



Linking heart and mind: development and evaluation of online information material on mental health disorders in children and adolescents with CHDs





Original Article

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Abstract

Psychiatric comorbidity is common in children and adolescents with CHDs. Early recognition and evidence-based treatments are crucial to prevent long-term consequences. To support early identification and reduce stigma, we 1) developed and 2) tested the usability and acceptability of online information material on common mental health disorders targeted healthcare professionals and affected families. Website content was shaped by insights from interviews with healthcare professionals across sectors, parents, and adolescents. Evaluations demonstrated promising acceptability and usability of the first prototype but indicated the need for improvements in specific aspects of content, navigation, and overall aesthetics.

Introduction

More than 97% of children with CHD live well into adulthood.¹ However, 35.1% are diagnosed with or treated for a mental health disorder by 18 years of age.² Compared to the general population, they have higher rates of neurodevelopmental disorders, including autism spectrum disorder and attention deficit hyperactivity disorder,²⁻⁴ severe stress reactions, tic disorders, attachment disorders, and eating disorders,² whereas data on anxiety and depression are conflicting.³ Even those with simple CHDs have a higher burden of mental health disorders in adulthood with higher use of psychotropic medication, lower work participation, and a higher use of social benefits.⁵⁻⁷ Early detection and evidence-based treatment are therefore crucial to lower the risk of repercussion into adulthood^{8,9} and shared care between mental healthcare- and CHD healthcare professionals have been called upon.¹⁰

Recommendations for neurodevelopmental and psychiatric screening in children with CHD exist,¹¹⁻¹³ but their clinical implementation is sparse.¹⁴ Furthermore, the majority of healthcare professionals as well as families are unaware of the need for such evaluations of children with CHD.¹⁵ Also, healthcare professionals in cardiology settings may hesitate to address this issue due to unclear responsibilities and the fear of uncovering psychosocial needs they lack the time, skills, and referral options to manage.¹⁶ Especially adolescents may also hesitate to seek professional help due to stigma, poor mental health literacy, and a preference for self-reliance.¹⁷ In summary, there is an unmet need for disseminating knowledge about neurodevelopmental and mental health disorders in children and adolescents with CHD to both healthcare professionals and affected families to support early identification and reduce stigma. Online resources can provide easily accessible, tailored information and are, along with the paediatric cardiologist, the most used source of information about CHD and associated challenges for parents.¹⁸ Additionally, adolescents generally find online mental health resources useful.¹⁹ We could only identify four English-language information sites targeted adolescents with CHD and their families on psychological aspects of living with CHD and with succinct information on stress, anxiety, and depressive symptoms. Despite attention deficit hyperactivity disorder and autism being the most well-documented neurodevelopmental comorbidities of CHD, no information hereof was identified.

This study aimed to (1) develop and (2) test the usability and acceptability of a website with Danish informational material on neurodevelopmental disorders mental health disorders, targeting adolescents, parents of children and adolescents with these problems, and various professionals.

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Materials and method

Setting and project group

This study, approved by the Data Protection Agency at Aarhus University and Central Denmark Region, is part of the *Mind the Heart* project (ClinicalTrials.gov Identifier: NCT05709470), which aims to test the feasibility of an online screening programme for common mental health disorders in children and adolescents with CHD. The website was collaboratively developed by the Department of Child and Adolescent Psychiatry at Aarhus University Hospital Psychiatry, Denmark, and the Department of Cardiothoracic Surgery at Rigshospitalet, Copenhagen, Denmark. The project group included specialists in child and adolescent psychiatry and CHDs.

Study design

To integrate needs, perspectives, and lived experiences of proposed end-users, the website, named *Mind the Heart*, was developed in an iterative design process aided by (1) parents of children and adolescents aged 0–17 with CHD, (2) adolescents aged 13–17 with CHD, (3) and professionals from different health care sectors, working with young people with CHD. The development included three phases: (A) preparation, (B) iterative cycles to develop first prototype, and (C) evaluation by end-users (See Figure 1).

