Designing eHealth interventions for children with complex care needs requires continuous stakeholder collaboration and co-creation

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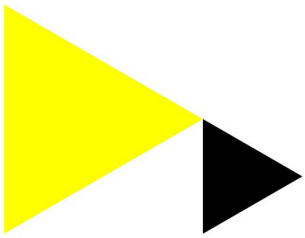
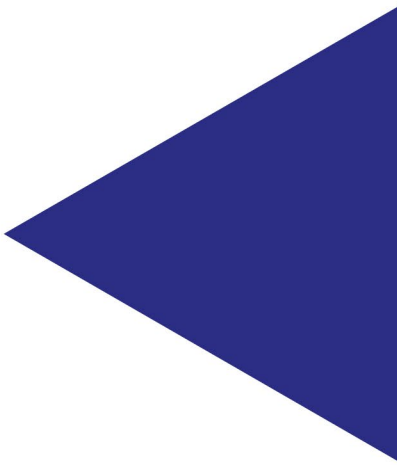
DOI
10.1016/j.pecinn.2024.100280

Publication date
2024

Document Version
Final published version

Published in
PEC Innovation





PEC Innovation 4 (2024) 100280

Contents lists available at ScienceDirect

PEC Innovation

journal homepage: www.elsevier.com/locate/pecinn

Designing eHealth interventions for children with complex care needs requires continuous stakeholder collaboration and co-creation

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ARTICLE INFO

Keywords:
Children with medical complexity
Hospital-to-home transition
SCREAM methodology
eHealth
Digital health
Design thinking
Model development

ABSTRACT

Objective: Hospital-to-home (H2H) transitions challenge families of children with medical complexity (CMC) and healthcare professionals (HCP). This study aimed to gain deeper insights into the H2H transition process and to work towards eHealth interventions for its improvement, by applying an iterative methodology involving both CMC families and HCP as end-users.

Methods: For 20-weeks, the Dutch Transitional Care Unit consortium collaborated with the Amsterdam University of Applied Sciences, HCP, and CMC families. The agile SCREAM approach was used, merging Design Thinking methods into five iterative sprints to stimulate creativity, ideation, and design. Continuous communication allowed rapid adaptation to new information and the refinement of solutions for subsequent sprints.

Results: This iterative process revealed three domains of care – care coordination, social wellbeing, and emotional support – that were important to all stakeholders. These domains informed the development of our final prototype, 'Our Care Team', an application tailored to meet the H2H transition needs for CMC families and HCP.

Conclusion: Complex processes like the H2H transition for CMC families require adaptive interventions that empower all stakeholders in their respective roles, to promote transitional care that is anticipatory, rather than reactive.

Innovation: A collaborative methodology is needed, that optimizes existing resources and knowledge, fosters innovation through collaboration while using creative digital design principles. This way, we might be able to design eHealth solutions *with* end-users, not just *for* them.

1. Introduction

The life expectancy of children with medical complexities (CMC) has increased substantially in recent decades. [1,2] Their complex care needs require collaboration between numerous healthcare professionals (HCP) in different settings alongside the active participation of their

Abbreviations: CMC, Children with Medical Complexity; H2H, Hospital to Home; HCP, Healthcare professionals.

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https://doi.org/10.1016/j.pecinn.2024.100280
Received 20 November 2023; Received in revised form 25 March 2024; Accepted 27 March 2024
Available online 1 April 2024

parents in every aspect of care. [2-4] The transition from hospital to home (H2H) poses a particular challenge, when parents have to become their child's primary caregiver, managing all complex care needs. [5]. Over time, technology-dependency may increase, such as the introduction of chronic ventilatory support, parenteral feeding or the placement of a tracheal canula. The H2H transition can be a time-consuming and overwhelming process for both parents and HCP, and not only impedes the child's development, but also affects family life. [6,7] Although hospital admissions can be very lengthy, a considerable amount of CMC care still takes place *outside of* the hospital environment. Many CMC families experience emotional, logistical, and financial difficulties once their child is home, which can compromise their position in their communities and, by extension, in larger society. [5,8-11]

The importance of Family-Integrated Care (FIC) is increasingly acknowledged, particularly in neonatal care with parents and HCP collaborating more closely in healthcare decision-making. [12-14] Still, an unfamiliar territory is parental involvement in the development of care interventions that directly affect them. Despite improvements such as post-discharge home visits and teleconsultations [15], HCP still have limited insight into CMC families' needs after discharge. This complicates the effective monitoring of their wellbeing, while also hampering the coordination of all HCP involved in their care. [9,16] To prevent the loss of families' self-sustainability and the disempowerment of all parties involved, adequate communication between HCP and CMC families and coordination of care is crucial. Without this, chronic care provision becomes fragmented and reactive. [17,18]

The high utilization of healthcare resources [19-25] and its profound impact on both individual and public health underscore the importance of optimizing – and redefining – care for CMC. The question is: can we provide CMC families and HCP with tools that help to empower them during and after the H2H transition, while also enhancing transdisciplinary communication? The domain of eHealth, which has contributed to personalized care and novel communication channels among and between professionals and patients, potentially offers solutions. [26,27] Numerous studies focused on the H2H transition for complexly ill children, demonstrated that parents hold a positive attitude towards the use of different eHealth applications, and in some cases even actively recommended its use. [28,29] Examples of these eHealth solutions encompass educational portals that show instruction videos, social media platforms fostering peer support, and improved communication with HCP through videocalls. Thus the use of eHealth could potentially facilitate more flexible follow-up strategies, moving away from traditional hospital visits. Another potential solution involves a cloud-based care plan designed to support coordination of care between HCP and families. [30] Despite the apparent experienced benefits, there is currently limited evidence on the effectiveness of eHealth tools, [28] and many eHealth solutions do not include all stakeholders in the design process, which interferes with both applicability and ease of use. [31] Our paper focuses on the latter by illustrating the importance of collaboration and co-creation in developing constructive eHealth applications. The necessary communication between CMC families and HCP is not only the result, but also a method *towards* the solution. The aim of our study is both to gain deeper insights into the H2H transition process and to work towards eHealth interventions for its improvement, by applying an iterative, practice-based methodology involving both CMC families and HCP as end-users.

2. Methods

2.1. Case study: improving the H2H transition for CMC families and HCP

A 20-week multidisciplinary co-creation process was initiated by the Dutch Transitional Care Unit (TCU) consortium. [32] A TCU, is a short-stay (maximum 3 months) nursing facility located on hospital premises, designed to mimic a home environment. The goal is to help CMC families enhance their self-sustainability during the H2H transition. This way, CMC families gradually become accustomed to home care practices while having a medical safety net at their disposal. In May 2022, a newly established TCU, known as the Jeroen Pit Huis, began operating in Amsterdam. [33] The aim of our case study was to generate insights on the H2H transition process to further facilitate the development of this TCU.

