges of child-patients' involvement did that in the context of health services research in general, and not research on health technology development in specific (Coyne 2010; Coyne et al., 2009; Huang et al., 2016; Kelly, 2007).

In summary, previous studies have created an understanding of the challenges that can occur when involving children in technology development and when involving child-patients in health services research. However, research specifically aimed at investigating the challenges that may arise when involving *child-patients in technology development*, has not yet been undertaken. In this paper, we aim to identify these specific challenges and address how they can be dealt with by future designers and researchers. Therefore, the following research question is formulated: "*What are the challenges of involving child-patients in technology development and in what ways can these be dealt with?*"

## 2. Background

### 2.1 Involving children in technology development

Children's involvement in technology development can occur at any stage, from initiating first thoughts and ideas to providing mid-term feedback and evaluating final designs (Markopoulos et al., 2021). To this end, children can adopt different roles in the development process, which, according to the pioneering work of Druin (2002), consist of user, tester, informant, and design partner. While the first two roles as user and tester can be considered passive participation (Sanders & Stappers, 2012), as children are not involved in designing the technology, the roles as informant and design partner indicate a more active role for children to play (Frauenberger et al., 2011; Sanders & Stappers, 2012). However, one

role is not superior to another, as the way of involving children depends on the circumstances at hand, such as the research questions, resources, and goals of the development process (Druin, 2002). Irrespective of children's role, their involvement in technology development implies having a real influence on the eventual output (Frauenberger et al., 2012). Therefore, "involvement" in this paper relates to any type of direct interaction between researchers and children in the development of technology (Kujala, 2003).

However, involving children in the innovation process, is not uncomplicated. According to Read et al. (2002), several factors must be considered in this process, such as the environment in which children participate, children's knowledge and skills, and the extent to which children feel safe or comfortable. For example, children may lack the cognitive skills to understand what the researcher asks them to do, which is why instructions must be easy for children to follow (Markopoulos et al., 2021). The need for such adjustments may result in the development process taking considerable time, which can be troublesome within project deadlines (Druin, 2002). Furthermore, research sessions must be scheduled into children's school structures, and if such sessions do not take place on school site, parents are burdened with bringing their child to the research location (Druin, 2002). Finally, children's views may result in ideas that are not aligned with the intended objectives of a technology (Tan et al., 2011), making children's contributions not always achievable in practice.

## *2.2 Involving child-patients in health services research*

A common identified challenge when involving child-patients in health services research relates to the role of gatekeepers in participant recruitment. The term "gatekeeper" refers to any person in the position to control a researcher's access to participants (Coyne, 2010). In pediatric care, healthcare professionals (HCPs) and parents occupy the role of gatekeeper (Coyne, 2010, Coyne et al., 2009; Kelly, 2007). While HCPs determine which patients can participate in research, parents are responsible for granting consent for their child's participation before children consent themselves. Consequently, if HCPs consider children not suitable for participation or parents refuse their consent, children might be excluded from voicing their opinions (Coyne, 2010).

When researchers do succeed in recruiting child-patients, scheduling issues may arise as research sessions must fit into children's care routines (Coyne et al., 2009). This can trouble organizing such sessions and researchers having to adapt their original research approach (Coyne et al., 2009). Child-patients are additionally a vulnerable group in terms of physical and psychological burdens (Coyne, 2006). This requires a careful approach of researchers towards child-patients to prevent additional stress and discomfort (Boles & Daniels, 2019; Huang et al., 2016). Moreover, children's health difficulties may result in them not feeling well enough to participate and withdrawing early from the study (Coyne et al., 2009).

### 3. Case description

#### 3.1 Case context

The case on which this paper is based, concerns research on the development of a mobile application called “The Self-Portrait”, which will be deployed in the course of 2024 at the Child Brain Lab (CBL) in the Sophia Children's Hospital, Rotterdam, The Netherlands. The Self-Portrait represents a digital medical record for children who visit the CBL and aims to stimulate children’s engagement in care to ensure that it is more responsive to their needs and preferences. The application’s main functions are to prepare children for the testing in the CBL and provide them with personal feedback on their results.

