Towards integrated paediatric rehabilitation through a shared health portal for children with disabilities: A qualitative study on professionals' perspectives

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Abstract

Background: Providing integrated care is essential in paediatric rehabilitation, given the multiplicity of settings and professions involved in children's rehabilitation care pathways and the need for a strong partnership between children with disabilities, families and professionals to improve children's participation. E-health tools, such as shared patient health portals, can support integrated care.

Objective: This study aims to explore the perspectives of paediatric rehabilitation professionals on the usefulness and desired features of a shared portal to support integrated care for children with disabilities, as well as the perceived challenges to its use.

Methods: An interpretive descriptive qualitative study was conducted. Data were collected through 32 semi-structured, online interviews with healthcare (n=15), education (n=11), recreation (n=5) and social professionals (n=1) involved in the rehabilitation pathways of children with motor and cognitive disabilities in France. Recruitment involved maximum variation and snowball sampling. Interview verbatims were analysed using NVivo14 by an interdisciplinary team of researchers, including parents and clinicians, following a thematic analysis approach. Data saturation was reached.

Results: Three main themes were identified: 1) opportunities for a shared health portal, 2) proposals for features, and 3) sources of ambivalence towards portal use, along with strategies to overcome these concerns. Professionals perceived a shared patient portal as an opportunity to 1) facilitate collaboration between healthcare, education, recreation and community services to create a rehabilitation continuum, 2) facilitate exchanges about the child's participation in different living environments to develop skills for everyday life, and 3) facilitate continuous engagement of children and families throughout the rehabilitation process. To fulfil these opportunities, the participants suggested features to be integrated into a shared patient portal: a calendar shared across sectors and providers, shared photos, videos, reports of the child functioning in different living environments and activities, and the ability to share progress with children and families to maintain their engagement in rehabilitation. Participants expressed ambivalence about the use of the tool, regarding confidentiality and transparency, especially with non-medical professionals; children's engagement and increased screen time; parental control of a shared patient portal; and the time spent using the portal. Despite these barriers, they showed strong interest in the portal.

Conclusions: This study highlighted the opportunities perceived by professionals for a shared patient portal to foster a true

partnership between children, parents, and professionals involved in the care pathways of children with disabilities. Concrete features were proposed to enhance stakeholder engagement and participation. Despite some challenges, the professionals perceived significant benefits of a shared patient portal in paediatric rehabilitation, reflecting an intention to use it in practice. These results will inform the development of digital tools designed to improve the quality of rehabilitation care offered to children. Clinical Trial: The procedures were registered at ClinicalTrials.gov under the identifier NCT06570148.

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Abstract

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Keywords: children with disabilities; paediatric rehabilitation; integrated care; shared health patient portal; patient and family-centred care; patient and family partnership; education; recreation and community; social; qualitative study.

Introduction

Children with disabilities face *"long-term physical, mental, intellectual, or sensory impairments that, when interacting with various barriers, may hinder their full and effective participation in society on an equal basis with others"* [1]. Rehabilitation, as a part of primary care, aims to optimise children's daily life functioning and participation in relation to the environment [2]. To provide comprehensive support for children across all spheres of their lives, paediatric rehabilitation adopts a broad approach to the child's life project, encompassing not only healthcare services but also education services [3]. Moreover, the therapeutic relationship has the specificity of involving not only the children but also the parents and caregivers, in a family-centred approach [4,5]. Coordination must be continuous over time, between visits and throughout children's lives, including periods of greater use of rehabilitation services and the transition from childhood to adulthood [6]. Effective information sharing and communication among children, families, and professionals is therefore essential to adapt care to the child's needs and preferences [7] and is key to delivering integrated care to optimize children's health [8]. Paediatric integrated care is defined as *"care coordinated across professionals, facilities and support systems; continuous over time and between visits; tailored to the patients' needs and preferences; and based on shared responsibility between patient and caregivers for optimizing health"* [9].

Nevertheless, in practice, delivering integrated care is challenging [10]. Children with disabilities have long-term needs that involve multiple settings, organisations and professionals [11]. The child's development, marked by evolving stages and a progressive need for autonomy, poses the challenge of providing adaptable support that addresses specific needs at each developmental stage while facilitating transitions of life and care. This complexity results in fragmented care pathways, with a lack of interprofessional and cross-sector collaboration, all of which hinder children's participation [12,13]. This fragmentation also negatively impacts families, who have to navigate a complex system that fails to align with their needs and values [14]. In many cases, families must manage their child's care coordination entirely on their own [15]. For professionals, poor care coordination leads to redundant efforts, inefficient communication, and increased workload [16]. These issues compromise the quality of care and patients' quality of life, heighten the risk of intervention failure [10], and lead to

an increased use of services [17].

E-health offers promising solutions to overcome these challenges and thus support integrated care [18,19]. By enabling remote management of people and communities with diverse needs, digital tools support people's ability to self-manage health and well-being with the support of different types of health and social professionals [20]. Specifically, shared digital portals accessible to patients, caregivers and professionals can improve patient-professional, interprofessional and cross-sector communication [21].

However, to our knowledge, no study has explored the potential benefits of digital tools and features needed to support integrated paediatric rehabilitation care. This is essential given the unique challenges of coordinating care in this context [11,22]. Furthermore, studies also report significant barriers to the use of e-health, many of which come from healthcare professionals [23–25]. Thus, to design e-health tools that support paediatric rehabilitation pathways and are aligned with the needs of professionals, it is essential to gather their points of view, including the challenges to their use [26]. Taking this feedback into account and co-designing digital technologies with users ensures that they address real-world needs and challenges [27].

This study aims to explore the perspectives of professionals involved in the paediatric rehabilitation pathway about the usefulness and desired features of a shared portal to support integrated care for children with disabilities and the perceived challenges of using it. Although this article focuses on professionals, it is part of a broader, qualitative project that also investigates the perspectives of children with disabilities and their families. The findings will inform the development of digital tools tailored to the needs of stakeholders, advancing integrated care in paediatric rehabilitation.

Methods

Study design

To ensure the project's relevance and to carry out the research, two mothers of children with disabilities (CK, AG) and paediatric rehabilitation professionals (TR, CP) were included in the research team. They were involved in all stages of the study design, from elaborating the objective to the publication [28].

An interpretive, descriptive, qualitative methodology was used [29]. Semi-structured individual interviews were conducted to explore professionals' thoughts, attitudes and perceptions in depth [30]. An interview guide was designed by MK and CP, with feedback from QNH, CK, AG and MPP. The guide was pre-tested with a physiotherapist with experience in different paediatric rehabilitation settings (hospital, rehabilitation centre, private practice) and modified throughout the interview process by the two interviewers (MK and TR). The final version of the guide contained nine open-ended questions with prompts (see Appendix 1). The first part focused on the opportunities and concerns perceived by professionals about the role of e-health in facilitating the provision of integrated care in paediatric rehabilitation and suggested features to improve the paediatric rehabilitation pathway. In the second part, features of an existing health portal developed for adult rehabilitation (https://deneo.app/) were shown to the participants: 1) sharing of reports, images, photos and videos between patients and professionals, 2) a database of validated rehabilitation measurement scales and questionnaires, 3) monitoring patient progress using graphs, and 4) prescription of self-rehabilitation exercises. This demonstration aimed to help professionals to visualize a concrete digital tool, explore the acceptance of using such a portal [31], and generate ideas for features. Finally, participants were invited to recommend strategies to implement a shared digital health portal in their practice.