Phase A: preparation

Review of existing literature and online resources

This step involved publication of a systematic review on mental health disorders in children and adolescents with CHD.³ Additional searches covered existing online materials on mental health issues in this group (see Supplementary 1), browsing relevant terms such as “CHD,” “young,” “adolescent,” “mental,” and “coping.” Scientific literature on potential aetiological factors and Danish national treatment guidelines for mental health disorders in young people were also reviewed.²⁰

Interviews with end-users

Website content was shaped by insights from interviews with three key user groups. Parents ($n = 7$) of children and adolescents with CHD and current/prior mental health issues (as defined by parental reports of child difficulties in the areas of emotions, concentration, behaviour or ability to get on with others) and adolescents ($n = 2$) with CHD and current/prior mental health issues (as defined by self-report). Parents and adolescents were recruited through a Danish online magazine for parents of children with CHD, a paediatric cardiology outpatient clinic at Aarhus University Hospital, and professional networks. The participating parents had a median age of 46 (range 39–57), with 85.7% being female. Their children had a median age of 13 (range 7–17); 37.5% had simple CHD, and 62.5% had complex CHD or cardiomyopathy diagnosed within the first year. Healthcare professionals ($n = 9$) were recruited through professional networks and represented different sectors (three [33.3%] from primary care, six [66.6%] from tertiary care) and professions (paediatric cardiologists [$n = 3$], general practitioners [$n = 2$], paediatric cardiology nurses [$n = 3$], and school psychologist [$n = 1$]). Seven (77.8%) were female, and five (55.5%) worked full-time in the field of paediatric cardiology.

A semi-structured interview guide was created for each group of end-users. For parents and adolescents, it had two parts: one on lived experiences (parents' guide for the qualitative study on lived experiences²¹ accessible at Open Science Framework, <https://doi.org/10.17605/OSF.IO/93NB6>), and another on their needs and

preferences for information on the new website. The guide for healthcare professionals focused on their experiences with young CHD patients with mental health disorders and the information they deemed important for the website for both professionals and families. All interviews were performed by JLH and SLJ and took place either online or in a hospital setting from November 21 to September 2022. Key points for each group of end-users were synthesised and categorised by JLH, then combined across user types. The final website categories were discussed by the entire research group.

Phase B: iterative development

The website content was generated based on Phase A results through iterative discussions and rewrites within the project group. A social worker specialised in child and adolescent psychiatry provided further insights on social support. The Patient Education Materials Assessment Tool²² was used as a guide to increase clarity and understandability, resulting in a first draft, which was subsequently refined and shortened by two communication specialists at Rigshospitalet in Copenhagen, Denmark.

Phase C - evaluation

In phase C, the first prototype of the website was evaluated based on a questionnaire survey targeting parents of children with a CHD and healthcare professionals working in the field of paediatric cardiology in Denmark.

Participant recruitment

Parents of children with CHD were recruited via flyers at two outpatient tertiary children's cardiology departments and a Danish Heart Foundation event in August 2023. Paediatric cardiologists, cardiologists, and cardiology nurses seeing children with CHD were recruited from all centres in Denmark.

Usability and acceptability

Two measures were applied to assess usability and acceptability of the website prototype:

- (1) The System Usability Scale, translated and validated for use in Danish,²³ consists of 10 items rated from strongly disagree (1) to strongly agree (5). Each item is a simple statement about usability (e.g., “I thought the system was easy to use”). The System Usability Scale score is calculated in two steps by adding odd-numbered questions (one subtracted from the response) with even-numbered questions (response subtracted from 5) and multiplying the total by 2.5. The total System Usability Scale score ranges from 0 to 100, with higher scores indicating better usability. A mean score above 71 is considered good.²⁴ In this study, the System Usability Scale was adapted by replacing “system” with “website” in each item.
- (2) A de novo questionnaire with 9 items rated on a 5-point Likert scale (from 1 [*strongly disagree*] to 5 [*strongly agree*]) to cover readability, satisfaction, and perceived usefulness of the website. The items were inspired by questions used in a similar study²⁵ and the Danish version of the Experience of Service Questionnaire.²⁶ Two final questions were open-ended and included “What did you find really good about the website?” and “Was there anything you didn't like or anything that needs improving?”. The questionnaire was pilot-tested prior to the study's commencement.