In the study, data was collected from October 2021 to January 2022 (project to design a prototype of the Self-Portrait) and November 2022 to June 2023 (project to evaluate this prototype). During these two periods, we involved multiple CBL stakeholders: HCPs, developers, academics, parents, and children. In this paper, we address the challenges of involving children (n=17) in our study. Of the 17 children (aged 6 – 18 years old), 12 were child-patients who were being treated or had finished treatment for a brain condition in the Sophia Children’s Hospital and 5 were healthy children without a brain condition.

#### 3.2 Development process

In the design phase, 10 child-patients participated in generative sessions, using various materials to express their thoughts and ideas regarding the design of the Self-Portrait (Sanders & Stappers, 2008). This ranged from discussing children’s needs for the application, and their feedback on design sketches to drawing an ideal application. The design phase resulted in a prototype of the Self-Portrait (Figure 1). Hereafter, 9 children evaluated this prototype: 4 child-patients and 5 healthy children. From this group, 2 child-patients had also participated in the generative sessions. Through interviews and focus groups, children evaluated what they liked and disliked about the Self-Portrait’s prototype and the reasoning behind their opinions. Table 1 presents an overview of the involved child-patients and healthy children, and their role in the development process.

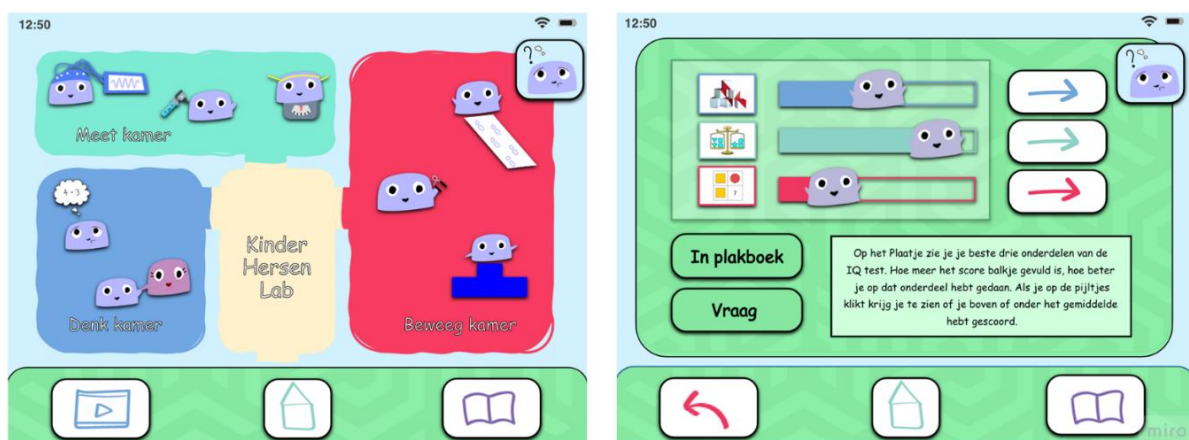


Figure 1 The Self-Portrait’s prototype.

Table 1. Participants.

	Children with a brain condition		Children without a (past) brain condition (n=5)	Total (n=17) *
	Being treated (n=9)	Declared healthy (n=5)		
<i>Development phase</i>				
Design	8	2	0	10
Evaluation	1	3	5	9

\*Note: two children with a brain condition participated in the design as well as the evaluation of the Self-Portrait. This involved one child-patient being treated in the design phase but declared healthy in the evaluation phase, and one child-patient declared healthy in both the design and evaluation phase. Therefore, 17 children participated in total.

In the remainder of this paper, we will refer to the generative sessions, interviews, and focus groups as “design research sessions.” In figure 2, the conducted design research sessions are chronologically presented.

