Scand J Pain 2023; 23(4): 646–655 DE GRUYTER

#### **Clinical Pain Research**

8

Eva Laerkner, Laila Bendix, Madalina Jäger, Maj-Britt Hansen and Henrik Bjarke Vaegter\*

# Experience and usability of a website containing research-based knowledge and tools for pain self-management: a mixed-method study in people with high-impact chronic pain

https://doi.org/10.1515/sjpain-2023-0044 Received March 30, 2023; accepted August 24, 2023; published online September 11, 2023

#### **Abstract**

**Objectives:** Smerteinfo.dk is a freely accessible Danish website containing research-based, up-to-date knowledge on chronic pain, written in lay language, with a focus on information, guidance and self-management tools, developed in collaboration between health professionals and persons with high-impact chronic pain. This mixed-method study explored experiences, perceived usability, and challenges of Smerteinfo among patients with high-impact chronic pain. **Methods:** Semi-structured interviews enabling thinking-aloud and participant observation while using Smerteinfo were performed in 11 patients with high-impact chronic pain. Survey data were collected three months after being invited to use Smerteinfo among 200 patients on waiting-list at a Pain Center in Denmark.

\*Corresponding author: Henrik Bjarke Vaegter, PhD, Department of Clinical Research, Faculty of Health Sciences, University of Southern Denmark; and Pain Research Group, Pain Center, Odense University Hospital, Heden 7–9, Indgang 200, DK – 5000 Odense, Denmark, Phone: +45 65413869, Fax: +45 65415064, E-mail: hbv@rsyd.dk. https://orcid.org/0000-0002-7707-9947

**Eva Laerkner**, Department of Anesthesiology and Intensive Care, Odense University Hospital, Odense, Denmark; and Department of Clinical Research, Faculty of Health Sciences, University of Southern Denmark, Odense, Denmark

**Laila Bendix**, Pain Research Group, Pain Center, Odense University Hospital, Odense, Denmark

Madalina Jäger, Department of Sports Science and Clinical Biomechanics, Research Unit for Musculoskeletal Function and Physiotherapy, University of Southern Denmark, Odense, Denmark; and Department of Physiotherapy and Occupational Therapy, Næstved-Slagelse-Ringsted Hospitals, Slagelse, Denmark

**Maj-Britt Hansen**, Patient and Relative Panel, Pain Center, Odense University Hospital, Odense, Denmark

**Results:** Three themes captured the depth and variation in patterns of experiences, usability and challenges using Smerteinfo during interviews: 1) Appreciated easy access to new knowledge yet strived for more personalized information, 2) Experienced incentives as well as challenges when navigating the website, and 3) Suggested earlier introduction to the website. Challenges concerned the unknown update frequency of the website, information consisting of mostly text and many links, lack of material to improve selfmanagement and too general information. Survey data revealed that 87 % found the language in the articles easy to understand and 73 % could recognize themselves and their challenges in the articles. A proportion of the respondents reported improved understanding of their pain condition (56%), improved coping (33%), and that they had made changes in their everyday life after reading on the website (33 %).

**Conclusions:** Patients with high-impact chronic pain found Smerteinfo valuable. The results suggest attention towards spreading knowledge of the website to general practitioners, who could introduce the site at an earlier stage of illness. Continuously improving the site and expand the applicable tools based on scientific evidence and in collaboration with end-users are crucial to ensure the usability of the website in the future.