2.2. The team

In addition to the TCU consortium, this research involved the collaboration of a diverse team: an interdisciplinary group of researchers, designers, and digital developers from the Digital Society School [34], affiliated to the Amsterdam University of Applied Sciences [35] ('AUAS representatives'). They formed a core group of twelve individuals who collectively shaped the project, collaborating with HCP from various fields and healthcare organizations, as well as CMC families. Together, the team explored and implemented a variety of co-creative methods to develop a useful and usable eHealth application.

2.3. SCREAM: a reusable framework with an individual approach

The iterative method that was applied in this study is called SCREAM – a variation of the wider-known agile workflow model of SCRUM, blended with multidisciplinary Design Thinking methods that foster creativity, ideation, and design. [36] An overview of all potential Design Thinking methods is presented in the Design Method Toolkit, developed by the Digital Society School. [37] The SCREAM method is not a fixed framework; instead, it provides guidance to collaborative and multidisciplinary teams that want to use an iterative approach, but leaves room for individual project variations. The SCREAM method focuses on enhancing collaborative teamwork, ensuring that each team member has the expertise appropriate for the specific project. This enables the team to operate with both collective cooperation and individual autonomy. [36] The design process is built bottom-up, with team input and insights gained through iterative *sprints* of each two to three weeks, adhering to the SCREAM principle of combining research, translation, and creation. [Fig. 1] During these *sprints*, the AUAS representatives designed several potential solutions for the H2H transition. During the *sprint review* that takes place at the end of each sprint, the AUAS representatives presented their interim results to members of the TCU consortium, who then provided additional feedback, after which the desired outcome of the project was redefined. This unfolded into a continuous feedback loop between all team members, allowing them to work efficiently and quickly adapt to new information. Contextual factors, such as available resources and agreed-upon timeframes, influence how the SCREAM approach is applied in each project. The ultimate goal of the SCREAM method is always to promote and actively engage in a creative, *collaborative* learning process.

2.4. Selection of participants

Participants were recruited using a two pronged approach. Initially, we applied purposeful sampling, drawing on the team's expertise to select individuals relevant to the topic (CMC families and HCP). [38] To minimize selection bias and assemble a heterogeneous group of participants for a comprehensive perspective on the topic, we added snowball sampling, where participants directed the team to other potential participants. [39] This can be particularly useful for engaging populations that are hard to reach through conventional sampling methods. Both methods ensured a diverse range of insights for the research question. An overview of participants per sprint can be found in Appendix A.

2.5. Data collection and analysis

The data collection and analysis involved interviews, for which we used a semi-structured topic list. The list encompassed questions

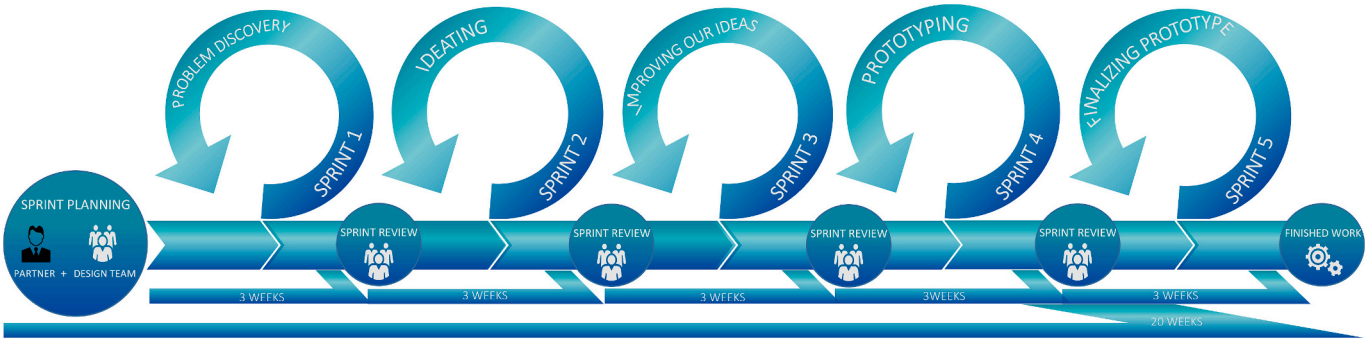

Fig. 1. The SCREAM method's structure involves sprint planning, followed by iterative sprints, each subsequently followed by a sprint review.

regarding the family situation, challenges encountered during hospital admissions and at home, experiences during the H2H transition, and expectations for the future. Notes were taken during the interviews, and the results were discussed with the team during sprint reviews. The aim was to avoid duplicating the same interview multiple times, and to quickly adapt to key insights. The topic list and the chosen DTM were continuously refined throughout the project, following the iterative SCREAM approach.

2.6. Research ethics

The Medical Ethics Review Committee of the Amsterdam University Medical Centres in Amsterdam approved the study protocol W22_058#22.090, hereby confirming that the Medical Research Involving Human Subjects Act did not apply, and the study was compliant with the 1975 Declaration of Helsinki. All stakeholders were informed that their participation was voluntary and that they had the option to withdraw from the study at any time. All stakeholders consented to their participation and the publication of the anonymized results.

2.7. Software

Due to COVID-19 regulations, most team meetings and stakeholder interviews were conducted via video call using Zoom (Zoom Video Communications Inc., 2016). The co-creation session took place online as well, using the digital collaboration platform MIRO (RealtimeBoard Inc., 2011). [40]

3. Results

3.1. SCREAM model application

Our 20-week collaboration consisted of five sprints, that each lasted approximately three weeks. During each sprint, the team explored extensive (user) research methods, ranging from participant observations to interactive design research to in-depth interviews [Table 1]. Neither the chosen methods nor the product was pre-defined or selected prior to the project; rather, the project was shaped bottom-up throughout the 20 weeks. Table 2 provides a full overview of the type and number of design thinking methods that were used throughout the 20-week collaboration. The constant interaction between all parties formed the foundation on which methods and solutions were continuously (re)selected, (re)calibrated and refined for subsequent sprint(s). This process continued until the study team sufficiently understood the varying needs of CMC families and HCP at different points in the H2H transition, to design the final solution. A detailed overview of the five sprints, including the Design Thinking Methods that were used and the key insights that led to the next sprint, can be found in Appendix A, Table A.1. In the following part we summarize the most important results per sprint and the considerations that shaped the following sprint.

Table 1
Type and number of research methods used.

Research methods	# total
Focus groups	11
Interviews	10
Participant observation	2
UX/UI test research	1
Document analysis	1

Table 2
Type and number of design thinking methods used.