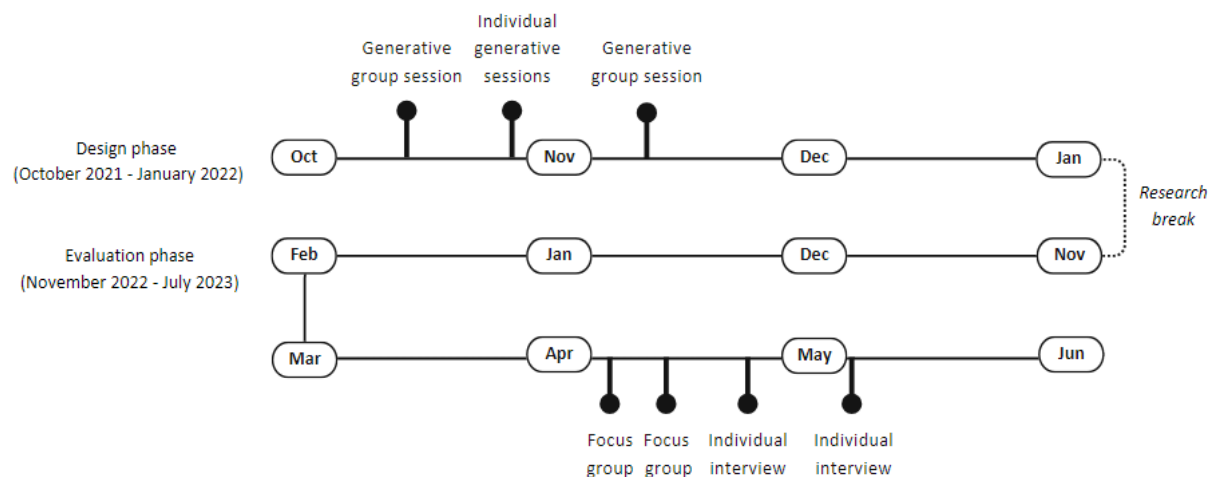


Figure 2 Timeline design research sessions.

### 3.3 Ethics

Children and their parents were provided with verbal and written information about the research and the purpose of children’s participation. Given Dutch law, children’s consent had been given (verbal or written) through their parents (for children up to 12), the parents and the child (for children 12 to 16), or only the child (for children above 16). All data was processed anonymously and treated confidentially.

## 4. Research approach

Our initial plan to involve child-patients entailed generative sessions in the design phase of the project and focus groups in the evaluation phase (which we planned to conduct with the same child-patients as in the design phase). We did not manage to follow our initial plan, both in set-up as in participants, due to several challenges.

To identify these challenges, we organized a discussion session with two researchers: one being one of the leads of involving child-patients in the project (CV), and the other having extensive experience in doing this in general (KT). Before the session, we made an overview of our design research set-up as we executed it (see again Figure 2). We identified who we involved in the project (child-patients (being treated and declared healthy), healthy children), how we involved them (generative session, focus group, interview), and the timing of their involvement (design phase, evaluation phase). We discussed the details of these sessions in terms of participants, recruitment, location, duration and used materials (Appendix A). Next, we elaborated on the reasons that led us to choosing a certain set-up, which resulted in two categories of challenges. We noticed that one of these challenges could be further divided into two, and that these final three challenges were related. Therefore, as a last step, we visualized the relation of these challenges and discussed the actions that we took to deal with them. These actions (“solutions”) were included in our final visualization. The challenges and their solutions were discussed with the other members of the research team (KA, MG, MW, MV). After making minor adjustments (e.g., terms to describe recruitment strategies), we finalized the challenges of and solutions for involving child-patients, as we encountered them in our project (discussed in Chapter 5, Results. See also Figure 3).

## 5. Results

The results reveal three categories of (related) challenges when involving child-patients in technology development. Figure 3 illustrates these challenges and their corresponding solutions.

