

Empathic eHealth for Children: A Genetic Literacy Case Study Using Think-Aloud and Co-Creation

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Abstract. Children affected by genetic conditions and their families have high needs for accessible and emotionally sensitive digital health information. However, most digital resources fail to meet the specific needs of children aged eight to twelve. This case study aimed to evaluate and improve the content and usability of a genetic information website for children (*ikhebdad.nl*). Five think-aloud sessions were conducted with parent-child dyads to identify usability problems and content gaps, along with a co-creation session with three children living with a genetic condition. Results show that while the website was generally perceived as educational, engaging, and visually appealing, there is a need for visual hierarchy, intuitive navigation, empathic language, and peer-based video content. This case offers design recommendations for child-oriented eHealth tools that go beyond readability to include emotional resonance and autonomy support.

Keywords. eHealth, Children, Co-creation, Usability

1. Introduction

Globally, over 6,000 genetic diseases impact families, many from an early age. In the Netherlands, approximately one in 33 children is born with a genetic disease [1]. Children affected by genetic conditions often face not only medical but also psychological and social challenges. Understanding heredity is essential for coping and for communicating within families [2,3]. However, digital health information on this topic is rarely aligned with the cognitive and emotional development of the affected child. Specifically, children require information that aligns with their language skills, attention span, and conceptual abilities [4-6].

Additionally, children's preferences in online content differ significantly from adults, requiring specific interface and narrative designs [7,8]. Moreover, children need gradual learning to build health literacy, but digital platforms often lack this support [9]. Lastly, empathy in content and clarity in interaction design are often overlooked in international eHealth research for children [6,10,11].

The website *ikhebdad.nl* (translation: 'I have that') was created in 2008 by the Dutch national information center on heredity ("Erfocentrum") to provide accessible information about genetic conditions for children aged 8 to 12 and their parents. Despite

this aim, usage statistics have declined from 40.000 to 20.000 per year, and insights into needs of current user are lacking. Therefore, this study investigates how the usability and content of the website “*ikhebdat.nl*” can be optimized by conducting think aloud user testing and a co-creation session involving the target group to gather recommendations for redesign.

2. Methods

Participants were passively recruited through flyers distributed on patient websites and Facebook-groups and a pop-up message on *ikhebdat.nl*, and actively recruited via personal networks from the researchers. Both think aloud tests and the co-creation session were conducted in Dutch and approved by the Amsterdam UMC ethics board (non-WMO, 2025.0327). All participants provided informed consent prior to participating.

First, usability evaluations including think aloud sessions and interviews with five parent-child dyads with lived experience with genetic diseases were conducted from April through May 2025. During the evaluation, children and their parents were asked to interact with the website guided by a think aloud protocol. After the think aloud session, participants were interviewed to gain deeper insights into their user-experiences. To conclude the session, parents completed the D-UMUX usability questionnaire [12]. Sessions lasted approximately 30 minutes each and were administered online using Microsoft Teams. Participants were rewarded with a €10 gift card for participating in the user testing.

In June 2025, a co-creation session was conducted with three children who had experience with genetic conditions, at one of the children’s home. During the session, they designed their ideal website using worksheets, stickers, and drawings. Participants were rewarded with a €15 gift card for participating in the co-creation session.

Data analyses comprised qualitative thematic analysis of the observational data of the think aloud sessions, interviews and co-creation session using MAXQDA software. The identified usability issues were categorized based on Nielsen’s heuristics and classified by severity [13].

3. Results

Children and parents generally found *ikhebdat.nl* educational, engaging, and child-friendly. Children appreciated the simple language, illustrations, and links to additional information, and highlighted videos as a helpful format for understanding content. Parents valued the practical, non-medical language, actionable tips, and the ability to connect features of conditions across pages. Visual elements were positively received, with suggestions to make the layout even more colorful and cheerful. Overall, the website received high ratings, with children giving an average score of 8.5 and parents 7.1, reflecting overall satisfaction.