Study participants and recruitment

The inclusion criteria were to be a professional involved in the rehabilitation pathway of children with physical, cognitive or mental disabilities in France. Purposeful sampling with maximum variation [32] was used to ensure participant heterogeneity. The variation criteria were working facility, profession, age, years of experience with children with disabilities, digital literacy and region of France. The region was included to account for inter-regional differences in the coordination of paediatric rehabilitation care that exist in France. First, participants were selected according to these criteria using FRISBEE (https://frisbee.bzh/), a network responsible for coordinating research, care and teaching in paediatric rehabilitation in France. After the first interviews, snowball sampling [33] was used to recruit additional participants. More specifically, the first five participants indicated the need to integrate school assistants and professionals from leisure, sports, and associations for people with disabilities into a shared health portal and provided the contact details of relevant professionals. That's why, from an integrated care perspective, both healthcare professionals (eg, physicians, occupational therapists, physiotherapists, kinesiologist, psychologists, speech therapists, nurses, educator) and non-healthcare professionals in the community (eg, teachers, sports coaches, social workers) were included. MK and CP then discussed each proposed participant's inclusion. Given the diversity of participants, we aimed to include professionals from all fields involved in the paediatric rehabilitation pathway, so at least 11 different professionals. Data saturation was used to determine the final sample size [34]. In total, 45 professionals were contacted by phone, e-mail or LinkedIn. Twelve professionals did not respond, and three refused because they considered themselves inexperienced (n=2) or had recently changed jobs (n=1).

Data collection

Interviews were conducted in French via videoconference (*Zoom pro*) between February and July 2024. They were audio-recorded and lasted an average of one hour (36 to 88 minutes). Two people conducted the interviews: MK, a PhD student experienced in qualitative research and an occupational therapist pursuing an MSc in research (TR). The interviewers had no prior relationship with the participants. After each interview, they discussed the process to ensure consistency in the questions asked and to adjust the guide if needed. They also took reflective notes to describe their post-interview impressions or any technical problems to be considered in the analysis. Participants' socio-demographic data were collected at the end of the interview (Table 1). The participants self-assessed Digital literacy using a Likert scale between 0 – no competence and 10 – full competence. A score of 10 meant being able to download an application, share files easily and take ownership of a new technology. Use of e-health included using apps, web platforms or health portals that were not electronic health records to communicate with providers or monitor children's progress.

Data analysis

The audio recordings were transcribed verbatim using artificial intelligence transcription software (https://easy-peasy.ai/) and double-checked by the interviewers. Analysis was carried out using *NVivo14* software, following the six steps of Braun & Clarke's (2006) thematic analysis. First, initial codes were independently generated from four interviews by two people (TR and GT) and discussed with the lead author (MK). Once agreement was reached on a list of codes, the interviews were individually coded (TR, GT, MK) and discussed with CP to assess whether data saturation had been reached. MK and TR identified themes with the help of CP and then presented them to QNH, MPP, CK and AG for review. MK and CP reviewed the final themes. The analysts considered that data

saturation had been reached after 30 interviews.

Several strategies were used to increase the scientific reliability of the research[36]. First, the team was interdisciplinary (occupational therapists, physicians in public health, paediatric physiatrists and parents of children with disabilities) to triangulate points of view. Also, the analyst team held regular meetings to share reflections about how each coder's personal and professional positioning may have influenced the analysis process [37].

The Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist was used to report the methodology of the study and ensure that information was complete [38] (Appendix 2).

Ethical considerations

Brest University Hospital's ethics committee approved the protocol (reference number: B2024CE.05). All participants received an information and consent form and consented to the audio recording. Each participant was assigned a pseudonym, and any identifying information was removed from the verbatim transcriptions of interviews. The names of the children mentioned in the verbatim were changed. Participants did not receive financial compensation for their participation.

Results

Participants' profiles

The final sample consisted of 32 professionals. Fifteen were healthcare professionals (n=6 working in hospitals, n=4 in rehabilitation centres, n=4 in health and social care and n=4 in private practice), 11 were educational professionals (n=9 working in schools and n=2 in nurseries), 5 were recreation and community professionals (n=3 working in sports associations and n=2 in leisure associations) and 1 was a professional in social administration. Three healthcare professionals were working in two different working facilities. The median age of the participants was 38 years (range: 30 to 57 years), with a majority of women (n=24, 75%), and they came from 11 regions of France (out of 13). The median digital literacy score was 7.4/10 (range: 4 to 10). Seven participants already used shared patient portals, but they were not specific to paediatric rehabilitation, and the exchanges between professionals were limited. Participants' characteristics are described in Table 1.

Pseudonym	Gender	Age	French region (out of 13)	Profession	Working facility	Experience in paediatrics (in years)	Paediatric speciality (specific: a particular disability or general: any type of disability)	Digital literacy from 0 to 10	Use of a shared patient portal (excluding electronic health records for clinicians)
P01	Woman	34	Brittany	Coordinator of a mobile rehabilitation team	Hospital, mobile rehabilitation team	12	General	8	yes
P02	Man	40	Brittany	Psychologist	Rehabilitation centre and private practice	10	General	8.5	yes
P03	Woman	30	Occitanie	Psychomotor therapist	Private practice	9	Specific	8	yes
P04	Man	31	Normandy	Physiotherapist	Rehabilitation centre and health and social care	9	Specific	7	No
P05	Woman	34	Paris	Nurse	High school	1	General	7	no

			region						
P06	Woman	32	Auvergne Rhônes Alpes	Occupational therapist	Hospital, reference centre	8	Specific	8	yes
P07	Woman	35	Brittany	Kinesiologist	Sports association	15	General	8	no
P08	Woman	52	Brittany	Occupational therapist	Health and social care and school	27	Specific	5	no
P09	Woman	42	Paris region	Team manager and occupational therapist	Health and social care	11	General	7	no
P10	Woman	32	Pays de La Loire	Kinesiologist	Hospital	7	Specific	7	no
P11	Woman	36	Brittany	Social worker and nurse	Social administration	2	General	7	no
P12	Woman	39	Brittany	Specialized teacher	Elementary school	23	General	8	no
P13	Woman	40	Centre Val de Loire	Physiatrist	Hospital	10		7	yes
P14	Woman	40	Auvergne Rhônes Alpes	Community sports manager and psychomotor therapist	Sports association	18	General	7	yes
P15	Woman	33	Provence Alpes Côtes d'Azur	Speech language therapist	Health and social care	9	Specific	8	no
P16	Woman	34	Paris region	Speech language therapist	Hospital, reference centre	9	Specific	9	no
P17	Man	55	Brittany	Referent teacher	Elementary school	34	General	7	no
P18	Woman	40	Auvergne Rhônes Alpes	Team manager and physiotherapist	Nursery and rehabilitation centre	14	General	7	no
P19	Man	49	Occitanie	Team manager and educator	Leisure association	18	General	8	no
P20	Woman	47	Paris region	Social worker	Middle school	8	General	7	no
P21	Woman	52	Auvergne Rhônes Alpes	Psychologist	Elementary school	25	General	6	no
P22	Woman	52	Brittany	Educational assistant	Middle school	6	General	7	no
P23	Man	36	Brittany	Team manager and kinesiologist	Leisure association	12	General	5	no
P24	Man	49	Bourgogne Franche Comté	Physiotherapist	Private practice	26	Specific	8	no
P25	Woman	34	Réunion Island	Physiatrist	Hospital, rehabilitation centre	7	Specific	7	no
P26	Woman	26	Auvergne Rhônes Alpes	Childcare assistant	Nursery	6	General	10	no
P27	Woman	31	Grand Est	Educator	Rehabilitation centre	5	General	4	no
P28	Woman	31	Pays de La Loire	Neuropsychologist	Health and social care	8	Specific	8	no

P29	Woman	44	Brittany	School physician	Middle school	11	General	7	no
P30	Man	27	Brittany	Sports coach	Sports association	3	General	8	no
P31	Man	54	Paris region	Coordinating teacher	Middle school	32	General	8	no
P32	Woman	46	Paris region	Paediatrician	Private practice	17	General	9	yes

Table 1: Sociodemographic characteristics of the participants

Specific results

Three main themes emerged from the interviews: 1) opportunities for a shared health portal in paediatric rehabilitation, 2) proposals for features to be integrated into a portal, and 3) sources of ambivalence about using a shared health portal, along with strategies to address these concerns. The themes are summarised in Figure 1.