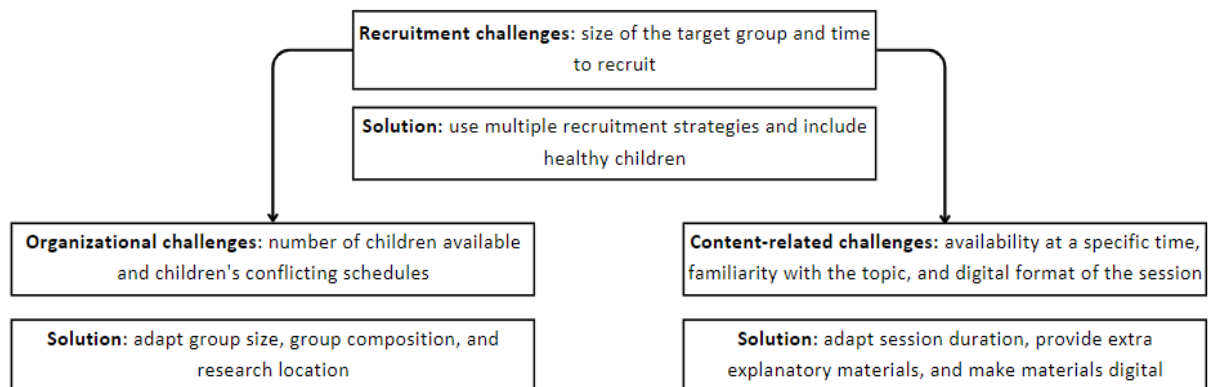


Figure 3 Challenges and solutions of involving child-patients in technology development.

### *5.1 Recruitment challenges: size of the target group and time to recruit*

For a technology to fit the end-user, it is important to include a representative group of participants in its development. Regarding the Self-Portrait, this was of special importance, given the specific characteristics of children with a brain condition (e.g., developmental age and cognitive functioning) which the mobile application must align with. This small target group, from one specific children's hospital as the technology was being developed for this context, resulted in only few children that could be reached out to. Even more so as not all of them could participate because of their personal situation (e.g., severity of the condition). Given the scarce number of child-patients available for our study, we needed multiple recruitment strategies to reach enough participants.

For the design of the Self-Portrait, we first recruited child-patients on the inpatient clinic, where children were hospitalized for a certain period due to treatment of their brain condition. The recruitment of hospitalized children was considered a pragmatic way to involve children in a generative session, as these children could participate during their spare time, which they would usually spend, for example, in the clinic's playroom. To include children, HCPs assessed which children were suitable for participation, depending on children's health status and the extent to which their participation would fit into their care schedule. In total, we were able to involve three child-patients from the inpatient clinic.

Secondly, we recruited children via the outpatient clinic, where children's consultations were held. First, the HCP (with whom the consultation was held) determined which children could be approached to participate in a session, also based on a child's personal (health) situation *and* considering the project's timeline. The children that were found suitable to participate and would be available for the project when needed, were invited by the HCP. Four child-patients were invited, and all agreed to participate. Three of these children participated in a design research session after their consultation and one joined a planned session later in time.

As we had not yet reached enough participants in the design phase of the Self-Portrait, we contacted the Children's Advisory Council (CAC) of the hospital, as our third approach. Child-patients (and possible next of kin) from the CAC provide the hospital with advice about issues regarding pediatric care. Child-patients with all conditions can be part of the CAC. We only invited those with a brain condition (three in total). All three children accepted the study invite and a session was scheduled in which they participated.

In the evaluation phase, we recruited child-patients again via their HCPs. Initially, we aimed to involve the same ten child-patients in the evaluation as in the design of the Self-Portrait. For these design research sessions, we planned to fit these into children's personal schedules instead of around their hospital visit (hospitalization or consultation) as these did not necessarily take place during the evaluation period or ended altogether because a child was declared healthy. The child-patients were approached by HCPs and, if interested in participating, were brought into contact with the researcher to schedule a session.