Some usability issues were observed (n=13). Children occasionally struggled with interface elements, failing to recognize clickable items or misunderstanding terms like

‘list of diseases’. A few expressed a desire to switch to WikiKids or YouTube, suggesting that the site’s structure did not always match their expectations. Parents noted that certain words, such as ‘disease’ or ‘handicap’, could evoke negative feelings, highlighting the importance of empathetic language. Children sometimes required help to locate disease-related information, and parents reported difficulty identifying the section intended for them ("Tips for Parents").

Most usability issues were identified based on Nielsen’s heuristics—Recognition rather than recall, Match between system and the real world, Consistency and standards, and Aesthetic and minimalist design—with 76.9% rated as major problems and 23.1% as minor. To provide more concrete results, we summarize key usability issues and their frequency across the five dyads in Table 1.

Table 1. Key usability issues observed during think-aloud usability tests (n = 5 dyads).

Usability Issue	Frequency	Severity
Could not identify clickable elements (e.g., text links)	5/5	3
Confused by menu labels (e.g., "List of Diseases")	4/5	2
Needed help from parent to find information	5/5	3
Switched attention to external platform	3/5	2
Difficulty understanding medical terms	3/5	2
Frustration with long text sections	4/5	2

D-UMUX scores from parents ranged from 66.7 to 95.8, with a mean of 81.7 (SD = 12.7), indicating high perceived usability among adults. However, this contrasted with children's difficulties, pointing to the importance of evaluating with the actual target group.

In the co-creation session, children proposed a playful, colorful website with features like a central search bar, back/exit buttons, YouTube video links, a page with emotional support, and a facts section marked with a microscope icon. They also suggested peer-led video stories to foster emotional recognition. The session revealed that children not only prioritize functionality but also emotional safety, familiarity, and the ability to express themselves visually and socially through content.

4. Discussion

The aim of this study was to investigate how the usability and content of the website *ikhebdat.nl* can be optimized by conducting think-aloud user testing and a co-creation session with the target group, in order to gather recommendations for redesign. Overall, children and parents found the website educational, engaging, and visually appealing. The findings reiterate that child-oriented eHealth requires up-to-date, intuitive interaction design, emotionally aware content, and autonomy in exploring health topics. Specifically, the difficulty children experienced with recognizing clickable elements and navigating content echoes previous findings on children's mental models [4,10,11,18]. Moreover, the emotional tone of language emerged as a key barrier. Parents found terms

like ‘disease’ negatively framed, highlighting the importance of empathetic language for engagement and recommendation [6,9,19].

The co-creation session offered unique insights into children's design logic. Their preference for peer video stories supports earlier research on the motivational and emotional value of such content [12,20]. However, this study adds that peer videos also meet children's needs for emotional validation and shared experience. This broadens the design rationale for including such media in child-focused eHealth platforms.

Furthermore, parents expressed a need for practical next steps, not just definitions or links to external sites. Their approach to seeking information is goal-driven and context-dependent, suggesting that eHealth platforms should align more closely with decision-making processes [9,13,21]. This implies that hybrid information architecture, which combines condition-specific paths with role-specific guidance (e.g., “What to do if your child was just diagnosed”), may better meet parental needs.

4.1 Strengths and Limitations

The study involved a small and partly convenience-based sample. Also, thematic coding was performed by a single researcher, which may introduce bias. Future work should include larger and more diverse samples, as well as multiple coders to ensure interrater reliability.

4.2 Implications for Practice and Research

These findings emphasize the importance of treating children not as passive recipients but as active co-designers of eHealth content. Iterative design, including usability testing and co-creation, is essential. Moreover, platforms should adopt emotionally sensitive terminology, prioritize visual clarity, and include peer-based media to enhance engagement [22,23].

5. Conclusions

This study shows that involving children and parents in the design process provides valuable insights into both strengths and areas for improvement in child-focused eHealth. *Ikhebdat.nl* was perceived as educational, engaging, and visually appealing, with simple language, illustrations, and videos supporting comprehension. Findings also highlight opportunities to enhance navigation, empathetic language, and practical guidance. A user-centered, empathic, and visually intuitive approach can improve engagement, understanding, and emotional support for children with genetic conditions.

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