**Keywords:** chronic pain; pain science education; self-management; Smerteinfo

## Introduction

Chronic pain constitutes an increasing health and social burden in Scandinavia [1]. In Denmark, more than one million people are living with chronic pain [2, 3]. In 2020, The Danish Health Authority estimated that the annual costs associated with chronic pain were DKK 17.8 billion [4], which exceeds the combined economic burden of heart disease and cancer [5]. The majority of individuals with chronic pain are

treated in the primary care sector, with a smaller part attending hospital departments (e.g., rheumatology or neurology) in secondary care. Because various biopsychosocial factors contribute to chronic pain [6] clinical guidelines recommend referral to interdisciplinary pain management programs in secondary or tertiary care settings for patients who do not benefit from primary care treatments [7, 8]. Some of these people are heavily burdened by the pain condition. They have high levels of disability and a low quality of life [9]. Inactivity and social isolation are common consequences of chronic pain, as are symptoms of anxiety and depression [10]. Chronic pain is also associated with high consumption of opioids and health care utilization, as well as a significantly increased risk of exclusion from the labor market [1, 2, 9, 11]. Based on recent data from the USA, approximately 5 % of the population report high-impact chronic pain, defined as persistent pain with substantial restriction of life activities lasting six months or more [12], indicating that 300,000 Danes above 18 years of age suffer from this condition and may need specialized pain treatment. However, systematic reviews have shown that such programs are not easily accessible [13] due to low capacity leading to long waiting time at the few interdisciplinary pain centers available. During this period, it is well known that chronic pain and the consequences often worsen [14]. Thus, easily accessible and safe treatment options for a patient group with few effective treatment options are needed.

Evidence-based guidelines recommend that people receive education about their pain condition and its prognosis to facilitate pain self-management of the condition [15]. Pain science education re-conceptualizing the threat value of chronic pain combined with self-management strategies is a well-documented intervention for chronic pain [16]. From daily contact with people living with chronic pain, we also know that there is a great need for access to research-based knowledge about chronic pain, and that patients ask for methods and tools by which they can actively achieve a greater degree of "self-control" and feel more confident about their pain condition. These needs have also been documented in previous studies [17, 18]. Digitally delivered pain education and self-management strategies is an independent and scalable intervention that can be delivered at home, either before, simultaneously or after other pain treatments, and overcomes the significant cost and limited access of face-to-face consultations. The effectiveness of digitally delivered pain education on pain and disability is supported by a recent systematic review with meta-analysis [19] showing that web-based stand-alone interventions provide small improvements in pain intensity and disability and thus should be considered in overburdened health systems. Thus, in collaboration with a patients and relatives advisory panel, the Pain Center at Odense University Hospital in Denmark has developed Smerteinfo.dk (Eng. Pain info), which is a freely available digital website containing research-based, up-to-date knowledge on chronic pain, written in lay language, with a focus on information, guidance and self-management tools (Figure 1). To gain knowledge to further develop the usability of the

The site was designed to meet the cognitive challenges experienced among people living with chronic pain:

- Short texts short paragraphs
- Illustrations supporting the
- Animations
- Possible to choose "read aloud" function
- Possible to switch between bright and dark background
- Theme articles guiding the reader
- A toolbox consisting of selfhelp activities

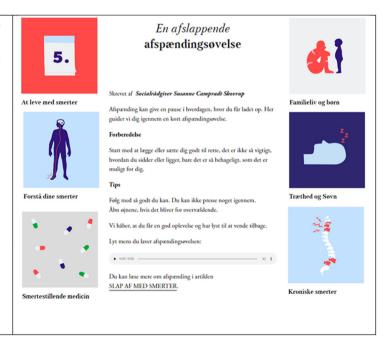


Figure 1: The Smerteinfo website.

website, this mixed-method study explored experiences, perceived usability, and potential challenges of Smerteinfo among people living with high-impact chronic pain.

# Methods and materials

This study employed a mixed-method design guided by the paradigm of pragmatism [20]. The rationale was to provide depth and breadth to the experiences and usability of a website containing evidence-based selfmanagement tools for people living with high-impact chronic pain.