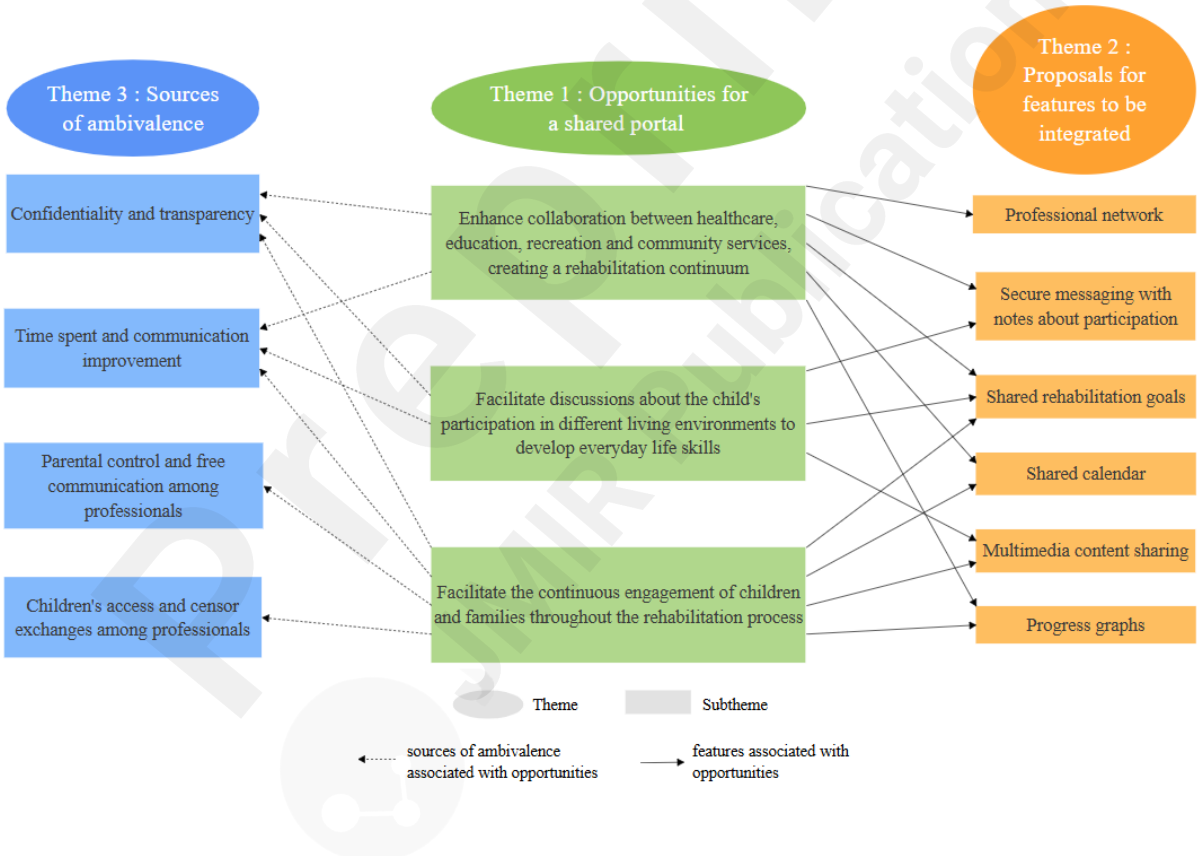

Figure 1: Summary of themes and subthemes identified

Theme 1: Opportunities for a shared health portal in paediatric rehabilitation

Participants perceived a shared patient portal specific to paediatric rehabilitation as an opportunity to 1) enhance collaboration between healthcare, education, recreation and community services, creating a rehabilitation continuum, 2) facilitate discussions about the child's participation in different living

environments to develop everyday life skills, and 3) facilitate the continuous engagement of children and families throughout the rehabilitation process.

1) Enhance collaboration between healthcare, education, recreation and community services, creating a rehabilitation continuum

The participants pointed out that paediatric rehabilitation pathways operate in “silos”, with a lack of collaboration between healthcare, education (school) and recreation and community services (extracurricular activities). Some participants noted divergences between these environments, with discrepancies in observations and discourse stemming from distinct working methods:

> *It’s often a phrase that makes me react: “with me, he does this, he does that...” “He doesn't do it with you? He does it!” [Health-school] meetings are a battle to know who [health professional or teacher] is going to succeed in doing something. We're too much in opposition. We don't work together. There's a school-care divide.* (P21, school psychologist)

> *The rehabilitation professional often works individually and observes things about behaviour in a dual relationship. But these observations are not necessarily the same in a group setting like the classroom. It needs to be refined so that these two worlds, which work in completely different ways, can agree on each other's needs.* (P17, teacher)

The absence of a common discourse or consensus on what can be offered to children can have negative effects on the support perceived by children and families, and therefore on the quality of care:

> *Children have a lot of different people working with them, and as it's always a dual relationship, if no one has a somewhat uniform discourse, it creates vagueness, and I think it's deleterious for the child.* (P29, school physician)

> *When there's a lack of communication between the different partners, the family might not adhere so well.* (P31, coordinating teacher)

For the participants, a patient portal shared between rehabilitation, school and parents could provide an opportunity to better coordinate the interventions implemented across the different environments in which the child develops:

> *What's really important is to coordinate what's being done at school, at home and in other care settings [...] An application would be great if it helped foster links between professionals and families.* (P15, speech therapist)

> *If we can link the school with rehabilitation and outpatient care. It would change our lives, that's for sure.* (P08, occupational therapist)

Thus, a common shared patient portal could place caregivers on an equal footing and foster a unified approach to the child, creating a sense of real collaboration. The participants emphasised the importance of valuing professionals’ observations across all the child's environments to enhance the understanding of the child’s participation:

> *There's a need for educational continuity [...] without splitting up the child and their pathway. [...] An educator who follows a child in a leisure setting provides information that is just as important because it's a social space that's different from home or school. [...] It*

has to be put on the same level, to create richness in terms of individual and group observations. (P19, educator and leisure centre manager)

Being all together on one platform puts everyone on an equal footing [...] It could allow people to feel like they're functioning together in the same direction for the child. (P21, school psychologist)

2) Facilitate discussions about the child's participation in different living environments to develop everyday life skills

The participants expressed a strong need to obtain more information about children's abilities in their different environments:

For young, autistic children in the early stages of the diagnosis, there is a very frequent need for information from the parents on all the stages of development, the children's progress, at home, at school, at the nursery, in the playground... (P28, neuropsychologist)

The participants highlighted the need to share information about adaptations made for children, monitoring equipment used in their usual environments, and negative symptoms such as pain or spasticity:

To be able to exchange [with school] on useful adaptations [...] alternative and augmentative communication tools [...] how to avoid stimuli that provoke a crisis [...] small things that we can all easily implement and that can be very, very facilitating for children. (P15, speech therapist)

The real benefit of rehabilitation is the monitoring of equipment and set-ups. [...] Teleconsultation enables us to see the child in their usual environment as well as with all the health care professionals, so we get much broader information. [...] or for pain or spasticity problems. (P13, physiatrist)

The participants believed that facilitating information exchange would improve children's participation and the transfer of the benefits of rehabilitation to the daily living environments (school, leisure activities, home):

A child with a motor disability can still participate in certain activities. I think this could reassure teachers about what they can expect from a pupil. Because they might be afraid of doing something wrong. (P20, school social worker)

At school, after 3 minutes, Sacha was red-faced and couldn't take it anymore. So, they'd quickly get worried and put him aside. As a result, he didn't do any sport at school. It would have been a good idea to tell them no, he can do it, to show them Sacha's limits, they would have known what's possible for him. (P30, sports coach)

To have a real continuity. Learning happens through repetition, and a one-hour-a-week session isn't enough [...] If on the app we can see where the child is at and say to parents: "he's capable of doing this, this week, you can encourage him to do it." [...] About the child's skills during the session and how we can transfer them to the classroom. (P08, occupational therapist)