Design thinking methods	# total
Designing transition journey map	3
Persona writing	3
Peer2Peer project feedback	3
Wireframe building	3
Desk research	2
Video editing	2
Stakeholder mapping	1
Prototyping (card game)	1
Prototyping (poster map)	1
Prototype testing	1
Brainwriting	1
Problem tree mapping	1
Prototyping (platform ideation)	1
Assumption mapper	1
Branding designing	1
Ideating (UX/UI) test strategies	1
Ideating (co-creation workshop strategies)	1
Developing showcase materials	1
Showcase event	1

Sprint 1 – Problem discovery

The main goal of sprint 1 was to discover and define the problem and to lay the groundwork for the project's further development. We created a *stakeholder map*, to visualize all parties involved. Also, the AUAS representatives designed a card game that served as a tool to facilitate conversations among stakeholders, addressing H2H transition needs, pain points and emotions. The game aimed to explore current gaps in transitional healthcare. Parents expressed a wide variety of needs, many of which were non-medical. These needs evolved over time and were shaped by contextual factors such as age, language and extended networks. Coordinating care providers and institutions emerged as one of the main stressors for parents. HCP emphasized that they often lacked insight into the family's life after discharge, which made it challenging to provide adequate support during readmissions or visits to the outpatient clinic. We aimed to address this invisibility in our second 'ideating' sprint, in which we also focused on gaining deeper insights into the H2H transition process, and the respective roles of all stakeholders involved. Moreover, in sprint 2, additional low-threshold

engagement methods were explored to improve involvement of CMC families, as the first sprint revealed this challenge, in part because parents were often preoccupied with (coordination of) care.

Sprint 2 – Ideating

In sprint 2, we combined literature studies, brainstorm sessions and in-depth interviews with multiple stakeholders to form ideas that could address problems found in the first sprint. We created *personas* and a *Transition Journey Map,* to visualize the extent of the care network around CMC families and to demonstrate how different types of stakeholders navigated the H2H transition. In addition to tackling the coordination of care, it became clear that parents also struggled with a lack of emotional support alongside feelings of social isolation. Both parents and HCP discussed a multitude of care initiatives, yet these were often unknown to those who would benefit from them the most. This gave us the key insight that rather than introducing another care initiative, our focus should be on creating a prototype to streamline existing care initiatives by connecting key stakeholders throughout the H2H transition. Therefore, one of the aims for sprint 3 was to create an inventory of existing initiatives. Another key insight was that considering the wide range of needs among CMC families, the prototype should not address each individual need, but enable families to organize and personalize their care coordination strategies, such as 'goal-setting'. Sprint 3 focused on exploring different formats for goal-setting. Finally, although engaging difficult-to-reach CMC families was a key aim to help inform the final prototype, it was a challenge for the team and remained as an objective for sprint 3.

Sprint 3 – Improving our ideas

During sprint 3, a low-fidelity application prototype was developed, drawing on insights from individual interviews with HCP involved in chronic healthcare (Fig. 2). A 'pain point' emerged regarding the responsibilities of HCP (especially nurses) who were expected to standardize practices, while CMC families desired tailored support. In addition, the need for increased continuity of care was expressed to provide care that was anticipatory rather than reactive in nature. The current multitude of care initiatives could be overwhelming for parents, negatively impacting their self-sustainability. A key insight was that empowering CMC families does not mean eliminating all uncertainties, but enabling them to be in control of the H2H transition, while simultaneously addressing their non-medical needs. To not add to their sense of being overwhelmed, the prototype should be well laid out and user-friendly. It should provide a space for CMC families to connect with peers and HCP to stimulate experience-based learning and to address social and emotional needs. After gathering all the information, designers from AUAS provided feedback on the prototype, which was to be elaborated in sprint 4. In preparation for sprint 4, a co-creation session was deemed necessary to allow all stakeholders to participate at the same time.

Sprint 4 – Prototyping

The fourth sprint was the ideal moment to organize a co-creation session, in which all stakeholders – including CMC families – could simultaneously share their ideas about the H2H transition and about the interim version of the prototype application. This session yielded valuable insights, such as the realization that the H2H transition should be treated as an ongoing process. This principle extends to family empowerment, as families continuously adapt and learn new information. To support parents of CMC effectively, a multidisciplinary and flexible approach is needed to meet varying and ever-changing needs. In contrast, the Dutch healthcare system is predominantly structured around distinct disciplines, including general practitioners, hospital care, and home nursing care. The absence of effective interdisciplinary communication and collaboration, limits flexibility to facilitate a multidisciplinary approach. This insight highlights the need for the prototype to offer overarching support to bridge the gap between the hospital and the home, creating a space for HCP and CMC families to remain connected. Through the input from the co-creation session combined with surveys and more in-depth stakeholder interviews, the prototype started to become increasingly concrete. Within our group of stakeholders, three domains of care kept surfacing throughout the project, 1) care coordination; 2) social wellbeing, and 3) emotional support. This information helped the team decide which features needed to be prioritized in the final prototype, which was the main goal of sprint 5.

Sprint 5 – Finalizing prototype

During the fifth and final sprint, both CMC families and designers from within the AUAS were consulted to receive final feedback on both the functionality and overall appearance of the prototype: an application called *Our Care Team*.[2] The prototype was tested within the team and a promotional video was made to explain the prototype to a lay audience. [41] Recommendations for further prototype development can be found in Appendix A, Table A.1. The three domains of care – care coordination, social wellbeing, and emotional support – shaped the final prototype. Below, we will present examples of how the application addressed each domain. For a more comprehensive overview, we refer to Appendix B, Table B.1, which illustrates the domains with stakeholder quotations and additional (eHealth) solutions.

3.2. Care coordination

The prototype provided a platform where parents could take the lead in coordinating a team of HCP, peers and their own personal network of family and friends. This enabled parents to involve others in the care of their child, share updates with their network and set personalized goals together, catered to the specific needs of each CMC family. The platform placed the family in the center, surrounded by all relevant stakeholders, to improve interdisciplinary communication and coordination of care.

3.3. Social wellbeing

While parents appreciated the information and training they received from HCP, they highlighted the additional value of practice-based insights that they received from other CMC families. These fellow families provided practical tips and tricks, and expanded their personal network for support. Therefore, we aimed to incorporate peer support within the application.

3.4. Emotional support

The team came up with a system to connect the hospital and home environments by integrating a smart lamp with the *OurCareTeam* application. A friend or relative could briefly change the color of the light in the hospital room, sending a visual signal to the CMC family to let them know they were thinking of them. This simple, yet impactful feature has the potential to alleviate feelings of isolation, a common challenge among CMC families. A video illustrating this feature can be found here: Animation smart lamp.

3.5. A summary of key insights

- The H2H transition for CMC families and HCP involved, is a continuous, non-linear process that requires adaptation and parent-professional collaboration.
- Our study yielded three domains of care that surfaced within the continuous H2H transition process: care coordination, social wellbeing, and emotional support. The prototype application *Our Care Team* provides potential solutions to address these domains of care.