The study had an exploratory sequential design [21], where the first qualitative phase combined semi-structured interviews and participant observation that mutually informed each other. This part was independently followed by a survey, providing merely a numeric, descriptive representation of the experiences of using the Smerteinfo website, which constituted the second quantitative phase of the study. By triangulating and integrating results from both the qualitative and quantitative part of the study, this sequential approach enabled us to achieve a comprehendible understanding of ways in which people with pain utilized the Smerteinfo website. We completed the checklist Good Reporting of A Mixed Methods Study (GRAMMS) to ensure the quality of the study [22] (Supplementary File).

#### Data collection and participants

The participants in the first, qualitative part were people living with high-impact chronic pain, who had just been enrolled in the Pain Center at Odense University Hospital. They were invited to participate in the interview when they completed the clinical questionnaire (PainData) [9] prior to commencing treatment in the Pain Center. Individuals who consented to participate were contacted by phone by a nurse from the pain center to provide further information about the interview, confirm participation and schedule time and place. Participants were purposively sampled, as we strived for variation in age, gender, duration of pain and current work status to enhance information power [23]. We chose individual semi-structured interviews to gain insight into the participants' experiences [24]. EL is an experienced interviewer and had no prior knowledge to any of the participants before conducting the interviews. The semi-structured interview guide (Supplementary File 1) was composed as to explore the participants' own experiences, usability and challenges using the website. It contained questions about their pain experience and everyday life as introduction, followed by questions about how they were introduced to the website, how they experienced the site, what worked well and what could be improved, as well as if they missed something on the website or could suggest improvements. All interviews were digitally recorded and transcribed verbatim. All participants were given the opportunity to comment on their transcribed

To enhance data richness about usability and challenges, we combined the interviews with observations of the use of the site. During the interview, the participants were encouraged to enter the website on whatever digital platform (smartphone, tablet or computer) they preferred. This way, they could "think aloud" [25] during the interview, while navigating on the site and reflect openly about their experiences and challenges using the site. The interviewer observed how the participants navigated on the site, supported by an observation guide (Supplementary File 2) inspired by the dimensions; activity, object,

goal, actions and emotions [26]. Observational notes of actions and expressions using the website during the interview, enabled us to capture contextual aspects and non-verbal activities while visiting the site.

The second, quantitative part was survey data collected consecutively among patients referred to the Pain Center. All newly referred patients (n=392) from January 1st 2022 to June 30th 2022 received an invitation letter in their e-books (official digital inbox used in Denmark) within 48 h after referral from their general practitioner, inviting them to visit the website (www.smerteinfo.dk) while they were waiting for their appointment at the Pain Center. A total of 370 letters were sent as 22 persons were not signed up for the use of e-books. Three months after the invitation letter a link to the survey about experience and usability was sent to their individual e-books. The questions in the survey were informed by The Generic Short Patient Experiences Questionnaire [27] with 5 point Likert scale response options (not at all to very much). In addition, two 0-10 numerical rating scale questions (How likely is it that you will use Smerteinfo in the future? and How likely is it that you will recommend Smerteinfo to others?) based on the Net Promoter Score (NPS) categorizing patient's response into promotors (response: 9 or 10), passive (response: 7 or 8) or detractors (response: 0-6) were also used [28].

#### **Analysis**

We analysed the data and presented the results from the qualitative and quantitative parts independently, followed by an integrated interpretation of the results [21]. Here we identified consistency and divergence complementing the qualitative and quantitative results.

Interview and observation notes from each interview were merged and analysed as text using an inductive, thematic analysis inspired by Braun and Clarke [29, 30]. EL and MJ did the initial analysis in close collaboration. Firstly, we read the transcripts and notes several times to become familiar with the data, secondly we coded data manually using schemes according to the aim of the study. Thirdly, we grouped coded data into preliminary themes on big whiteboards. Fourthly, all members of the study-group including a patient representative (MH) living with chronic pain discussed and reviewed these initial themes into sturdy themes across the data. This was an ongoing process where we constantly went back and forth between data and themes to ensure reflexivity and coherence in the development of themes in correspondence to explore the experiences, usability and challenges with use of the Smerteinfo website as addressed by the participants. Finally, we selected illustrating quotes to support the identified themes and to ensure transparency and consistency between data and the analytical work of emerging themes. Survey data were analyzed with descriptive statistics and reported in tables and figures as count and percentages.