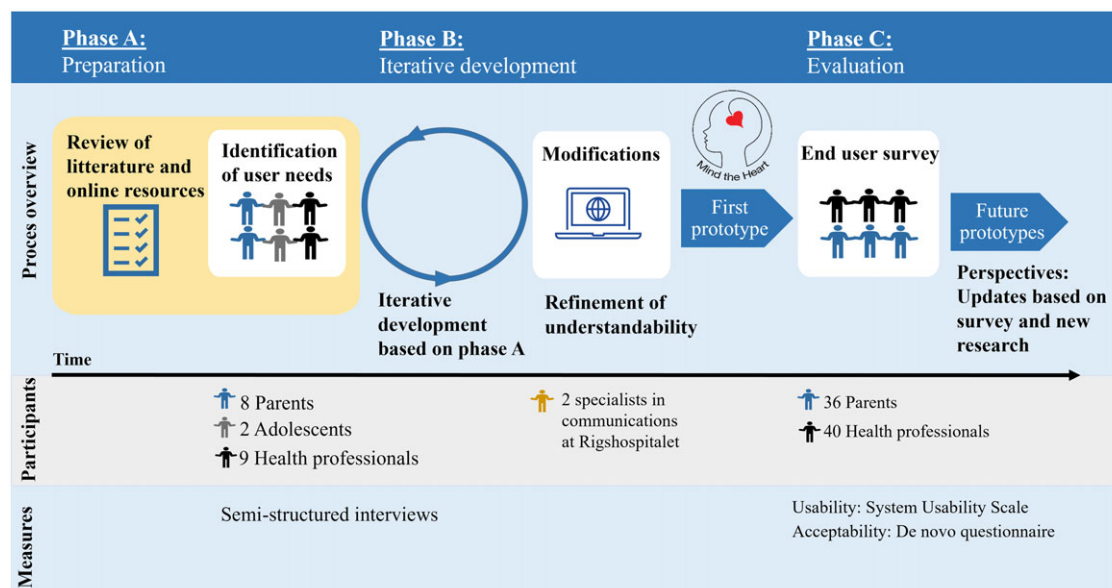


Figure 1. Development of the first prototype of the mind the heart website.

Usage

Usage of the *Mind the Heart* website was measured using the objective Siteimprove Analytics data.

Data collection and analysis

Parents and healthcare professionals completed electronic questionnaires using the secure, web-based software RedCap (Research Electronic data capture),²⁷ hosted by Aarhus University. Parents accessed the questionnaire anonymously via a QR code, while professionals used a personal access code and received four personalised reminders to boost participation.

Statistics

Data from Phase C are presented descriptively with numeric data presented as mean (Standard Deviation) and categorical data presented as numbers (%). Analyses were performed using STATA version 18.0 for Windows.²⁸

Results

Phase A – preparation

Interviews with healthcare professionals, parents, and adolescents identified four key themes for the website: (1) Common signs and symptoms, (2) Information on aetiology, (3) Coping with mental health issues and seeking help, and (4) Dispelling stigma and misconceptions. Healthcare professionals emphasised not causing unnecessary worry and reducing shame while instilling hope. Some were concerned about redundant psychologisation of the children. Parents requested information on preventing mental health issues by reducing psychological distress during postoperative recovery and wanted evidence-based information on the causes of mental health disorders linked to CHD. Both parents and professionals suggested including personal stories from adolescents and families.

Phase B: iterative development

The first prototype of the website was launched in February 2023 and hosted at Rigshospitalet, Denmark, where surgical/

interventional treatment of all children in Denmark with CHD is located (Figure 2).