[2] Original Dutch version: Ons Zorgteam

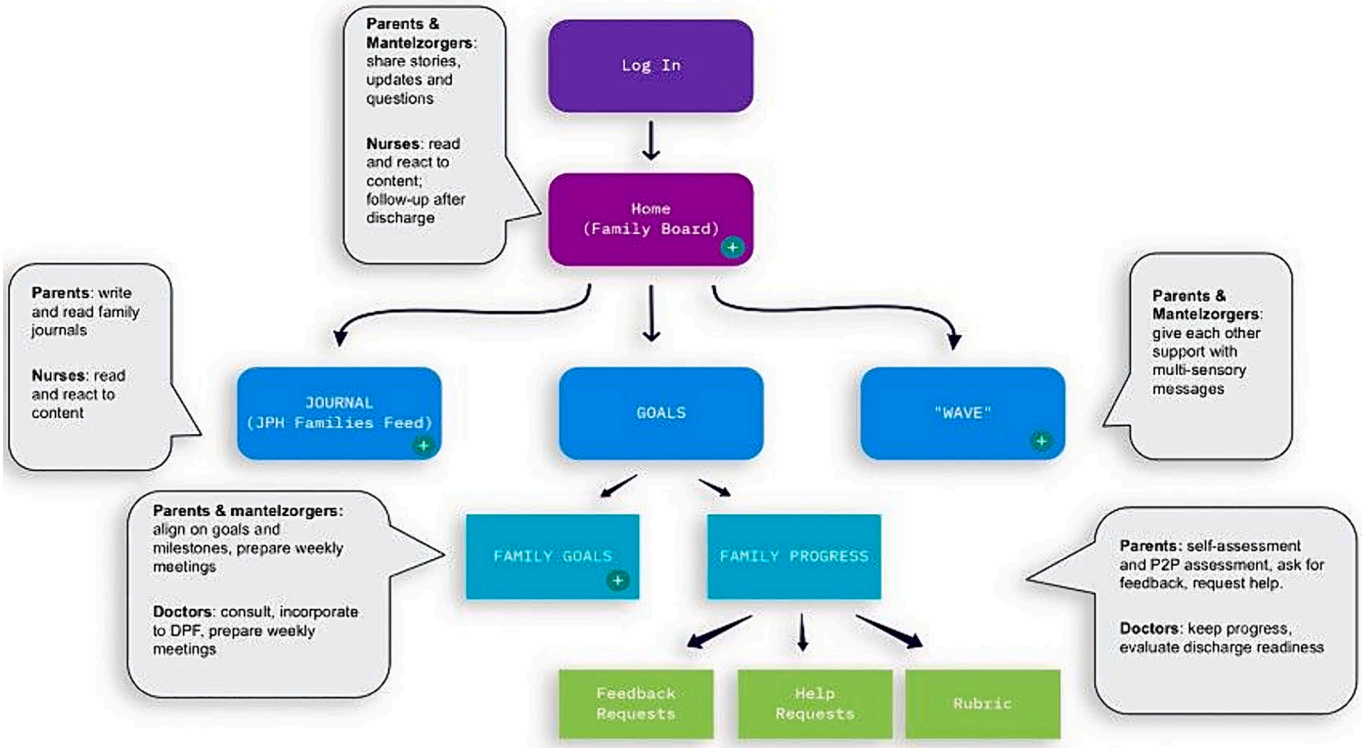

Fig. 2. Example of prototype platform.

- The H2H transition never truly ends, hospital readmissions and continuously adapting to new situations can be inevitable.
- Empowering CMC families takes time, and much like the H2H transition process itself, requires ongoing adaptation from CMC families and HCP involved.
- The needs and skills of CMC families continuously evolve over time.
- Development of eHealth applications benefits from co-creation processes, in which developers, end-users and other stakeholders continuously work together and design solutions.
- Collaboration and communication are key in providing and innovating care.

4. Discussion and conclusion

4.1. Discussion

Exploring an iterative, practice-based methodology like the one in this study, created opportunities on two levels. First, as multidisciplinary teamwork is integral to the SCREAM approach, our multidisciplinary range of expertise may have provided new, nuanced perspectives on the roles of all stakeholders and their needs during the H2H transition. Secondly, the SCREAM approach facilitated the opportunity to not only think about, but also design, eHealth solutions *with* all involved stakeholders; not just *for* them. This approach is supported by existing literature, which previously argued for multidisciplinary research and development teams contributing to intervention design, [27] as well as involving multidisciplinary end-users throughout all stages of the development process. [42,43] This approach is also in line with the rare disease community: 'about us is never without us'.

An overarching insight that emerged during this study was that the *H2H transition is a continuous process*, and that there is in fact no final moment in which H2H transition is completed. Continuous learning and adaptation are required, as family situations and CMC needs change over time. This may change the way we address interventions aimed at improving CMC care. We know from previous research that CMC families face many obstacles, but also that they vary in their care needs and their perceptions of the care they receive. [44] Still, a recent meta-aggregation of the H2H needs of CMC families yielded two important insights. [7] First, without diminishing the individual aspect of complex CMC cases, there are in fact many similarities between CMC families when it comes to their H2H transition needs. Secondly, more surprising, mastering the medical aspects of care was not the main obstacle CMC families faced. Greater struggles included feelings of bereavement, as well as the time required to find new routines and to feel sufficiently empowered to fulfill their new roles as primary caregivers.

Within this continuous H2H transition process, three domains of care were repeatedly highlighted by all stakeholders: care coordination, social wellbeing, and emotional support. We can only speculate whether these domains are indeed the most relevant to all CMC families and HCP, but they deeply resonated within our group of stakeholders. Many CMC endure frequent and lengthy hospital admissions. [22,23,45] While some of these may be unavoidable, CMC families and HCP are often caught off guard when they occur. It is in those moments where the lack of transdisciplinary communication, care coordination and a solid support system is most visible, aggravating the emotional stress and wellbeing of the entire family. We may not be able to prevent all adverse events, such as readmissions. However, we may be able to translate the needs into an intervention, making H2H transition for CMC families and HCP more anticipatory, instead of reactive. The final prototype of this study, *Our Care Team*, puts CMC families in the center of CMC care and gives them the agency to coordinate every stakeholder involved. At the same time, the prototype enabled connections among HCP, family, and friends with the potential to prevent isolation – a common challenge among CMC families that significantly impacts their social and emotional wellbeing. [7,46] By connecting parents with fellow CMC families through the application, it could offer an easily accessible form of peer support. A study by Niela-Vilèn et al. further underscores the value of internet-based peer support alongside traditional support from

HCP, as there are no barriers caused by geographical distance or time constraints. [47]

4.2. Innovation

The power of iteration

In the domain of intervention research, end-user requirements have been mainly explored though qualitative focus groups and surveys. [42,48,49] While these studies provide us with valuable insights, their methodologies are inherently retrospective. A strength of the prospective, iterative SCREAM method is the direct translation of knowledge into a solution – learn as you go – to ensure that all stakeholders can repeatedly learn from each other. [36] Truly understanding the H2H process for CMC families and the role of each stakeholder within that process is the first step towards improving it. Certain Design Thinking methods used in this study, such as a co-creation session and sprint reviews, allowed all stakeholders to share their perspectives simultaneously. This way, their respective roles during the H2H transition could be clarified and they were given the agency to communicate their needs through a continuous loop of communication. Another strength of this iterative method lies in its ability to generate long-term effects through the learning process itself. Each team member contributes their equally important expertise, whether grounded in scientific principles, drawn from personal experiences, or focused on the social context of the relevant issue – in this case the H2H transition for CMC families. As a team, we gained new insights from each other's perspectives and collectively redefined the issue, encompassing not only the medical aspects, but also the challenges of social isolation and care coordination. This type of transdisciplinary science then aims to create a sustainable outcome, that is applicable within the social context in which the problem occurs. [50,51]