## Results

#### Qualitative results

This part of the study was conducted from October to end of December 2021. A total of 27 persons with high-impact chronic pain were approached. Of these, 13 declined to participate and three withdrew their participation due to lack of physical and mental energy at the time of the study.

Eleven persons participated (Table 1). The interviews took place in an office in the pain center (n=3) or in the participants' own homes (n=8) on their request. The interviews lasted between 33 and 107 min. Two participants wished to read their transcribed interview, but had no comments to the content.

We identified three themes capturing the depth and variation in patterns of experiences, usability and challenges in using the website. Table 2 illustrate the connection between data examples from interviews and observations and the emerged themes.

## Appreciated easy access to new knowledge yet strived for more personalized information

The participants stated that it was trustworthy that the authors of the website were health professionals, who have clinical experience with chronic pain. Moreover, it was important that the site was developed in collaboration with people, who themselves experienced high-impact chronic pain. Participants raised concerns towards how often the website was updated with evidence, since they strived for new information about treatment of chronic pain.

The language was understandable and the information was of an appropriate length on the site. Participants revealed that reading long texts could be difficult, since some of them struggled with cognitive challenges such as difficulty concentrating. The information on the site was valuable, but maybe too general. The participants felt that the information was nice to know but somewhat difficult to relate to their own situation. They requested more personalized information regarding their specific pain and challenges in everyday life. Especially, the toolbox on the site was perceived as too superficial and it did not provide enough material to improve self-management.

## Experienced incentives as well as challenges when navigating the site

The participants appreciated several of the visual and auditory effects on the site. The ability to change the background light and the opportunity to have some of the articles read aloud were highlighted as particularly important for people with chronic pain, who could experience challenges with light sensitivity and concentration.

Some of the participants felt challenged that the information on the site was mostly text, because the extensive reading could be overwhelming due to the cognitive deficits. The participants suggested that more information could be through short movies, pictures and interactive models.

Table 1: Demographic characteristics of interview and survey study participants.

	Interviews (n=11)	Survey total	Did visit Smerteinfo	Smerteinfo
		(n=190)	(n=115)	(n=75)
Age (years)	44.5 ± SD	51.8 ± 13.9	51.3 ± 13.6	53.5 ± 14.2
(mean, SD,	(29-59)	(20-82)	(22-81)	(21-82)
range)				
Gender				
Female, %	72.7	66.7	68.7	61.3
Male, %	27.3	33.3	31.3	38.7
Marital status				
Single, %	36.4	33.8	32.9	34.0
Married/living	63.6	66.2	67.1	66.0
with partner, %				
Employment				
Normal working	27.3	16.5	15.9	17.0
hours, %				
Reduced work-	18.2	3.8	0.0	10.6
ing hours, %				
Sick leave (part	36.3	17.3	17.1	14.9
time or full				
time), %				
Public support	18.2	18.8	24.4	10.6
(other than sick				
leave), %				
Retired, %		18.9	26.8	31.9
Studying, %		4.5	6.1	2.1
Unemployed, %		3.8	2.4	6.4
Other, %		6.8	7.3	6.4
Education				
Primary school	9.1	9.8	9.8	10.6
education, %				
Upper second-		8.3	9.8	6.4
ary education, %				
Vocational edu-	18.2	27.8	28.0	27.7
cation and				
training, %				
Short cycle ed-	27.3	11.3	12.2	8.5
ucation, %				
Vocational	36.3	32.3	35.4	29.8
bachelor educa-				
tion, %				
Masters pro-	9.1	5.3	1.2	8.5
gram, %				
Other, %		5.3	3.7	8.5

The participants found the site a bit difficult to navigate, and mentioned that the many links in the texts to some extend made the site incoherent and sometimes confusing.