The website covers the four themes identified in Phase A, with customized language and content tailored specifically for professionals, parents, and adolescents. Adolescent content is shorter and simplified, while professional content avoids medical jargon for readability to teachers and psychologists. The first prototype focuses on four neurodevelopmental and mental health disorders: attention deficit hyperactivity disorder, autism, anxiety, and depression, detailing common signs and symptoms and explanations of the multifactorial nature of these disorders and their potential links to CHD. It provides coping strategies and treatment information for parents and adolescents, while offering professionals advice on supporting families, details about the stepped-care model in mental health care, and guidance on further assistance. Invented narratives based on interviews with parents and adolescents are included to dispel stigma, offer hope, and reassure families that they are not alone (see Supplementary 2 for details). Further, links to other relevant websites are included to provide easy access to sites with more detailed information and self-help resources on mental health disorders in general, i.e., Mindhelper.dk.

Phase C - evaluation of the Mind the Heart website

A total of 84 eligible paediatricians, cardiologists, and cardiology nurses were invited to participate in the survey, with 40 (47.6%) responding. Thirty-eight parents entered the survey, where two provided incomplete data leaving 36 participants for the analyses. Participant characteristics and demographics are summarised in Table 1.

Usability and acceptability

Results on usability and acceptability are summarised in Table 2. The average System Usability Scale scores indicated a good usability. Some of the parents ($n = 22$) and healthcare professionals ($n = 28$) commented in the open-ended questions on what they found good about the website, which concerned usability (easy to navigate) and acceptability (easy to understand, relevant information, differentiated content to end-users). Comments on desired