4.3. Limitations

Research during COVID-19

This collaboration was initiated during the international pandemic due to COVID-19. The Netherlands went into lockdown at the start of sprint 2 of our study. Subsequently, all interactions between all involved parties were carried out online. This affected the chosen selection of methods, limited access to CMC families and HCP, and opportunities for prototyping. While this may have caused delays or alterations to the design process and final prototype, it may have also yielded positive outcomes. For example, the team was forced to explore out-of-the-box ideas and generate new approaches to reach participants. They were able to maintain the project's process, while fostering their creativity. Furthermore, the lockdown increased the isolation that was already being experienced by many CMC families, emphasizing the necessity for improved communication and coordination of care. The *OurCareTeam* application has the potential to fulfill this need by facilitating accessible interaction between CMC families and HCP. In addition, the provision of peer support through the application could improve the social and emotional wellbeing of all CMC families.

This study was conducted in the Netherlands, linked to the Dutch healthcare system. As a result, our findings may be influenced by cultural, financial, and logistical factors, specific to this context, limiting their direct applicability to other healthcare systems. Inherent to this collaboration and the implementation of the SCREAM approach by the AUAS, is the structure of a 20-week project, with sprints that last two to three weeks on average. The time constraints may have restricted the maturity of the final prototype. Yet, this limitation is inherent to an iterative approach, where development is an ongoing process without a definitive endpoint. Also, a follow-up project is currently being carried out to further develop and implement the findings derived from this study, to ultimately support parents with digital tools to have more control over the complex care for their child.

4.4. Conclusion

The continuously evolving H2H transition process for CMC families and the challenges that they encounter, are not resolved with a one-size-fits-all solution. They require adaptive interventions that empower all stakeholders (in this case CMC families and HCP) to deal with the continuous and complex nature of CMC care. Inevitably, medical knowledge systems and research methods will have to merge with other areas of expertise to create these adaptive interventions. What is needed is not so much an array of eHealth interventions or more data on CMC care: there is in fact more than plenty available [7]. The current gap is a collaborative methodology that can properly position the resources and knowledge already at our disposal. We propose an iterative methodology, such as the SCREAM approach used in this study, that supports innovation through collaboration while using creative digital design principles. This way, we might be able to design eHealth solutions *with* end-users, not just *for* them. While the SCREAM approach adheres to a framework of iterative sprints, it allows for flexibility, creativity and tailored solutions. Given the growing interest in personalized care, this approach may align well with the needs of patients facing complex care situations, such as CMC.

Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

CRediT authorship contribution statement

Liz van de Riet: Writing – original draft, Visualization, Methodology, Formal analysis, Data curation, Conceptualization. **Anna M. Aris:** Writing – original draft, Methodology, Formal analysis, Data curation, Conceptualization. **Nick W. Verouden:** Writing – review & editing, Supervision, Methodology, Conceptualization. **Tibor van Rooij:** Writing – review & editing, Supervision, Conceptualization. **Job B.M. van Woensel:** Writing – review & editing, Supervision, Methodology, Conceptualization. **Clara D. van Karnebeek:** Writing – review & editing, Supervision, Methodology, Conceptualization. **Mattijs W. Alsem:** Writing – review & editing, Supervision, Methodology, Investigation, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgments

The authors are thankful to all CMC families and HCP for their participation in this study and for sharing their individual experiences and ideas. Furthermore, the authors want to thank the trainees from the Digital Society School that collaborated with us throughout the project: Daniel García, Danaë Skrobiszewski, Florence Leung, Dácio Alves Florêncio, and Dheeresh Madhav.

Appendix A

Sprint 1			
Research methods		**Participants**	
Type	*Description*	*Target group(s)*	*# Participants*
Participant observation	Two field trips to the Emma Children's Hospital, affiliated with Amsterdam UMC, PICU	MDs, nurses, CMC families, AUAS representatives	15
Interview	Short interview with CMC parent at the PICU	CMC parent	1
Focus group ('translate session')	Brainstorm meeting with selected expert(s) to gain a more in-depth understanding of stakeholder climate and brainstorm together on possible solutions	PhD candidate Pediatrics/ TCU development	1
Focus group ('sprint review')	TCU consortium meeting to test prototype concept, gather data, determine next steps	Members of TCU consortium	2
Key insights			
1. Within the H2H transition, coordination of care is the main stress factor for CMC families, as desired 'routes' towards the moment of discharge are unclear or undefined. 2. There is a wide range of CMC family needs, influenced by covariates such as class, age, language and extend of network. 3. CMC family needs vary per phase in the H2H transition. 4. Despite the diverse needs of CMC families, most needs were organizational rather than medical. 5. Digital infrastructure circulating patient information between hospitals is fragmented and/or software is not compatible. This makes understanding patient needs more time-consuming for HCP. 6. HCP indicate the need for a better overview of CMC family life outside the hospital.			
Other (design research) methods			
Type	*Description*		
Desk research	Explore current H2H transition for CMC families at Amsterdam UMC; find comparable examples of TCU interventions worldwide; identify relevant stakeholders, areas of improvement in H2H transition; theoretically define 'empowerment'		
Stakeholder mapping	Visualizing known stakeholders to better understand current healthcare landscape surrounding H2H, and identify unknowns		
Card game prototyping	Prototyping a card game as a conversation starter between various stakeholders with the goal to define respective needs towards each other and to the project team		
Poster map prototyping	Designing TCU map, stickers and QR-code as a low-threshold data gathering method: Posters + stickers to map needs from HCP and CMC families, to distribute across the Emma Children's Hospital		
Prototype testing	Prototype testing		
Deliverables			
1. Stakeholder Map 2. Conversational card game 3. Poster map			
Considerations for next sprint			
1. Ideally, CMC families are actively involved wherever possible during the research & development process, but they are also very difficult to reach because they are already preoccupied with (coordination of) CMC care. More low-threshold engagement methods need to be explored. 2. The project team needs to be aware of systemic blind spots: most of CMC family life is not yet visible to the TCU consortium members (the initiator) nor AUAS representatives. 3. A better definition and approach of the H2H transition must be explored. 4. The demand for organizational support within CMC families is substantial, but the engagement between HCP and CMC families remains limited: eHealth solutions should address this gap.			