#### Suggested earlier introduction to the site

The participants found that the site could be useful for people living with chronic pain. The different topics

Table 2: Qualitative analysis with themes.

Quotations from interview	Coding	Theme		
"But I think that it (the site is authored by health professionals and people living with pain in collaboration) <sup>a</sup> is important. That there is someone behind, who knows what they are talking about. I must honestly admit that. Because it makes me know that I can trust what they write" (Participant 6)	Trusting the site	Appreciated easy access to new knowledge yet strived for more personalized information		
The toolbox is probably the most important part for me, but it is too empty [activating the "toolbox" showing six topics]. I would like this part to be more developed (Participant 9)	Seeking more tools			
" depending on whether you find something that you can use (on the site), then you might get back to it, and if you don't then the chance is probably small. It could also be that you could create some kind of profile, where you could point out what your particular interest is. Mine is headache and if something new comes up that fits into the headache category, I could receive an email" (Participant 11)	Strived for Personal- ized information			
"So I actually like that you, up here in the corner [Moves the cursor up to the right corner of the page] can switch to light and dark [the background change between light and dark]. Because it's really nice for the eyes. I also know there are people with migraines who need this" (Participant 7)	Adjusting the light	Experienced incentives as well as challenges when navigating the site		
"I do find it very confusing [Points the cursor on "themes" and enter into the heading "understand your pain"] that is, when I read personally I do not like to read a text where there are many links to something else [Activating the link "Is chronic pain dangerous?"] because then I jump back and forth all the time. Then I feel that there is no coherence in the subject" (Participant 4)	Too many links			
" and it is also, with the knowledge they (the Pain Center) have to make such a page [Pointing at Smerte.info] available while waiting (From referral to consultation in the Pain Center), right? It (Smerte.info) can be a support for someone" (Participant 9)	Early support	Suggested earlier introduction to the site		
"So it (Smerte.info) has to "be sold" (Talking about that persons with chronic pain and their relatives should be made aware of the site), because it is a useable website. That's for sure" (Participant 2)	Useable website			

<sup>a</sup>Brakets (...) contains contextual information from the interviews to enhance understanding of what the participants talked about. <sup>b</sup>Square brackets [..] captures the observations made during the interview.

concerning pain treatment, everyday life with chronic pain addressing work and family issues as well as the toolbox were all perceived as highly relevant. However, none of them had heard about the site before they were referred to the Pain Center. At that time, most of them had lived with chronic pain for a long time, and some of the information on the site was no longer relevant. The participants suggested that people with chronic pain should be introduced to the site earlier in the illness trajectory, e.g. by their general practitioner.

Moreover, the participants highlighted the importance of introducing the site to their relatives and network. They addressed how the information on the site could be useful for others, such as general practitioners and counselors in the municipality, who are in contact with people with chronic pain. Even though the site is freely accessible on the internet, the information about the site could be improved so more people would benefit from it.

#### **Quantitative results**

This part of the study was conducted from April 2022 to end of September 2022. Out of the 370 invited patients, 200 (54 %; Table 1) responded to the survey. In total, 159/200 patients (80 %) reported having read the invitation while 30 (15%) reported that they did not read the invitation and 11 did not provide an answer. One hundred fifteen patients/ 200 (58%) reported having visited the website while 75 patients expressed that they did not (10 patients did not respond to this questions). Most of the participants not visiting the website quoted forgetfulness as the main reason for not visiting the website (38/75, 51 %). In total, 104 of the 115 participants answered a question regarding which article they remembered reading on Smerteinfo website. Most of them remembered having read articles about living a better life with pain (84%), cognitive disturbances (77%), being physically active (75%) and sleep

and chronic pain (73 %). 84/115 patients responded that they could recognize themselves and their challenges somewhat, a lot or very much in the articles read on the website. Moreover, 100 patients (87%) found that the language in the articles was easy to understand. Improved understanding of their pain condition after reading on the website was reported by 56 % of patients, and 38 patients (33 %) reported improved coping after visiting the website. One third of the patients (n=37) visiting the website reported that they had made some kind of changes in their everyday life after reading information on the site (Table 3). Thirty four patients were categorized as promotors for the question How likely is it that you will recommend Smerteinfo to others? (Figure 2). The calculated NPS was -6.1.