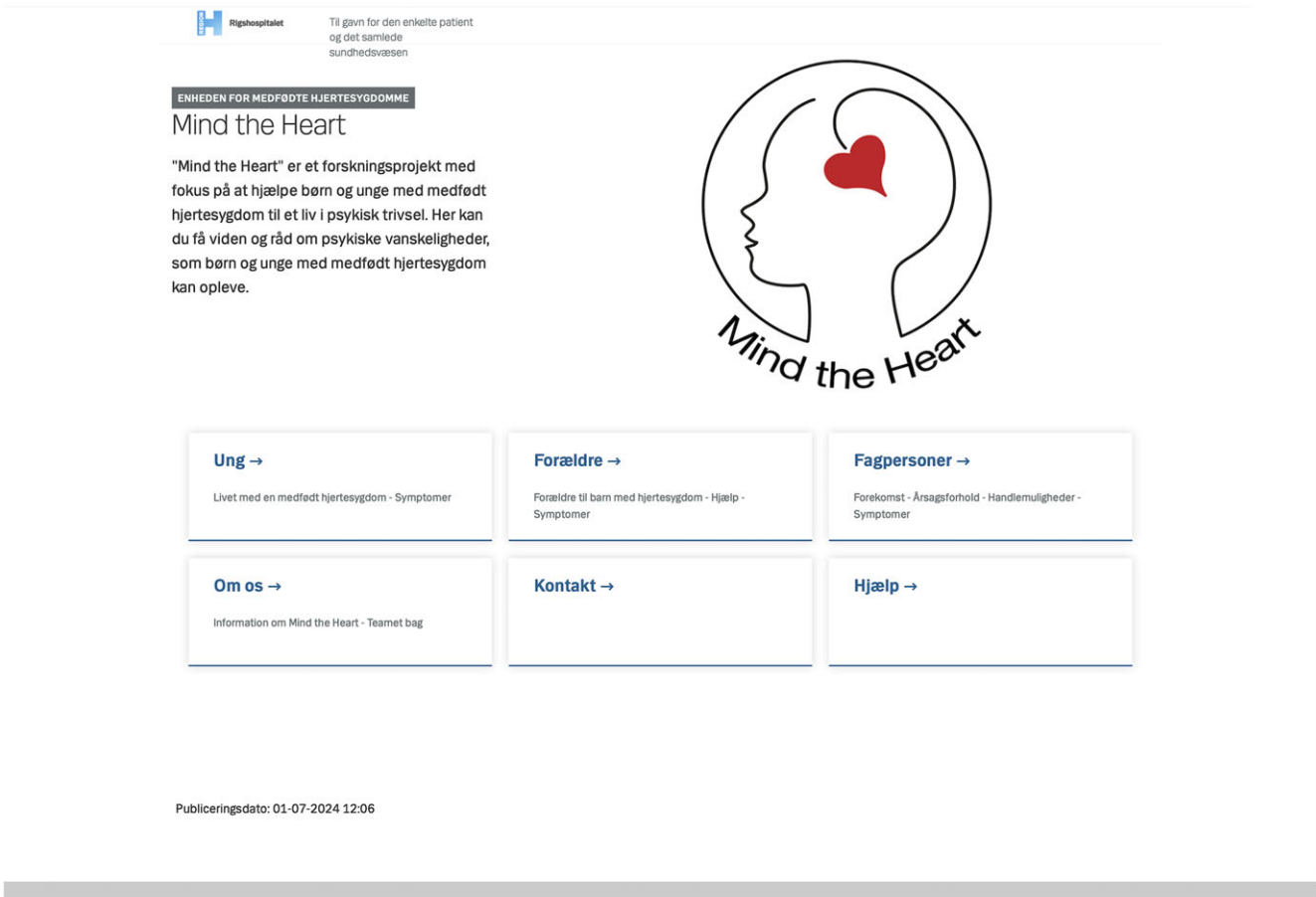


Figure 2. The front-page of the Mind the Heart website. The front-page of the website prototype 1. The three types of end-users are addressed in separate sections where separate buttons indicate the entry for “Adolescents” (Ung→), “Parents” (Forældre→) and “Professionals” (Fagpersoner→). The button named Help (Hjælp→) contains information on where and how to get help. The button named “Contact” (Kontakt→) contains contact information and “About us” (Om os→) provides information on the overall Mind the Heart project.

improvements from parents ($n = 18$) and healthcare professionals ($n = 20$) concerned readability (simplify language, short videos as a supplement to the written), design (more pictures and colours), and content (more invented narratives, more information including on more types of mental health disorders (not specified) and developmental delays, similar information on mental health disorders in adults with CHD), and usability (better navigation options between subpages, assistive tools for dyslexic readers). Four healthcare professionals expressed worries that the website might cause unnecessary worry and lead to psychologisation of children with CHD.

Usage

From launch in January 2022 to July 2024, the website had 10,667 visits from 9,300 unique visitors. The subpages on attention deficit hyperactivity disorder and autism were visited the most.

Discussion

The website provides information on attention deficit hyperactivity disorder, autism, anxiety, and depression to increase awareness and knowledge on presentation, coping strategies, and support resources for these disorders. Invented narratives are included to reduce stigma and offer hope, and explanations on the multifactorial nature of mental disorders and their potential links

to CHD might further reduce self-blame and guilt. In general, the website was usable and acceptable to parents and professionals. The identified topics were based on end-user interviews and included classical components of psychoeducation.²⁹ The content for adolescents was aligned with Lal et al.’s findings, which indicated that young adults experiencing first-time psychosis valued peer-lived experiences and factual information about symptoms, coping strategies, and treatment.³⁰ Similarly, personal stories of hope eased feelings of being alone and hopelessness in adolescents with juvenile arthritis and their parents.³¹ Parents in this study especially appreciated personal stories from other families, links to additional websites, and updates on the latest research, which aligned with the findings on eHealth preferences in parents to children with complex CHD by Kasparian et al.¹⁸ Mothers of children with CHD found that personal stories on CHD experiences reduced feelings of isolation, boosted hope, and enhanced their understanding of their child’s condition,³² and invented narratives in *Mind the Heart* might affect parents of this study in a similar matter. Some healthcare professionals expressed concerns that the website might cause unnecessary worries or psychologisation. Such concerns could potentially hinder a greater focus on the psychosocial well-being of children and adolescents in CHD clinics and warrant further investigation.