Sprint 2			
Research methods		**Participants**	
Type	*Description*	*Target group(s)*	*# Participants*
Focus group ('translate session')	Brainstorm meeting with selected expert(s) to gain a more in-depth understanding of stakeholder climate and brainstorm together on possible solutions	Design Thinking professional, organizational anthropologist, 2 MDs	4
Focus group ('sprint review')	TCU consortium meeting to test prototype concept, gather data, determine next steps	Members of TCU consortium	2
Interview	Gathering insights about comparable TCU interventions abroad	TCU expert Canada	1
Interview	Gathering insights into CMC families' daily hurdles and ways in which CMC families are empowered during H2H transition	Parent/initiator specialized day care	1
Key insights			
1. Despite the typically rare conditions among CMC, required care and additional support initiatives are in fact available. However, not all CMC families are aware of their existence, or do not know how to coordinate and personalize available resources. 2. The pandemic illustrates that CMC families of lower socio-economic backgrounds are difficult to reach: the final prototype needs to increase their accessibility to care coordination resources and strategies. 3. Since the digital information architecture supporting patient data is very fragmented, the final prototype should provide a reflexive space for CMC families and HCP to align, discuss and clarify individual needs. 4. Considering the wide range of organizational, emotional and social needs among CMC families, the final prototype should enable a format of organizing and personalizing possible care coordination strategies rather than trying to address each individual need.			
Other (design research) methods			
Type	*Description*		
Brainwriting	Ideating/categorizing/prioritizing new possible eHealth solution concepts		
Desk research	Scientific literature CMC family needs in the Netherlands, design literature cultural probes		
Designing Transition Journey Map	Defining the H2H further and developing a framework of understanding the H2H transition better through data visualization		
Problem tree mapping	Further defining and categorizing CMC family problems and needs as link them better to solutions		
Platform prototype ideation	Developed a first draft concept for an interactive platform, connecting CMC families to each other and to HCP in order to create better overview, define H2H transition goals and provide opportunity for mutual feedback		
Persona writing	Categorizing data on CMC families into 'personas' to identify unknowns, explore and challenge assumptions, identify new relevant stakeholders and help shape platform prototype		
Deliverables			
1. Personas 2. Two transition journey map drafts 3. Our Care Team prototype version 1			
Considerations for next sprint			
1. The final prototype should streamline available care resources and key stakeholders throughout H2H transition, from the moment of birth. Contact details of existing interventions and initiatives for CMC families could be integrated. 2.Explore different formats for 'goal-setting' between CMC families and HCP that can be integrated in the platform prototype. 3. Explore creative formats to engage difficult-to-reach CMC families: this is both a research challenge for the AUAS team as well as a key ingredient for the final prototype. 4. Design a co-creation session format during next sprint that will involve parents, MDs, nurses and other key stakeholders. Goal: test assumptions and prioritize different features of the prototype-in-progress. 5. Explore the possibility to integrate the Digital Patient File into the prototype.			

Sprint 3			
Research methods		**Participants**	
Type	*Description*	*Target group(s)*	*# Participants*
Focus group ('translate session')	Brainstorm meeting with selected expert(s) to gain a more in-depth understanding of stakeholder climate and brainstorm together on possible solutions	MD/Professor Pediatric Intensive Care, MD Rehabilitation & Development specialist, PhD candidate Pediatrics	3
Focus group ('sprint review')	TCU consortium meeting to test prototype concept, gather data, determine next steps	Members of TCU consortium	3
Interview	Gaining insights into similar platforms addressing CMC family needs	Product owner care platform	1
Interview	Gaining insights into empowerment and learning of CMC families in pediatric care	Ambulatory counselor	1
Interview	Gaining insights into CMC family needs and daily routines at home	Assistant General Daily Life Activities	1
Interview	Gaining insights into overall dynamics between HCP and CMC families and difficulties addressing all needs	Medical head PICU Emma Children's Hospital	1
Key insights			
1. Tension between responsibilities of HCP (in particular nurses) and CMC family needs: HCP are expected to standardize their practice wherever possible; families need tailor-made support wherever possible. 2. Privacy considerations and contact data sensitivity also form a road block between CMC families-HCP communications. Both groups indicate a need for higher accessibility. 3. CMC families are only 'ad hoc' in touch with HCP during emergencies; families indicate that more regular check-ins could be helpful. 4. Certain PICU readmissions could possibly be prevented if parents were less overwhelmed with care coordination. 5. The high number of available initiatives for CMC families can in fact contribute to a sense of overwhelm. 6. Empowerment, to CMC families, is not about taking away uncertainties completely but rather about enabling them to stay on top of the H2H transition and also address non-medical needs.			
Other (design research) methods			
Type	*Description*		
Wireframe building	Designing wireframes for a draft version of Our Care Team in order to identify and clarify user needs		
Ideation co-creation workshop	Conceptualization and logistical preparations for a co-creation session scheduled for sprint 4		
Peer2Peer project feedback	Pitching the prototype to peer trainees at AUAS and receiving feedback		
Designing Transition Journey Map	Defining the H2H further and developing a framework of understanding the H2H transition better through data visualization (updated version)		
Persona writing	Categorizing data on CMC families into updated 'personas' to identify unknowns, explore and challenge assumptions, identify new relevant stakeholders and help shape a platform prototype		
Deliverables			
1. Our Care Team platform prototype version 2 2. Refined version Transition Journey Map 3. Wireframes prototype 4. Refined personas			
Considerations for next sprint			
1. CMC family needs tracking systems exist within hospital environments but not yet in home environments. This is an opportunity of explore during the next sprint. 2. The final prototype should not overwhelm CMC families further: UX interface and concept needs to be simple to understand and not time-consuming. 3. The final prototype should provide a space for CMC families to check in with peers and HCP to stimulate experience-based learning and minimize reliance on external expertise.			

Sprint 4			
Research methods		**Participants**	
Type	*Description*	*Target group(s)*	*# Participants*
Focus group ('translate session')	Workshop with Design Thinking expert to finetune preparation for the co-creation session	Design Thinking expert	1
Focus group ('co-creation session')	Validate elements of the current prototype design + explore new ideas for prototype features	Members of TCU consortium; Design Thinking experts; various HCP; CMC parents	10
Focus group ('sprint review')	TCU consortium meeting to test prototype concept, gather data, determine next steps	Members of TCU consortium	2
Document analysis	Analyze available interview data from AMC to identify key stakeholders for the prototype	CMC families	-
Interview	Gaining insights about institutional barriers preventing CMC interventions	Manager child home care institution	1
Interview	Gaining insights into factors that block CMC family empowerment + identifying points of improvement	Parent/initiator specialized daycare	1
Interview	Gaining insights into emotional needs CMC families and opportunities for CMC family networks	Parent/initiator platform for informal caregivers	1
Key insights			
1. The H2H transition has no end point: readmissions occur frequently and CMC care needs evolve over time. 2. The process of CMC family empowerment therefore also never ends: families constantly adapt and learn. 3. Parents listed three domains of care needs that significantly impact their process of empowering: care coordination, social well-being and emotional support. 4. Empowerment of CMC families requires a multidisciplinary approach; the Dutch healthcare system is structured around specific specializations and therefore lacks the necessary flexibility for multidisciplinary practices. 5. For similar reasons, prior CMC family interventions have been difficult to integrate into the overall structures of Dutch healthcare.			
Other (design research) methods			
Type	*Description*		
Wireframe building	Updated, clickable wireframes for Our Care Team prototype		
Persona writing	Updated versions of earlier personas for the Our Care Team prototype		
Assumption mapper	Team brainstorm to identify team members' underlying assumptions and narrow down what needs to be incorporated into the final prototype		
Peer2Peer project feedback	Pitching the prototype to peer trainees at AUAS and receiving feedback		
Video editing	Creating a video pitch about CMC family problems, identified insights and proposed solution		
Branding design	Explore and test different opportunities for Our Care Team branding		
Ideate testing strategies	Decide on UX/UI plan to test the final version of the prototype		
Deliverables			
1. Our Care Team platform prototype version 3 2. Clickable wireframes for the prototype 3. Refined personas 4. Draft video pitch Our Care Team 5. Branding for Our Care Team			
Considerations for next sprint			
1. Key healthcare stakeholders must be connected to the final prototype that would guard and facilitate networks between CMC families and other HCP. 2. UX/UI testing of the final prototype needs to be conducted during the final sprint to guarantee its user-friendliness. 3. Verify which features need to be prioritized in the final prototype.			