3) Facilitate the continuous engagement of children and families throughout the rehabilitation process

The participants also perceived a shared portal as a means to enhance children and families' engagement in the rehabilitation pathway, encourage adherence and maintain motivation through shared goals, especially given the long duration of the rehabilitation pathway and the potential exhaustion of children and families. In this way, the tool could provide more effective support for parents:

> *In high school, rehabilitation follow-up is often more difficult because it's the teenage period. Young people are a little fed up with rehabilitation.* [The app] *would give them a global vision of what it's all about, what is the purpose and everything they've achieved.* (P20, school social worker)

> *The coordination provided by the app would make it possible to have coherent and consistent care for children. They would see that everyone is working towards the same goal, and that there isn't one professional doing one thing, and another doing something else and another different technique at school [...] Maybe* [the families] *they would feel less exhausted and alone.* (P01, rehabilitation coordinator)

Regarding engaging adolescents, the participants mentioned the benefits of providing them with more transparent access to their health data, encouraging them to be more active in managing their health, thereby increasing empowerment and self-determination. In addition, the participants highlighted the value of a patient portal for certain adolescents who have difficulty expressing themselves during consultations:

> *A digital tool, especially for teenagers, who don't necessarily talk during consultations because their parents are present. [...] It has to be the child who fills in the application so that they're invested in it. That they have access to their data and distribute it to whoever they wish* (P25, physiatrist)

Finally, the participants highlighted the potential of e-health tools to support partnerships with children and families:

> *The relevance of this tool compared to others would be the patient partnership. It's not a transmission software between professionals; it's rather a tool that enables collaboration with patients. That would be the real added value.* (P02, psychologist)

> *[in rehabilitation] we have a different approach with children and families, considering them as partners, with a more inclusive approach, coordinating care, school and leisure activities, with the ultimate aim of achieving self-determination in adulthood. That's why e-health has an important role in the coordination, follow-up and participation of patients and families.* (P13, physiatrist)

Theme 2: Proposals for features to be integrated into a shared health portal

The participants proposed features to be integrated into a shared patient portal, which were grouped into six subthemes: 1) visualising child's rehabilitation network, 2) shared calendar, 3) tracking shared rehabilitation goals, 4) secure messaging with notes about participation, 5) displaying graphs of the child's progress, and 6) sharing multimedia content. The features suggested are summarised in Table 2.

Features / Opportunities	Child's rehabilitation network	Shared calendar	Tracking shared rehabilitation goals	Secure messaging with notes about participation	Progress graphs	Multimedia content
Facilitate collaboration between health, education, and recreation and community services to create a rehabilitation continuum	*A list and photos with regular monitoring, other professionals involved in the past, present and future.* (P12, teacher)	*It's useful to see the child's schedule. If there is a free slot, an absence, to notify all partners at the same time.* (P12, teacher)		*A text feature to ask the healthcare team for advice. [...] people could respond when they want, it's less official than sending an e-mail, finding the right address.* (P21, school psychologist)	*Highlighting the child's shared progress would help the school feel more connected with the collective success.* (P21, school psychologist)	
Facilitate exchanges about the child's participation across different living environments to foster the development of skills for everyday life			*Knowing what the goals of rehabilitation, medical follow-up or school are would allow us to say "perhaps we can do the same.* (P23, kinesiologist and leisure centre manager)	*Something like a life notebook at school, to share everything the child does on a daily basis between partners, in order to be able to generalize all their learning.* (P28, neuropsychologist)		*Tying shoelaces is something we can do […] With a short video, we would know how to explain it to him.* (P26, childcare assistant in a nursery)
Facilitate continued engagement of children and families throughout the rehabilitation process		*Children could use it to find their way in time, what day it is, where I'm going, what time, etc. Sometimes, we don't realize that he has three paramedical appointments in the same day.* (P09, team manager and occupational therapist)	*Seeing they are the ones who set the goals and the goals are worked on by all stakeholders, through something coordinated, families would be more willing to participate in rehabilitation.* (P01, rehabilitation coordinator)		*A lot of kids doubt their skills. [...] Having graphs could help them to see their progress from the beginning and see they succeeded quite well in the exercises.* (P16, speech therapist)	*Being able to validate children's progress through videos would be motivating for the child. I am sometimes quite surprised by how a child does not realize the extent of their skills.* (P08, occupational therapist)

Table 2: Correspondence table between opportunities for a shared patient portal and features to be integrated to improve the delivery of integrated paediatric rehabilitation services.

Theme 3: Sources of ambivalence about using a shared health portal and strategies to overcome it

The participants' concerns and positive insights regarding using a shared patient portal were sometimes contradictory. They raised issues and challenges about integrating it into their practice, but they also expressed the benefits of shared portals and proposed strategies to overcome the challenges. Four main sources of ambivalence were identified: 1) the confidentiality and transparency of the portal, 2) parental control over the portal and "free communication" among professionals, 3) children's access to the portal and censor exchanges among professionals, and 4) time spent using the portal and communication improvement.

1) Confidentiality and transparency of the portal

Some healthcare professionals expressed concerns about sharing information with non-medical professionals in the educational and social sectors, given medical confidentiality:

> *In healthcare, there's a certain level of security, but when you mix with school... During team meetings with the school, we don't talk much about medical information in front of educators and teachers. So, there's a concern about data protection, when you involve a lot of people from different backgrounds.* (P24, physiotherapist)

To overcome this challenge, participants agreed that access to a shared patient portal should be sector-specific with dedicated sections: the school would have access to certain information and healthcare professionals could share their reports in a language accessible to them:

> *We could imagine specific access for teachers [...] I used to write my reports in such a way that they could be read by the teachers, always, always, always. So that this exchange could take place.* (P16, speech therapist)

Another issue related to sharing observations about the child through digital platforms was avoiding misinterpretation by certain professionals, which is why the participants recommended that the information in a shared patient portal be well contextualised:

> *Control the dissemination of data to avoid interpretations that could be prejudicial to young people. [...] If you take an event out of its context and the whole history of the young person, it can be dangerous, because you can stick a label on a young person.* (P31, coordinating teacher)
> *From one environment to another, children's reactions are going to be different. So, we can't restrict ourselves to the platform and information from other professionals.* (P23, kinesiologist and manager in a leisure centre)

2) Parental control and "free communication" among professionals

Participants expressed major concerns about the role of parents in a shared patient portal. Some felt

that parent access could be a barrier to “free communication” in certain circumstances:

> *When children have behavioural or psychological difficulties, it's not easy. The child's legal representatives shouldn't have access because it's complicated. Sometimes, it's hard to talk about certain things.* (P16, speech therapist)

> *There's information that I wouldn't want to tell the family but that I would want to tell other professionals.* (P03, psychomotor therapist)

Other participants felt that it was fundamental for parents to have access to all their child’s information and to control it. They suggested that professionals could use other means of communication if they want to share confidential information:

> *I wouldn't feel comfortable putting up documents that parents couldn't access. [...] For me, parents are 100% responsible for their child's care. [...] I'm not going to share concerns about abuse on this platform for the attending physician to see. I would just drop in or make a phone call. So, it would be better for parents to keep control of the application.* (P28, neuropsychologist)

Participants’ opinions diverged regarding parent involvement. Some professionals wanted to include parents as partners, and others wanted to be able to have “uncensored” exchanges between professionals in the portal. Despite these differences, their suggestions aligned regarding sharing information with non-medical professionals, with a need to make the information provided in a shared patient portal accessible to the family:

Sharing emotions between professionals is part of our job, and the parents should not necessarily take part in that… But on the other hand, if they have access, the idea is for patients and parents to be partners. After that, it's up to the professionals to adapt, to share the difficulties they encounter with patients and parents too, and to use words that everyone can understand. (P06, occupational therapist)

3) Children’s access and censor exchanges among professionals

Viewpoints also diverged regarding children's access to a shared patient portal. Some participants were concerned about giving children access prematurely, which could censor exchanges between professionals, particularly in complex situations:

> *We already use filters with parents, but if the child has access, we’ll filter even more. […] There are meetings in which the situation is very complicated but we don't want to hurt the parents so nothing is said during the meeting. And then when we come out, no one is happy because we didn't address the real problems and we didn't want to get in the way. So, I think it’s better if the child is not in the app too early.* (P29, school physician)

The participants were concerned about changes in the children's consent and the possibility that children might later regret having shared certain information:

> *There are perhaps not the same commitments in terms of consent when you are 6 years old or when you are 17.* (P19, educator and manager in a leisure centre)

> *[for patients] not realizing what they are sharing and then regretting it, that's what scares me a little.* (P04, physiotherapist)

Another professional's concern was the "tracking" of children through a shared patient portal:

> *Not everyone should know everything, we are in a bit of a culture today of sharing everything and I think we have to be wary because it is good for a young person to go to a place where not everyone knows their whole life story and their whole disability.* (P14, community sports manager)

> *We must give others the freedom to be and to do what they want, and not to be tracked in terms of behaviour or events. I would freak out if I had information about me saying that I was at the leisure centre this summer, I was really nice and then afterwards, I got a little angry. That's life, actually! [...] There's a red flag on that.* (P19, educator and manager in a leisure centre)

Finally, the children's screen time was a major concern for professionals, even if this subject was also ambivalent:

> *We are already trying to tell parents to reduce screen time so much! If we offer videos or things on screen to children who are non-readers, I think it will have to be done well.* (P15, speech therapist)

> *We try to get them off the screens and then we give them an app! But at the same time, it's also a tool that can be used positively, so it's both.* (P10, kinesiologist)

4) Time spent using the portal and communication improvement

Some professionals mentioned the additional workload and difficulty of integrating the tool into their daily work, especially if they had to enter information into several types of information and communication technologies, such as medical records:

> *We're already swamped with paperwork and things to do. At work, they're already asking me to fill out more and more documents. If, on top of that, I have an app where I have to fill in even more, that would be a huge hindrance for me.* (P24, physiotherapist)

> *The barrier is the time it takes to use it. Because, the way things are going, we are using digital tools more and more, and that doesn't always save time* [laughs]. (P29, school physician)

On the other hand, other professionals perceived the tool as a way of reducing work time because of repetitions associated with lack of coordination:

> *I spend a lot of time and energy communicating the same information to everyone, and I find that quite exhausting*. (P01, rehabilitation coordinator)

> *I'm rubbish at computers. I'd say to myself: "Oh no, another tool!" [laughs]. It probably wouldn't be easy to use at first, and I'd have to learn to use it, but afterwards I'd save time.*

> *And there would be a more fluid link.* (P08, occupational therapist)

Finally, some participants felt that the perception of extra time would depend on each professional's point of view and beliefs about coordination:

> *It's typically the kind of platform where people who believe that the more information we have and cross-reference, the better we manage to take care of the child. Some will see it as a kind of burden or extra work, and others will say it's a great tool and part of the job of taking care of young people.* (P31, coordinating teacher)

Discussion

Principal results

To our knowledge, this study is the first to focus on e-health as a means to improve integrated care in paediatric rehabilitation from the perspective of healthcare, education, and recreation and community professionals. The findings revealed significant opportunities for a shared patient portal to enhance a rehabilitation continuum, communication about children's participation across different environments, and the continuous engagement of children and families throughout the rehabilitation process, with concrete proposals for portal features. However, professionals expressed ambivalent perspectives, highlighting tensions between confidentiality and transparency, parental control over the portal and "free communication" among professionals, children's access to the portal and censor discussions among professionals, and time spent using the portal and communication improvement.

A shared portal could serve as a crucial communication tool to facilitate continuity across healthcare, education and community services, factors that are key determinants of integrated rehabilitation care. This is consistent with the need to redesign systems for children with disabilities using a systemic approach that addresses all health determinants, not just healthcare services [39]. Cross-sector collaboration, particularly with education professionals, is critical to promote children's development and participation [12,40]. However, the participants identified several barriers to collaboration between healthcare and education professionals, such as differing work methods and approaches, which present a significant challenge to achieving inclusive schooling [41]. The findings suggest that a shared portal could address these barriers through features such as a shared calendar, shared goals, and options for sharing observations and tracking children's progress through photos or videos. By providing structured and transparent communication, the portal could support professionals in aligning their interventions and ultimately enhancing children's abilities to participate successfully in school [3]. Beyond education, professionals emphasized the importance of involving recreation and community stakeholders to better understand children's participation across diverse environments outside healthcare settings. The participants highlighted the possibility for children to engage in school sports activities by facilitating communication between community and school providers – a collaboration that is currently absent. Although this reflects a critical aspect of care integration for children with disabilities, it also reveals a gap in the literature on professional collaboration for children with disabilities. Specifically, recreation and community providers are often overlooked as key stakeholders [42]. By enabling real-time information sharing, the portal could provide a more holistic understanding of children's participation and needs across different environments, facilitating tailored interventions.

The second opportunity for a shared portal concerned the need to gather more information about children's participation in different daily activities, such as leisure, sports, school, and home. This is

particularly relevant to paediatric rehabilitation, which requires collaboration between multiple providers and parents across diverse environments to enhance children's participation [43]. A shared portal could facilitate the exchange of such information, aligning with the “F-word” framework, which highlights six key aspects of childhood disability: Functioning, Family, Fitness, Fun, Friends and Future [44]. This study offers practical approaches to promote these six concepts by enhancing information sharing about children's skills across different daily life environments. This includes sharing goals, notes, photos, and videos about suitable adaptations or exercises to practice at home, helping integrate these skills into everyday life. Incorporating family training and defining goals with parents significantly improves success in therapy [45]; therefore, promoting rehabilitation continuity at home is essential. As mentioned by the participants, time spent in therapy is insufficient to transfer skills to the home setting, underscoring the need for effective communication tools with parents. A shared portal could address this need by fostering greater continuity in rehabilitation interventions, benefiting both children and their families.

Professionals also identified the portal’s potential to enhance child and family engagement in the rehabilitation process. By promoting greater consistency, the portal could help reduce family exhaustion, a critical issue given the challenges parents face in coordinating care (37, 38). Additionally, professionals mentioned the shared portal as a means to foster a partnership relationship with children and parents. Although patient- and family-centred approaches are frequently mentioned in paediatric rehabilitation, the concept of patient and family partnership remains less explored [48]. Partnership extends beyond a centred model, advocating for a more egalitarian relationship based on co-construction and shared decision-making [49]. A shared digital tool could enhance transparency by providing parents with access to rehabilitation objectives and progress tracking, fostering their active engagement in the rehabilitation process [50]. Additionally, such a tool could help professionals make their communication more accessible to children and families, thereby improving digital health literacy, which is a major determinant of health [51]. For children, features such as goals defined with them and progress graphs hold great potential to offer positive expectancies, support autonomy, and build supporting relationships, all of which are key to improving self-determination [52]. Furthermore, given the long-term nature of pediatric rehabilitation, innovative strategies are needed to sustain engagement over time[53].

Nevertheless, the professionals mentioned several sources of ambivalence regarding the use of a shared patient portal. Issues such as confidentiality and the time required for portal use are consistent with previous studies [21,25]. However, concerns about school access are specific to paediatric rehabilitation and extend beyond confidentiality issues. To avoid misinterpretation, the professionals recommended making the portal sector-specific and ensuring that observations about children are properly contextualized according to the time of day and the environment in which the event took place. Regarding family access, the professionals faced a dilemma: while they recognized the importance of family engagement in the rehabilitation process, they were hesitant to grant full families control over the portal. This finding may reflect power dynamics within the therapist-parent relationship, as some families perceive their role as collaborative partners (42, 43). Studies have shown that parental engagement can be influenced by the therapist-parent relationship [56]. Different perspectives regarding family-centred care [57] may further challenge using a shared health portal by hindering shared decision-making [58]. Other concerns related to children’s access, including fears about screen time [59] and age-related consent, echoing studies on children’s cyber safety and the limited literature on these issues [60]. This vigilance is justified given the dual vulnerability of the population of minors with disabilities. At the same time, it aligns with studies on barriers to participation in paediatric rehabilitation, which highlight protective attitudes toward children among professionals [61].