However, HCPs ever-demanding professional duties and responsibilities in medical practice, often caused children and/or parents to be approached later than planned. In addition, once HCPs invited children for participation, they could stumble upon parents who disapproved their child's participation in the study. Reasons for children and/or parents to decline the invite related to the progression or recurrence of a child's brain condition or busy school schedules. Also, some children were (recently) cured and only wanted to visit the hospital if essential for their treatment. On other occasions, HCPs received no reaction, and it remained unclear whether children themselves had been informed of the invitation. Of the ten child-patients approached, only two agreed to participate in the Self-Portrait's evaluation. Therefore, also two other child-patients (not previously involved in the design phase) were contacted, which resulted in four child-patients in total participating in the evaluation of the Self-Portrait.

Given these difficulties, we decided to include healthy children without a brain condition for the evaluation as well. In total, five healthy children were recruited through the personal network of one of the researchers, of which all children were familiar with each other because of family and friendly ties. We included these children to meet the project deadlines, which created pressure to recruit enough children within a short timeframe.

In summary, several approaches were used to gain access to children for the design and evaluation of the Self-Portrait, namely 1) recruiting through HCPs for a design research session around children's hospital attendance in the inpatient or outpatient clinic, 2) recruiting in the hospital's Children's Advisory Council for a planned design research session, 3) recruiting through HCPs for a planned design research session, and 4) recruiting healthy children via one of the researcher's network for a planned design research session.

Collectively, these methods proved to be successful in reaching enough children to participate in our study. However, the different approaches had several implications for the organization and content of our design research sessions, in which flexibility and adaptability were essential.

## *5.2 Organizational challenges of design research sessions: number of children available and children's conflicting schedules*

As mentioned earlier, children were approached via four recruitment strategies. We initiated these strategies at different times, as we gradually noticed that a single strategy would not result in enough participants for our study. In the design phase, we recruited at the inpatient and outpatient clinic to organize design research sessions around children's hospital attendance. Hereafter, we also invited children from the CAC for planned design research sessions. In the evaluation phase, we diverted to recruiting healthy children after having approached child-patients via HCPs for a planned session.

Despite their collective success, the strategies had different speeds in recruiting children, resulting in children being available for participation at other points in time. Once multiple children were available, it was not always possible to schedule a group session, as their

school schedules, treatment trajectories, and other obligations differed. To deal with these challenges, we organized sessions with different group sizes depending on how many children were available at a certain point in time, we held multiple sessions to deal with conflicting schedules, and we were flexible in terms of the research location (at the hospital, at home or digitally) for that reason too.

In the design phase, we organized two generative sessions: one with three children recruited from the inpatient clinic and one with four children, of which three recruited from the CAC and one from the outpatient clinic. Both sessions were organized face-to-face at the hospital at a day and time that fit the children's schedule. In addition, three children recruited via the outpatient clinic participated in a face-to-face individual session right after their consultation.

In the evaluation phase, we organized a focus group with two child-patients at first, and we diverted to individual interviews as it was not possible to engage the two other child-patients together due to their schedules and preferences. The location of the sessions varied: one interview was held in the hospital, and one interview and focus group were held digitally. The reasons for this differed. For example, one child-patient preferred an online interview because of a care appointment (not in the hospital) later that day. Another child-patient did not mind coming to the hospital as it was known territory. Lastly, we held a focus group with five healthy children (all family and friends), to adhere to our project deadlines. These children preferred a focus group at home in their own environment, but not digitally, as that would give them associations with online education during the COVID-19 pandemic. Therefore, the researcher held the session at one of the children's homes to accommodate their preference. While parents were present, they did not participate in the session but observed it, unobtrusively, at a distance.