. (*continued*).

Sprint 5			
Research methods		**Participants**	
Type	*Description*	*Target group(s)*	*# Participants*
Focus group ('translate session')	Get feedback on UX/UI design to finalize prototype	UX/UI experts	3
Focus group ('sprint review')	TCU consortium meeting to reflect on overall consortium and identify opportunities for future research	Members of TCU consortium + guest stakeholder from PICU Emma Children's Hospital	3
2x UX/UI research tests	Test round with intended users to validate and improve Our Care Team interface and user experience	Parent; HCP	2
Recommendations for future research			
1. Explore diversity of CMC families and stakeholders in more depth, more quantitative analysis. 2. Use Our Care Team insights for research and protocols Amsterdam TCU. 3. Validate Transition Journey Map with higher diversity of stakeholders.			
Other (design research) methods			
Type	*Description*		
Wireframe building	Final version of clickable wireframes for Our Care Team prototype		
Video editing	Updated video pitch about CMC family problems, identified insights and proposed solution		
Developing showcase materials	Making a project page website + interaction format to present the final prototype for Our Care Team with wider audiences		
Designing Transition Journey Map	Final, updated version of the Transition Journey Map		
Peer2Peer project feedback	Pitching the prototype to peer trainees at AUAS and receiving feedback		
Showcase event	Network event to pitch Our Care Team, gather final feedback and connect with relevant stakeholders		
Deliverables			
1. Project page and video pitch 2. Final version of Our Care Team prototype 3. Final version Transition Journey Map			
Recommendations for further prototype development			
1. Add personalized interfaces for different users. 2. Develop symptom-tracking functionality. 3. Improve/align integration with (under development) systems and protocols of the Amsterdam TCU. 4. Explore feasibility of Our Care Team in other healthcare environments. 5. Improve integration of Our Care Team and other available CMC interventions.			

. (*continued*).

Appendix B

Table B.1
The three domains of care that surfaces within the continuous H2H transition process, illustrated by stakeholder quotations and potential (eHealth) solutions.

H2H transition is a continuous – not a linear – process			
"You never stop learning. There are moments when you think you finally have a grip on the situation, but meanwhile, your child and their condition have already evolved. Then something unexpected happens, you end up back in the Intensive Care Unit, and it feels like you must start learning all over again." - parent			
Domains of care	**Key insights**	**Stakeholder quotations**	**Potential (eHealth) solutions**
Care coordination	Multidisciplinary stakeholder networking	"I don't need more medical skills; I need networking skills"	Personal goal setting together with HCP
	Needed expertise is not only medical, but organizational	"I cannot possibly oversee everything"	Direct access to HCP and peers
	Social, 'soft' skills need to be learned to gain organizational expertise	"We would need to make a [coordination] plan together with all care providers [across organizations]"	Strong focus on learning 'soft' skills Constant updating of personal goals
	Class, language, and size of peer network are key influences in coordination of care	"Care coordination is 'easier' for wealthy, native speaker parents. They can better navigate the medical network and often have bigger networks that can also help"	

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Table B.1 (*continued*)

H2H transition is a continuous – not a linear – process			
	Empowerment 'progress' is best monitored as CMC families' ability to adapt		
Social wellbeing	Empowerment is a collective process involving CMC families *and* HCP	"It's so valuable to give and receive advice to and from other parents"	Sharing practical tips & tricks - enlarging personal networks
	Fellow CMC families provide practice-based expertise in ways that HCP cannot offer	"You really learn on the job"	Direct communication platform with fellow CMC families
	Practice/peer-based knowledge needs to be accessible to HCP	"They don't know anything about your child at the ICU. They really need to listen better to the experiences of parents"	Practice-based data from parents needs to be directly accessible to HCP
Emotional support	Continuous feedback loop between CMC families and HCP is key for keeping overview, time-management, and emotional well-being	"How can we think about our relationship [marriage] as well?"	Light lamp to connect with family and friends
	CMC families risk becoming isolated from friends and family, who are both key sources of support in CMC family empowerment	"I don't know how I will keep my job and explain at work how our lives have changed"	Extended family as an option in the application, allowing parents to build their own support system
	Medical well-being cannot be actualized without integrating social, emotional, and psychological well-being	"The other siblings also need our support and attention to cope with the situation"	
	CMC well-being is highly dependent on the overall well-being of their families	"Friends and family often help out in the beginning, but this tends to become less and less over time"	

Abbreviations: H2H – Hospital to Home; CMC – Children with Medical Complexity; HCP – Healthcare professionals