Not all aspects suggested in Phase A were included on the website. Thus, parents requested information on preventing

Table 1. Participant characteristics and demographic details in Phase C

	Health professionals <i>n</i> = 40	Parents <i>n</i> = 36
Age, <i>n</i> (%)		
20–30 years	4 (10)	
31–40 years	7 (17)	7 (19)
41–50 years	10 (25)	19 (53)
>51 years	19 (48)	10 (28)
Sex, <i>n</i> (%)		
Female	27 (69)	20 (56)
Care level, <i>n</i> (%)		
Secondary/ Tertiary	7 (17)/33 (83)	N/A
Position, <i>n</i> (%):		
Resident or fellow MD	4 (10)	N/A
Attending MD	17 (42)	
Nurse	19 (48)	
Full-time occupation in paediatric cardiology, <i>n</i> (%):		
Yes/ No	18 (45)/22 (55)	N/A
Experience within paediatric cardiology, <i>n</i> (%):		
<1 years	5 (12)	N/A
1–3 years	4 (10)	
4–10 years	13 (33)	
>10 years	18 (45)	
Experience level on use of computer, mean (SD)**	4.6 (0.5), <i>missing</i> = 3	4.2 (0.9), <i>missing</i> = 1
Experience level on use of Internet, mean (SD)***	4.6 (0.5), <i>missing</i> = 1	4.4 (0.8)
Highest level of education, <i>n</i> (%)		
Vocational education and training	N/A	9 (25.0)
Lower secondary, general upper secondary and academy profession programmes		7 (19.5)
Professional bachelor's programmes		12 (33.3)
Bachelors' and Masters' programmes		8 (22.2)
Children's age, <i>n</i> (%)		
0–10 years	N/A	11 (31.4)
11–15 years		11 (31.4)
16–20 years		9 (25.7)
>20 years		4 (11.4)
		<i>missing</i> = 1
Children's sex, <i>n</i> (%)		
Female	N/A	12 (35.29), <i>missing</i> = 2
Children's heart diagnosis, <i>n</i> (%)		
Simple/complex****	N/A	4 (11.1)/32 (88.9)
Parent reported child difficulties in the areas of emotions, concentration, behaviour or ability to get on with others.		
Yes, N(%)	N/A	21 (61.76), <i>missing</i> = 2
Children's psychiatric diagnosis,		
Yes, N(%)	N/A	3 (8.57), <i>missing</i> = 1

** 1 = not at all experienced, 5 = very experienced.

***1 = not at all experienced, 5 = very experienced.

****Simple CHD included atrial and ventricular septal defect. Complex CHD included atrioventricular septal defects (AVSD), transposition of the great arteries (TGA), univentricular heart, coarctation of aorta, tetralogy of Fallot, congenitally corrected transposition of the great arteries (CCTGA), hypertrophic and dilated cardiomyopathy, TGA with VSD and pulmonary stenosis and valve disease.

Table 2. End user survey results (Phase C)

	Health professionals <i>n</i> = 40	Parents <i>n</i> = 36
Usability, mean (SD) (range 0–100)	75 (9.1), <i>missing</i> = 5	73 (12.9), <i>missing</i> = 6
Acceptability, mean (SD)*		
The website increased my understanding of mental health issues in children and adolescents with CHD	3.7 (0.9)	3.8 (0.7), <i>missing</i> = 4
I found the content on the website easy to understand	4.3 (0.7)	4.2 (0.6), <i>missing</i> = 3
I was happy with the content on the website	4 (0.6), <i>missing</i> = 1	3.8 (0.8), <i>missing</i> = 3
The content on the website fulfilled my expectations	3.9 (0.8)	3.5 (0.9), <i>missing</i> = 3
I found the content on the website useful	4.2 (0.7), <i>missing</i> = 1	4.1 (0.7), <i>missing</i> = 3
I was happy with the style of writing on the website	4.1 (0.8)	4.1 (0.7), <i>missing</i> = 3
I was happy with the amount of text on the website	3.7 (1.0), <i>missing</i> = 1	3.7 (0.9), <i>missing</i> = 3
If my child experienced mental health issues, I would use the website	N/A	4.1 (0.6), <i>missing</i> = 3
I will recommend the website to other parents to children with a CHD and mental health issues	N/A	4.3 (0.7), <i>missing</i> = 3
The website helps me advice children and adolescents with a CHD and mental health issues and their parents on where to get help	3.7 (0.8), <i>missing</i> = 1	N/A
I will recommend the website to adolescents and to parents to children and adolescents with a CHD and mental health issues	4.4 (0.7), <i>missing</i> = 1	N/A