### *5.3 Content-related challenges of design research sessions: availability at a specific time, familiarity with the topic, digital format of the session*

Two strategies (recruiting via the outpatient clinic and recruiting healthy children) had consequences for the content of the design research sessions. Namely, three child-patients participated right after their consultation as they were available at that moment and place in time. Therefore, we adapted the originally two-hour, generative group sessions beforehand to a one-on-one, twenty-minute set-up. We also had to adjust the content of the focus-group regarding the healthy children. Namely, at the beginning of each design research session, all children were provided with information about the purpose of the study and their participation. We explained the testing in the CBL and the aim of the Self-Portrait. As the healthy children in our research had no experience in pediatric brain care, this required us to provide these children with additional explanation about the CBL. Therefore, we showed them a video from the Dutch Youth News ("Jeugdjournaal"), in which the CBL was explained in a child-friendly manner.

Finally, we had to adjust the content of the digital sessions. Initially, we aimed to conduct all design research sessions face-to-face. Children's schedules and preferences during the

evaluation phase, however, required us to also conduct sessions digitally. Therefore, we could not show the prototype of the Self-Portrait in real life, and the use of post-it's (which we used during the face-to-face sessions) to encourage interaction were considered impractical when interviewing digitally. Therefore, we proceeded to only use digital materials by sharing our computer screen.

## 6. Discussion

In this paper, we aimed to provide an answer to the following research question: *“What are the challenges of involving child-patients in technology development and in what ways can these be dealt with?”* To answer this question, we have identified several challenges, all of which can be linked to the most significant one, namely the recruitment of child-patients. In our study, we gradually deployed multiple recruitment strategies, as using only one strategy appeared insufficient in reaching enough participants.

The recruitment of child-patients based on hospital attendance, through the inpatient or outpatient clinic, was an effective approach for involving children. This can be explained by the fact that these children were already present in the hospital for treatment or consultation, making it convenient to participate during this same period. These child-patients also had the necessary knowledge to contribute to the design of the Self-Portrait, which adds to the success of this strategy. In contrast, the recruitment of child-patients who were *not* already present in the hospital was more complex. We initially planned to involve the same ten children in the evaluation as in the design of the Self-Portrait. However, only two agreed to participate, as the children and parents that were approached often refused participation or gave no reaction. This required us to expand our recruitment to other child-patients as well.

Another complexity was HCPs busy work schedules that caused children to be approached later than planned. Recruitment in this manner indicates a clear role for “gatekeepers” (Coyne, 2010; Coyne et al., 2009; Kelly, 2007). Namely, when design research sessions were performed during the same period as children were present in the hospital, their response rate was higher than when not present. Not only does this suggest that HCPs must cast their web wider when recruiting child-patients for planned design research sessions as to ensure enough participants will be available. Also, it may require them to create more awareness among parents and/or children on the value of participation in technology development. For design researchers it may indicate that they should be flexible in aligning their studies with child-patients' hospital attendance.

Although previous studies have identified the complexity of gatekeepers in pediatric care before (Coyne, 2010; Coyne et al., 2009; Kelly, 2007), our study nuances these findings by showing that this complexity may be particularly pressing when design research must be performed at specific moments in time and flexibility is not possible.

Our results also suggest the potential of involving children from the CAC and healthy children in design research. Regarding the insights provided by the healthy children, we

noticed that these did not differ greatly from those provided by children with a brain condition, even though the healthy children had no experience of pediatric brain care. Hence, their input can complement those of children in the target group being studied. This is consistent with similar research by Lindberg et al. (2017), in which they reveal how healthy children have the potential to serve as proxies for child-patients in technology development. Although it would have been ideal to solely involve children with a brain condition as end-users in the development of the Self-Portrait (Jones et al., 2020; Sanders & Stappers, 2012), our research uncovers opportunities to additionally involve healthy children in the development of care technology, when dealing with low attendance of child-patients.