References

[1] Cohen E, et al. Children with medical complexity: an emerging population for clinical and research initiatives. Pediatrics 2011;127(3):529–38.
[2] Burns KH, et al. Increasing prevalence of medically complex children in US hospitals. Pediatrics 2010;126(4):638–46.
[3] Berry JG, et al. Ways to identify children with medical complexity and the importance of why. J Pediatr 2015;167(2):229–37.
[4] Glader L, Plews-Ogan J, Agrawal R. Children with medical complexity: creating a framework for care based on the international classification of functioning, disability and health. Dev Med Child Neurol 2016;58(11):1116–23.
[5] Desai AD, Durkin LK, Jacob-Files EA, Mangione-Smith R. Caregiver perceptions of hospital to home transitions according to medical complexity: a qualitative study. Acad Pediatr 2016;16(2):136–44.
[6] van de Riet L, et al. Delineating family needs in the transition from hospital to home for children with medical complexity: part 2, a phenomenological study. Orphanet J Rare 2023;18:387.
[7] van de Riet L, et al. Delineating family needs in the transition from hospital to home for children with medical complexity: part 1, a meta-aggregation of qualitative studies. Orphanet J Rare 2023;18:386.
[8] Brenner M, et al. Parents' perspectives of the transition to home when a child has complex technological health care needs. Int J Integr Care 2015;15:e035.
[9] Leyenaar JK, et al. Families' priorities regarding hospital-to-home transitions for children with medical complexity. Pediatrics 2017;139(1).
[10] Kokorelias KM, Gignac MAM, Naglie G, Cameron JI. Towards a universal model of family centered care: a scoping review. BMC Health Serv Res 2019;19(1):564.
[11] Kuo DZ, et al. A national profile of caregiver challenges among more medically complex children with special health care needs. Arch Pediatr Adolesc Med 2011;165(11):1020–6.
[12] van Veenendaal NR, et al. Family integrated care in single family rooms for preterm infants and late-onset sepsis: a retrospective study and mediation analysis. Pediatr Res 2020;88(4):593–600.
[13] Waddington C, et al. Family integrated care: supporting parents as primary caregivers in the neonatal intensive care unit. Pediatr Investig 2021;5(2):148–54.
[14] Ding L, et al. Effect of family integrated care on breastfeeding of preterm infants: a scoping review. Nurs Open 2023;10(9):5950–60.
[15] Hamline MY, et al. Hospital-to-home interventions, use, and satisfaction: a meta-analysis. Pediatrics 2018;142(5).
[16] Leyenaar JK, et al. Importance and feasibility of transitional care for children with medical complexity: results of a multistakeholder Delphi process. Acad Pediatr 2018;18(1):94–101.
[17] Bishop S, Waring J. From boundary object to boundary subject; the role of the patient in coordination across complex systems of care during hospital discharge. Soc Sci Med 2019;235:112370.
[18] Sobotka SA, Lynch E, Agrawal R. The role of care coordinators for children with respiratory technologies and home nursing. Pediatr Allergy Immunol Pulmonol 2022;35(2):49–57.
[19] Namachivayam P, et al. Three decades of pediatric intensive care: who was admitted, what happened in intensive care, and what happened afterward. Pediatr Crit Care Med 2010;11(5):549–55.
[20] Namachivayam P, et al. Long-stay children in intensive care: long-term functional outcome and quality of life from a 20-yr institutional study. Pediatr Crit Care Med 2012;13(5):520–8.
[21] Namachivayam SP, et al. Five-year survival of children with chronic critical illness in Australia and New Zealand. Crit Care Med 2015;43(9):1978–85.
[22] Kanthimathinathan HK, et al. Trends in long-stay admissions to a UK paediatric intensive care unit. Arch Dis Child 2020;105(6):558–62.
[23] Chan T, et al. Pediatric critical care resource use by children with medical complexity. J Pediatr 2016;177:197–203 e1.
[24] Berry JG, et al. Inpatient growth and resource use in 28 children's hospitals: a longitudinal, multi-institutional study. JAMA Pediatr 2013;167(2):170–7.
[25] Cohen E, et al. Patterns and costs of health care use of children with medical complexity. Pediatrics 2012;130(6):e1463–70.
[26] Odone A, et al. Public health digitalization in Europe. Eur J Public Health 2019;29(Supplement_3):28–35.
[27] Rooij TV, Marsh S. eHealth: past and future perspectives. Pers Med 2016;13(1):57–70.
[28] Dol J, Delahunty-Pike A, Anwar Siani S, Campbell-Yeo M. eHealth interventions for parents in neonatal intensive care units: a systematic review. JBI Database System Rev Implement Rep 2017;15(12):2981–3005.
[29] Lakshmanan A, et al. Viewpoints from families for improving transition from NICU-to-home for infants with medical complexity at a safety net hospital: a qualitative study. BMC Pediatr 2019;19(1):223.
[30] Desai AD, et al. Caregiver and health care provider perspectives on cloud-based shared care plans for children with medical complexity. Hosp Pediatr 2018;8(7):394–403.
[31] Scott KM, Gome GA, Richards D, Caldwell PHY. How trustworthy are apps for maternal and child health? Health Technol 2015;4(4):329–36.
[32] The TCU Consortium. January 26, 2023, Available from: https://www.tcuconsortium.nl/.
[33] Het Jeroen Pit Huis. January 26, 2023, Available from: https://hetjeroenpithuis.nl/.
[34] Digital Society School. February 26, 2024; Available from: https://digitalsocietyschool.org/.
[35] Amsterdam University of Applied Sciences, Faculty of Digital Media and Creative Industries. February 26, 2024; Available from: https://www.amsterdamuas.com/faculty/fdmci/programmes/digital-society-school/digital-society-school.html.
[36] van Hout M, Gootjes G. SCREAM! - an integrated approach for multidisciplinary design teams in higher education. In: Edulearn15. Spain: Barcelona; 2015. p. 1–12.
[37] the Digital Society School. A.U.o.A.S. *Design Method Toolkit*. February 26, 2024; Available from: https://toolkits.dss.cloud/design/.
[38] Creswell JW, Clark VLP. Designing and Conducting Mixed Methods Research. SAGE Publications; 2011.
[39] Naderifar M, Goli H, Ghaljaie F. Snowball sampling: a purposeful method of sampling in qualitative research. Strides Dev Med Educ 2017;14(3).
[40] MIRO. Digital collaboration platform MIRO. 2011.
[41] the Digital Society School. A.U.o.A.S. *Project Jeroen Pit Huis: How can we support families of chronically ill children in their transition from hospital to home?*. February 26, 2024; Available from: https://digitalsocietyschool.org/project/jeroen-pithuis/.
[42] Wentink M, et al. How to improve eRehabilitation programs in stroke care? A focus group study to identify requirements of end-users. BMC Med Inform Decis Mak 2019;19(1):145.

[43] Smits DW, et al. Designing a tool to support patient and public involvement in research projects: the involvement matrix. Res Involv Engagem 2020;6:30.
[44] Alsem MW, et al. Assessment of family needs in children with physical disabilities: development of a family needs inventory. Child Care Health Dev 2014;40(4):498–506.
[45] van de Riet L, Otten MH, van Karnebeek CD, van Woensel JBM. Long stay and frequent readmission in the pediatric intensive Care in the Netherlands; 15-year time trends. Crit Care Explor 2022;4(12):e0798.
[46] van de Riet L, et al. Delineating family needs in the transition from hospital to home for children with medical complexity: part 2, a phenomenological study. Orphanet J Rare Dis 2023;18(1):387.
[47] Niela-Vilén H, Axelin A, Salanterä S, Melender HL. Internet-based peer support for parents: a systematic integrative review. Int J Nurs Stud 2014;51(11):1524–37.
[48] Wentink MM, et al. What is important in E-health interventions for stroke rehabilitation? A survey study among patients, informal caregivers and health professionals. Int J Telerehabil 2018;10(1):15–28.
[49] Wentink MM, et al. Teachers' and students' perceptions on barriers and facilitators for eHealth education in the curriculum of functional exercise and physical therapy: a focus groups study. BMC Med Educ 2019;19(1):343.
[50] Regeer B, Bunders J. Knowledge co-creation: interaction between science & society. A transdisciplinary approach to complex societal issues. 2009.
[51] Klein JT, et al. Transdisciplinarity: Joint Problem Solving among Science, Technology, and Society An Effective Way for Managing Complexity. 2001.