*1 = strongly disagree, 5 = strongly agree.

mental health issues by reducing child postoperative psychological distress. Research indicates encouraging effects of family centred care in the paediatric cardiac ICU,^{33,34} and research and implementation of effective practices in paediatric cardiac ICU are strongly encouraged. However, such initiatives are too complex to be distilled into concrete advice on a website and further require specific training of paediatric cardiac ICU health professionals. Likewise, parents requested information on developmental delays. Survivors with complex CHD have significantly higher risks of developmental delays in language and motor skills and cognitive deficits,²⁰ and parents to children with CHD are reported to normalise their child's developmental delays and mental health issues, which might dissuade them from seeking help and thus delay timely support.^{21,35,36} Thus, increased awareness of these issues as well is warranted.

As parents struggle assessing the credibility of online information and view endorsement by health institutions as a mark of quality,¹⁸ hosting the site at an official health institution in Denmark was important despite constraining overall design to the institutional visual identity. Analytics data revealed 9,300 unique visitors since its launch in January 2022. Denmark has about 5,000 children aged 5–17 with CHD, so the 9,300 visitors indicate strong end-user interest and effective dissemination of the website's existence. Preferred pages include those on attention deficit hyperactivity disorder and autism, which fits with estimates of high prevalence of these particular disorders in the CHD population.^{3,4}

Strengths and limitations

Some limitations should be mentioned. Recruiting adolescents for Phase A was challenging, limiting their input on the website content. Adolescents are reported to prefer more engaging, interactive material like videos, animations, and peer communication.³⁷ However, this study prioritised a less costly resource that could cater to a wider range of end-users. Only paediatric

cardiology professionals participated in Phase C, leaving usability and acceptability for other potential users, like teachers and psychologists, unexplored. Further, approximately 50% of invited healthcare professionals in Phase C participated, so we cannot confirm if they represented the entire group. Additionally, both parents and healthcare professionals were experienced internet users. Parents' recruitment at a related seminar may have influenced their interest and understanding of the website. Lastly, more systematic end-user involvement at every development step might have optimised the content and usability further. The study also had several strengths. The research team included researchers with experience in child and adolescent psychiatry (CUR and JLH) and in CHD (VH and SLJ), respectively, ensuring expert knowledge in both fields. Further, participating parents and healthcare professionals in Phase A constituted a heterogeneous group thus broadening perspectives. In Phase C, all medical doctors and nurses in Denmark working in paediatric cardiology were invited to participate, further broadening perspectives on website acceptability and usability.

Clinical implications

Improved awareness and information on mental health disorders in children and adolescents with CHD among healthcare professionals and families may be an important first step towards better psychosocial care for these individuals.

Conclusion and perspectives

In a three-phase process informed by target end-users, we designed a novel website with informational material for professionals and families of children with CHD, covering attention deficit hyperactivity disorder, autism, anxiety, and depression. This first-of-its-kind website offers information on symptoms, aetiology, coping, and treatment of common neurodevelopmental and mental health

disorders in this patient group, enabling actions to improve their mental well-being. Evaluations showed parents and healthcare professionals found the content useful, suitable, and understandable but suggested further improvements in navigation, language, and content. They also worried it might be too text-heavy for adolescents, recommending complementary videos. Moving forward, these suggestions will be considered, along with more narratives and information on developmental delays and various mental disorders as requested by parents.

Supplementary material. The supplementary material for this article can be found at <https://doi.org/10.1017/S1047951124035960>.

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Competing interests. The authors declare none.

Ethical standards. The authors assert that all procedures contributing to this work comply with the ethical standards of the Danish Research Ethics Committee (case no. 1-10-72-274-21) and with the Helsinki Declaration of 1975, as revised in 2008, and has been approved by the Data Protection Agency at Aarhus University (journal no. 2016-051-000001, 2730) and at Central Denmark Region (case no. 759727).

During the preparation of this work, the authors used ChatGPT 4.0 in order to improve language. After using this tool, the authors reviewed and edited the content as needed and took full responsibility for the content.

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