Overall, the professionals' ambivalence reflects an intention to integrate a patient portal into their practice, aligning with the technology acceptance model [62], as they perceive the digital tool as useful. However, the concerns identified by the professionals must be considered to ensure the full adoption of a portal in paediatric rehabilitation. This includes managing the significant changes required, such as improving interprofessional and cross-sector collaboration, particularly with school, and fostering patient- and family- partnerships, including shared-decision making. This finding is consistent with Goodwin's work, which argues that successfully redesigning paediatric healthcare to achieve integration relies on a dual disruptive innovation: (1) transforming how healthcare providers collaborate to achieve the best outcomes for patients and families, and (2) the use of digital technologies to facilitate integrated care as a key enabler [63].

Strengths and limitations

The sample of participants was unbalanced, with more healthcare professionals than education, community and social professionals, which may have influenced the results. This may be explained by the initial recruitment via the FRISBEE network, which is mainly composed of healthcare professionals. Additionally, the investigators were mostly healthcare professionals who had little access to education and community networks. This is also a limitation of snowball sampling, in which participants often recommend interviewing people who are similar to themselves [64]. Nevertheless, the maximum variation sampling generated a variety of participants, and the research team specifically sought people who would not have spontaneously responded to a recruitment advertisement. This combination of two sampling strategies enabled us to obtain a rich and nuanced account of the phenomenon under study [34].

Regarding the data collection method, the individual interviews allowed us to explore a broad range of opportunities and barriers, which was relevant given the variability of rehabilitation facilities in France. However, focus groups could have allowed participants to compare their viewpoints and generate additional ideas on the implementation strategies for a portal, for example [65].

Regarding the data analysis, the majority of analysts were healthcare professionals, sharing similar characteristics with some of the participants, which may have influenced the analysis. However, the team was multidisciplinary (paediatric physiatrists, occupational therapists and physicians in public health), and regular meetings were held for reflexive analysis. Moreover, the inclusion of parent partners' perspectives contributed to a more comprehensive and in-depth analysis [37].

Perspectives

These findings provide tangible insights into the development of shared digital tools to enhance the integration of care for children with disabilities, adopting a pragmatic approach that considers the challenges of its use. They offer direct guidance for digital solution developers aiming to design shared portal that could interoperate with electronic health records. Furthermore, these results open promising avenues for broader applications, particularly for populations with complex care needs and their caregivers, including adults with disabilities and the elderly, that could meet some of the needs expressed by this population [66].

Conclusion

As a preliminary step in designing a shared patient portal for integrated care of children with disabilities, this study identified specific opportunities and features for integrated paediatric rehabilitation pathways through e-health, from the professionals' perspective. These opportunities include a healthcare-education-community continuum with enhanced communication across disciplines and sectors, the exchange of information about children's participation across different environments, and increased engagement of children and families through shared calendars, goals, photos and videos. Despite some sources of ambivalence regarding the portal's confidentiality, time spent using it, and access/control for children and families, the professionals recognized the potential value of this tool in improving the quality of care for children with disabilities and their families. Future studies should explore the perspectives of children and families on a shared portal and align stakeholder needs and concerns regarding the tool's features. The findings will guide the development of e-health tools that are better tailored to stakeholder needs and that can effectively promote integrated paediatric rehabilitation care.

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Authors' Contributions

The study was conceptualized by MK, CP, SB, QNH and MPP. Participant recruitment was undertaken by MK, EF and CP. Data collection was undertaken by MK and TR. Data analysis was undertaken by MK, TR, GT and CP. The paper was written by MK, edited by CP, and reviewed by all the authors. CK and AG, parents' partners, contributed to all these stages.

Conflicts of Interest

None declared.

References

1. International Classification of Functioning, Disability and Health (ICF). Accessed September 18, 2024. https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health

2. *Rehabilitation in Health Systems*. World Health Organization; 2017. Accessed January 11, 2024. http://www.ncbi.nlm.nih.gov/books/NBK552492/

3. Campbell W, Missiuna C, Dix L, Whalen SS. Partnering for Change: collaborating to transform occupational therapy services that support inclusive education. *Front Public Health*. 2023;11. doi:10.3389/fpubh.2023.1275920

4. Bamm EL, Rosenbaum P. Family-Centered Theory: Origins, Development, Barriers, and Supports to Implementation in Rehabilitation Medicine. *Arch Phys Med Rehabil*. 2008;89(8):1618-1624. doi:10.1016/j.apmr.2007.12.034

5. King G, Williams L, Hahn Goldberg S. Family-oriented services in pediatric rehabilitation: a scoping review and framework to promote parent and family wellness. *Child Care Health Dev*. 2017;43(3):334-347. doi:10.1111/cch.12435

6. Roquet M, Garlantezec R, Remy-Neris O, et al. From childhood to adulthood: health care use in individuals with cerebral palsy. *Dev Med Child Neurol*. 2018;60(12):1271-1277. doi:10.1111/dmcn.14003

7. González-Ortiz LG, Calciolari S, Goodwin N, Stein V. The Core Dimensions of Integrated Care: A Literature Review to Support the Development of a Comprehensive Framework for Implementing Integrated Care. *Int J Integr Care*. 2018;18(3):10. doi:10.5334/ijic.4198

8. Singer SJ, Burgers J, Friedberg M, Rosenthal MB, Leape L, Schneider E. Defining and measuring integrated patient care: promoting the next frontier in health care delivery. *Med Care Res Rev MCRR*. 2011;68(1):112-127. doi:10.1177/1077558710371485

9. Ziniel SI, Rosenberg HN, Bach AM, Singer SJ, Antonelli RC. Validation of a Parent-Reported Experience Measure of Integrated Care. *Pediatrics*. 2022;138(6):e20160676. doi:10.1542/peds.2016-0676

10. McLellan SE, Mann MY, Scott JA, Brown TW. A Blueprint for Change: Guiding Principles for a System of Services for Children and Youth With Special Health Care Needs and Their Families. *Pediatrics*. 2022;149(Supplement 7):e2021056150C. doi:10.1542/peds.2021-056150C

11. Kuo DZ, McAllister JW, Rossignol L, Turchi RM, Stille CJ. Care Coordination for Children With Medical Complexity: Whose Care Is It, Anyway? *Pediatrics*. 2018;141(Supplement_3):S224-S232. doi:10.1542/peds.2017-1284G

12. Kinnunen A, Jeglinsky I, Vänskä N, Lehtonen K, Sipari S. The Importance of Collaboration in Pediatric Rehabilitation for the Construction of Participation: The Views of Parents and Professionals. *Disabilities*. 2021;1(4):459-470. doi:10.3390/disabilities1040032

13. Peters VJT, de Winter JP. Integrated care for children living with complex care needs: navigating the long and winding road. *Eur J Pediatr*. 2023;182(4):1437-1438. doi:10.1007/s00431-023-04892-7

14. E B, Fr V, Aj H. Opportunities for Improving Programs and Services for Children with Disabilities. PubMed. doi:10.17226/25028

15. Gupta VB, O'Connor KG, Quezada-Gomez C. Care coordination services in pediatric practices. *Pediatrics*. 2004;113(5 Suppl):1517-1521.

16. Horsky J, Morgan SJ, Ramelson HZ. Coordination of care for complex pediatric patients: perspectives from providers and parents. *AMIA Annu Symp Proc*. 2014;2014:681-690.