Despite the success of using various recruitment approaches, these had implications for the organization and content of our design research sessions. Regarding the organization of the sessions, adjustments were needed depending on how many children were available at a given time and the conflicting schedules children had. As such, we organized group and individual generative sessions, focus groups, and individual interviews. Involving children in a group setting is often considered good practice for obtaining a rich amount of data (Peterson-Sweeney, 2005) and an efficient way of involving multiple participants (Adler et al., 2019; Barrett & Twycross, 2018). Although we planned to engage children in face-to-face group sessions, our recruitment issues caused us to hold both group and individual sessions to accommodate all children in the study, which is a frequent issue in pediatric research (Coyne et al., 2009).

Regarding the group sessions that we held, we noticed that the ones with most interactions, involved children who knew each other (second generative group session with four children, of which three from the CAC, and second focus group with five healthy children). Group sessions commonly create increased dynamics compared to individual sessions, as children can respond to each other (Heary & Hennesy, 2006; Peterson-Sweeney, 2005; Vogl et al., 2023). In these group sessions, the interaction seems to be enhanced by a shared bond (Coyne et al., 2009). Namely, the healthy children were familiar with each other because of family and friendly ties, whereas the other group consisted of child-patients who (had) all experienced a brain condition and of which most were part of the CAC. Their familiarity may have influenced their level of comfort in expressing thoughts and ideas to each other. In addition, the shared experience of children from the CAC in voicing their opinions on hospital care may have contributed to the dynamics within their group. Thus, although heterogeneity in the range of stakeholders in design research is recommended (Lee et al., 2018), it seems that homogeneity *within* groups of stakeholders holds positive value for the workflow and richness of data.

Concerning the content of the design research sessions, we needed to shorten the duration of the sessions held after children's consultation. Furthermore, we used additional materials among the healthy children, as these children had a knowledge gap regarding pediatric brain care, compared to the child-patients. A change in materials was also needed when sessions were held digitally instead of face-to-face, as we were not able to use physical interactive materials. Although such materials are considered to increase interaction with children

Table 2. Five guidelines to involve child-patients in technology development.

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<b>Recruitment of child-patients</b>
<b>1. Use multiple recruitment approaches.</b> Recruit early and widely to accommodate enough child-patients within project deadlines. We recommend three strategies: <ul style="list-style-type: none"><li>• Recruit children around their hospital attendance.</li><li>• Recruit children in the CAC (if available in the care organization).</li><li>• Recruit healthy children as proxies for child-patients.</li></ul>
<b>Organization of design research sessions</b>
<b>2. Adapt the group sizes and composition of design research sessions.</b> Consider children's (school and care) schedules and preferences. Therefore, when organizing design research sessions, be flexible in terms of group size (individual or group sessions). Also, create homogeneity within group sessions to encourage interaction.
<b>3. Adapt the research location of design research sessions.</b> Provide opportunities for children to engage both physically and digitally in design research sessions to promote inclusivity.
<b>Content of design research sessions</b>
<b>4. Adapt the duration of design research sessions.</b> Shorten design research sessions when you schedule them around children's hospital attendance, addressing the key points.
<b>5. Adapt materials used in design research sessions.</b> When including children outside of the target group, provide them with extra explanatory materials to inform them of relevant knowledge. Additionally, when enabling digital participation, adapt the interactive materials accordingly.

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(Sanders, 2018), we noticed no differences in the richness of data between the digital and physical sessions, with or without physical interactive materials. Instead, children generally expressed the same answers, despite the different interview format. Hence, although digital sessions are often characterized by a lack of direct interaction among participants and difficulties in engaging them in the conversation (Slingerland et al., 2022), such challenges were not apparent in our sessions. Moreover, digital sessions enabled more children to participate, given that some children could or preferred not to come to the hospital. Therefore, digital opportunities support more inclusive design research sessions among children (Nofal et al., 2022; Slingerland et al., 2022).