17. Allshouse C, Comeau M, Rodgers R, Wells N. Families of Children With Medical Complexity: A View From the Front Lines. *Pediatrics*. 2018;141(Suppl 3):S195-S201. doi:10.1542/peds.2017-

1284D

18. Cassidy L, Quirke MB, Alexander D, et al. Integrated care for children living with complex care needs: an evolutionary concept analysis. *Eur J Pediatr*. 2023;182(4):1517. doi:10.1007/s00431-023-04851-2

19. Steele Gray C. Integrated Care's New Protagonist: The Expanding Role of Digital Health. *Int J Integr Care*. 2021;21(4):1. doi:10.5334/ijic.6437

20. Al Knawy B, McKillop MM, Abduljawad J, et al. Successfully Implementing Digital Health to Ensure Future Global Health Security During Pandemics: A Consensus Statement. *JAMA Netw Open*. 2022;5(2):e220214. doi:10.1001/jamanetworkopen.2022.0214

21. Kruse CS, Bolton K, Freriks G. The Effect of Patient Portals on Quality Outcomes and Its Implications to Meaningful Use: A Systematic Review. *J Med Internet Res*. 2015;17(2):e3171. doi:10.2196/jmir.3171

22. Miller AR, Condin CJ, McKellin WH, Shaw N, Klassen AF, Sheps S. Continuity of care for children with complex chronic health conditions: parents' perspectives. *BMC Health Serv Res*. 2009;9:242. doi:10.1186/1472-6963-9-242

23. Borges do Nascimento IJ, Abdulazeem HM, Vasanthan LT, et al. The global effect of digital health technologies on health workers' competencies and health workplace: an umbrella review of systematic reviews and lexical-based and sentence-based meta-analysis. *Lancet Digit Health*. 2023;5(8):e534-e544. doi:10.1016/S2589-7500(23)00092-4

24. Busetto L, Luijkx K, Calciolari S, Ortiz LGG, Vrijhoef HJM. Barriers and Facilitators to Workforce Changes in Integrated Care. *Int J Integr Care*. 2018;18(2):17. doi:10.5334/ijic.3587

25. Borges do Nascimento IJ, Abdulazeem H, Vasanthan LT, et al. Barriers and facilitators to utilizing digital health technologies by healthcare professionals. *Npj Digit Med*. 2023;6(1):1-28. doi:10.1038/s41746-023-00899-4

26. Noorbergen TJ, Adam MTP, Teubner T, Collins CE. Using Co-design in Mobile Health System Development: A Qualitative Study With Experts in Co-design and Mobile Health System Development. *JMIR MHealth UHealth*. 2021;9(11):e27896. doi:10.2196/27896

27. Bird M, Li L, Ouellette C, Hopkins K, McGillion MH, Carter N. Use of Synchronous Digital Health Technologies for the Care of Children With Special Health Care Needs and Their Families: Scoping Review. *JMIR Pediatr Parent*. 2019;2(2):e15106. doi:10.2196/15106

28. Forsythe LP, Carman KL, Szydlowski V, et al. Patient Engagement In Research: Early Findings From The Patient-Centered Outcomes Research Institute. *Health Aff (Millwood)*. 2019;38(3):359-367. doi:10.1377/hlthaff.2018.05067

29. Thorne S. *Interpretive Description: Qualitative Research for Applied Practice*. 2nd ed. Routledge; 2016. doi:10.4324/9781315545196

30. DeJonckheere M, Vaughn LM. Semistructured interviewing in primary care research: a balance of relationship and rigour. *Fam Med Community Health*. 2019;7(2). doi:10.1136/fmch-2018-000057

31. Kim J, Park HA. Development of a Health Information Technology Acceptance Model Using Consumers' Health Behavior Intention. *J Med Internet Res*. 2012;14(5):e2143. doi:10.2196/jmir.2143

32. Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N, Hoagwood K. Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Adm Policy Ment Health*. 2015;42(5):533. doi:10.1007/s10488-013-0528-y

33. Pahwa M, Cavanagh A, Vanstone M. Key Informants in Applied Qualitative Health Research. *Qual Health Res*. 2023;33(14):1251. doi:10.1177/10497323231198796

34. Hennink M, Kaiser BN. Sample sizes for saturation in qualitative research: A systematic review of empirical tests. *Soc Sci Med*. 2022;292:114523. doi:10.1016/j.socscimed.2021.114523

35. Braun V, Clarke V. Using thematic analysis in psychology.

36. Morse JM. Critical Analysis of Strategies for Determining Rigor in Qualitative Inquiry. *Qual Health Res*. 2015;25(9):1212-1222. doi:10.1177/1049732315588501

37. Braun V, Clarke V. Toward good practice in thematic analysis: Avoiding common problems and be(com)ing a knowing researcher. *Int J Transgender Health*. 2023;24(1):1-6. doi:10.1080/26895269.2022.2129597

38. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349-357. doi:10.1093/intqhc/mzm042

39. Kuo DZ, Rodgers RC, Beers NS, McLellan SE, Nguyen TK. Access to Services for Children and Youth With Special Health Care Needs and Their Families: Concepts and Considerations for an Integrated Systems Redesign. *Pediatrics*. 2022;149(Suppl 7). doi:10.1542/peds.2021-056150H

40. Garcia-Melgar A, Hyett N, Bagley K, McKinstry C, Spong J, Iacono T. Collaborative team approaches to supporting inclusion of children with disability in mainstream schools: A co-design study. *Res Dev Disabil*. 2022;126:104233. doi:10.1016/j.ridd.2022.104233

41. Inclusive education and cross-sectoral collaboration between education and other sectors - UNESCO Bibliothèque Numérique. Accessed October 19, 2024. https://unesdoc.unesco.org/ark:/48223/pf0000373664

42. Styczen LM, Helseth S, Groven KS, Hauge MI, Dahl-Michelsen T. Interprofessional collaboration for children with physical disabilities: a scoping review. *J Interprof Care*. Published online February 10, 2024:1-17. doi:10.1080/13561820.2023.2295922

43. An M, Palisano RJ. Family–professional collaboration in pediatric rehabilitation: a practice model. *Disabil Rehabil*. 2014;36(5):434-440. doi:10.3109/09638288.2013.797510

44. Rosenbaum P, Gorter JW. The "F-words" in childhood disability: I swear this is how we should think! *Child Care Health Dev*. 2012;38(4):457-463. doi:10.1111/j.1365-2214.2011.01338.x

45. Baker T, Haines S, Yost J, DiClaudio S, Braun C, Holt S. The role of family-centered therapy when used with physical or occupational therapy in children with congenital or acquired disorders. *Phys Ther Rev*. 2012;17(1):29-36. doi:10.1179/1743288X11Y.0000000049

46. Cady RG, Belew JL. Parent Perspective on Care Coordination Services for Their Child with Medical Complexity. *Children*. 2017;4(6):45. doi:10.3390/children4060045

47. Myers S, Collins B, Maguire S. Care coordination for children with a disability or developmental difficulty: Empowers families and reduces the burden on staff supporting them. *Child Care Health Dev*. 2024;50(1):e13158. doi:10.1111/cch.13158

48. Fragasso A, Pomey MP, Careau E. Vers un modèle intégré de l'Approche famille-partenaire auprès des enfants ayant un trouble neurodéveloppemental. *Enfances Psy*. 2018;79(3):118-129. doi:10.3917/ep.079.0118

49. Pomey MP, Hihat H, Khalifa M, Lebel P, Néron A, Dumez V. Patient partnership in quality improvement of healthcare services: Patients' inputs and challenges faced. *Patient Exp J*. 2015;2:29-42. doi:10.35680/2372-0247.1064

50. Melvin K, Meyer C, Scarinci N. What does a family who is "engaged" in early intervention look like? Perspectives of Australian speech-language pathologists. *Int J Speech Lang Pathol*. 2021;23(3):236-246. doi:10.1080/17549507.2020.1784279

51. van Kessel R, Wong BLH, Clemens T, Brand H. Digital health literacy as a super determinant of health: More than simply the sum of its parts. *Internet Interv*. 2022;27:100500. doi:10.1016/j.invent.2022.100500

52. Antoniadou M, Granlund M, Andersson AK. Strategies Used by Professionals in Pediatric Rehabilitation to Engage the Child in the Intervention Process: A Scoping Review. *Phys Occup Ther Pediatr*. 2024;44(4):461-488. doi:10.1080/01942638.2023.2290038

53. Meyns P, Roman de Mettelinge T, van der Spank J, Coussens M, Van Waelvelde H. Motivation in pediatric motor rehabilitation: A systematic search of the literature using the self-determination theory as a conceptual framework. *Dev Neurorehabilitation*. 2018;21(6):371-390. doi:10.1080/17518423.2017.1295286

54. Klatte IS, Ketelaar M, de Groot A, Bloemen M, Gerrits E. Collaboration: How does it work according to therapists and parents of young children? A systematic review. *Child Care Health Dev*. 2024;50(1):e13167. doi:10.1111/cch.13167

55. Reeder J, Morris J. Becoming an empowered parent. How do parents successfully take up their role as a collaborative partner in their child's specialist care? *J Child Health Care Prof Work Child Hosp Community*. 2021;25(1):110-125. doi:10.1177/1367493520910832

56. Smith KA, Samuels AE. A scoping review of parental roles in rehabilitation interventions for children with developmental delay, disability, or long-term health condition. *Res Dev Disabil*. 2021;111:103887. doi:10.1016/j.ridd.2021.103887

57. MacKean GL, Thurston WE, Scott CM. Bridging the divide between families and health professionals' perspectives on family-centred care. *Health Expect*. 2005;8(1):74-85. doi:10.1111/j.1369-7625.2005.00319.x

58. Boland L, Graham ID, Légaré F, et al. Barriers and facilitators of pediatric shared decision-making: a systematic review. *Implement Sci IS*. 2019;14:7. doi:10.1186/s13012-018-0851-5

59. Muppalla SK, Vuppalapati S, Pulliahgaru AR, Sreenivasulu H. Effects of Excessive Screen Time on Child Development: An Updated Review and Strategies for Management. *Cureus*. 2023;15(6):e40608. doi:10.7759/cureus.40608

60. Lamond M, Renaud K, Wood L, Prior S. SOK: Young Children's Cybersecurity Knowledge, Skills & Practice: A Systematic Literature Review. In: *Proceedings of the 2022 European Symposium on Usable Security*. EuroUSEC '22. Association for Computing Machinery; 2022:14-27. doi:10.1145/3549015.3554207

61. Teleman B, Vinblad E, Svedberg P, Nygren JM, Larsson I. Exploring Barriers to Participation in Pediatric Rehabilitation: Voices of Children and Young People with Disabilities, Parents, and Professionals. *Int J Environ Res Public Health*. 2021;18(19):10119. doi:10.3390/ijerph181910119

62. Gagnon MP. Using a Modified Technology Acceptance Model to Evaluate Healthcare Professionals' Adoption of a New Telemonitoring System.

63. Goodwin N. Tomorrow's World: Is Digital Health the Disruptive Innovation that will Drive the Adoption of Integrated Care Systems? 2018;18(4):14. doi:10.5334/ijic.4638

64. Naderifar M, Goli H, Ghaljaei F. Snowball Sampling: A Purposeful Method of Sampling in Qualitative Research. *Strides Dev Med Educ*. 2017;In Press. doi:10.5812/sdme.67670

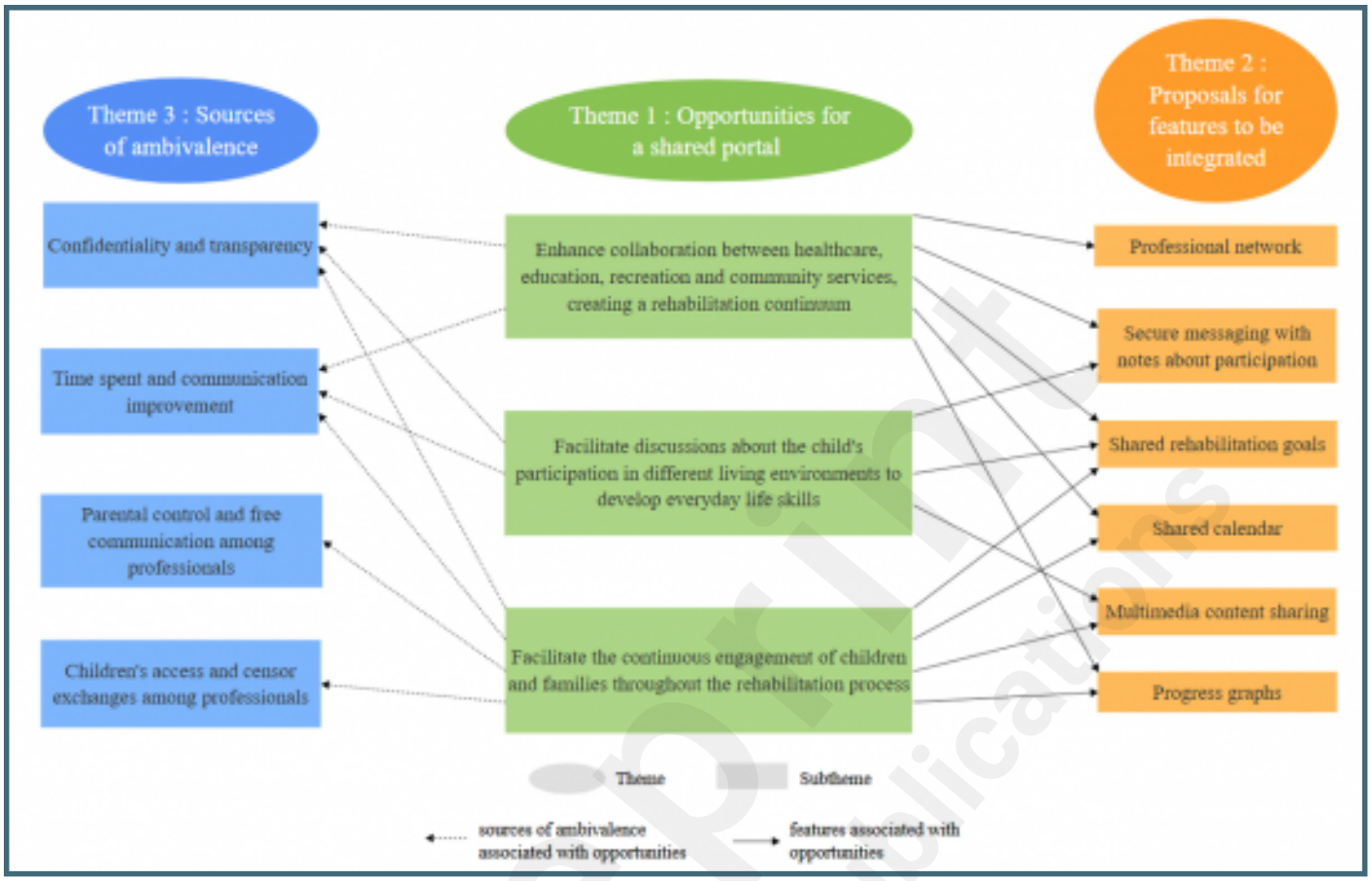
65. Guest G, Namey E, Taylor J, Eley N, McKenna K. Comparing focus groups and individual interviews: Findings from a randomized study. *Int J Soc Res Methodol Theory Pract*. 2017;20(6):693-708. doi:10.1080/13645579.2017.1281601

66. Bally ELS, Cheng D, Grieken A van, et al. Patients' Perspectives Regarding Digital Health Technology to Support Self-management and Improve Integrated Stroke Care: Qualitative Interview Study. *J Med Internet Res*. 2023;25(1):e42556. doi:10.2196/42556

Supplementary Files

Figures

Summary of themes and subthemes identified.



Multimedia Appendixes

Interview guide.
URL: http://asset.jmir.pub/assets/0e6e30340b9a1a55feddc0b6f3b62096.docx

COREQ Checklist.
URL: http://asset.jmir.pub/assets/1deac8d6d602f834f505f416d607dccd.docx