Altogether, the use of multiple recruitment strategies and their implications for the set-up of our design research sessions imply the need for a flexible and adaptive approach when involving child-patients in technology development. This contradicts the notion of following

a predetermined research set-up. Rather, being reflexive to the complex environment of pediatric care in technology development is necessary for better involvement and representation of the target group. In table 2, we present five guidelines on how to do so.

## 7. Conclusion

To our knowledge, this is the first study that explicitly focuses on the challenges of involving child-patients in technology development, and how these can be dealt with. Our study reveals that various recruitment strategies are needed to involve child-patients in the development of technology. In turn, these different approaches have implications for the organization and content of design research sessions, varying from the number of children available (at a specific time), children's conflicting schedules, children's familiarity with the topic, and the digital format of the session. Despite such challenges, our research offers opportunities to overcome these. Accordingly, our study supports the complementary role of involving healthy children, the effectiveness of homogenous groups of children, and the role of digital sessions to generate more inclusivity of children. When involving child-patients in technology development, designers and researchers must allow flexibility and adaptability in their research set-up to accommodate the target group.

**Acknowledgements:** We thank all participating children for their time and efforts made in our research. We also express our gratitude to the staff of the Child Brain Lab (Sophia Children's Hospital, Rotterdam, The Netherlands) for enabling and facilitating our study, and to Loes Tielen for her involvement in the development of the Self-Portrait. Finally, we thank the reviewers for their contributions to further refinement of this paper.

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**Appendix A. Characteristics of the participants and the design research sessions.**

<b>Child involvement</b>	<b>Gender</b>	<b>Age category</b>	<b>Health condition</b>	<b>Recruitment for session</b>	<b>Location of session</b>	<b>Duration of session</b>	<b>Materials used in session</b>
<b>Generative group session</b>	Male	6 – 12	Child-patient – being treated	Inpatient clinic	Hospital	Planned duration	Physical
	Male	6 – 12	Child-patient – being treated	Inpatient clinic	Hospital	Planned duration	Physical
	Male	6 – 12	Child-patient – being treated	Inpatient clinic	Hospital	Planned duration	Physical
<b>Individual generative session</b>	Female	6 – 12	Child-patient – being treated	Outpatient clinic	Hospital	Shortened duration	Physical
<b>Individual generative session</b>	Male	6 - 12	Child-patient – being treated	Outpatient clinic	Hospital	Shortened duration	Physical
<b>Individual generative session</b>	Female	> 12	Child-patient – being treated	Outpatient clinic	Hospital	Shortened duration	Physical
<b>Generative group session</b>	Female	> 12	Child-patient – being treated	CAC	Hospital	Planned duration	Physical
	Female	> 12	Child-patient – declared healthy	CAC	Hospital	Planned duration	Physical
	Female	> 12	Child-patient – being treated	CAC	Hospital	Planned duration	Physical
	Female	> 12	Child-patient – declared healthy	Outpatient clinic	Hospital	Planned duration	Physical
<b>Focus group</b>	Male	6 – 12	Child-patient – declared healthy	Via HCP's planned	Digital	Planned duration	Digital

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	Female	> 12	Child-patient – declared healthy	Via HCP’s planned	Digital	Planned duration	Digital
<b>Focus group</b>	Female	6 – 12	Healthy	Researcher’s personal network	Home	Planned duration	Physical
	Female	6 – 12	Healthy	Researcher’s personal network	Home	Planned duration	Physical
	Male	6 – 12	Healthy	Researcher’s personal network	Home	Planned duration	Physical
	Male	6 – 12	Healthy	Researcher’s personal network	Home	Planned duration	Physical
	Male	6 - 12	Healthy	Researcher’s personal network	Home	Planned duration	Physical
<b>Individual interview</b>	Male	6 – 12	Child-patient – declared healthy	Via HCP’s planned	Hospital	Planned duration	Physical
<b>Individual interview</b>	Male	> 12	Child-patient – being treated	Via HCP’s planned	Digital	Planned duration	Digital