# Integration of qualitative and quantitative results

#### Consistency

Both quantitative and qualitative results showed how the participants found the site valuable. Almost nine out of 10 patients found that the language in the articles was easy to understand. This corresponds well with the qualitative findings where participants expressed that the site was relevant, and the length and the language of the information were appropriate according to persons with high-impact chronic pain, who could experience cognitive challenges.

Several respondents reported improved understanding of their pain condition, improved coping, and that they had made changes in their everyday life after reading on the website. These advantageous quantitative results is in line with the qualitative findings, suggesting that the site is highly relevant for some people living with chronic pain,

because it covers different topics concerning pain treatment and everyday life. Moreover, the quantitative results strengthens the qualitative theme suggesting an earlier introduction to the site. Here, persons with high-impact chronic pain may improve their understanding as well as become better to manage their pain by reading the information on the site earlier.

#### **Divergence**

The results are divergent in the way that one out of three respondents reported that they had become better at managing their pain after reading on Smerteinfo. This positive feedback was not captured in the qualitative findings, where the participants perceived the toolbox superficial and the site too general and strived for more personalized information. This is to some degree in contrast with the quantitative results where more than 70 % could recognize themselves and their challenges in the information on the site.

## **Discussion**

Based on a mixed-method approach, we explored the experiences of people living with chronic pain, their perceived usability and potential challenges using the freely accessible website Smerteinfo. Persons with high-impact chronic pain found the website valuable as it contained important information and relevant support tools. The usability of the website was assessed quite high for some participants. The fact that the website was developed in collaboration between health professionals with special interest in chronic pain and persons with high-impact chronic pain was highlighted as important in this study, and made the site trustworthy. This correspond well with other studies pointing at

Table 3: Survey results presented as counts and percentage.

Survey item/response	Not at all	A little	Somewhat	A lot	Very much	Missing
Can you recognize yourself and your challenges in the articles you have read on Smerteinfo?	4 (3.5 %)	14 (12.2 %)	14 (12.2 %)	44 (38.3 %)	26 (22.6 %)	13 (11.3 %)
Are there topics on Smerteinfo that are relevant to you?	6 (5.2 %)	10 (8.7 %)	24 (20.9 %)	44 (38.3 %)	20 (17.4 %)	11 (9.6 %)
Have you improved your understanding of your pain after reading on Smerteinfo?	12 (10.4 %)	33 (28.7 %)	38 (33.0 %)	15 (13.0 %)	5 (4.3 %)	12 (10.4 %)
Have you become better at managing your pain after reading on Smerteinfo?	31 (27.0 %)	33 (28.7 %)	32 (27.8 %)	5 (4.3 %)	1 (0.9 %)	13 (11.3 %)
Have you made any changes in your everyday life after reading on Smerteinfo?	33 (28.7 %)	32 (27.8 %)	27 (23.5 %)	7 (6.1 %)	3 (2.6 %)	13 (11.3 %)

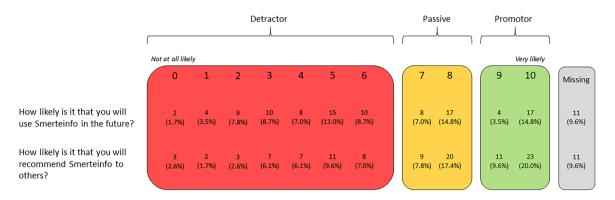


Figure 2: Categorization of Net Promotor Score (count and percentage).

the growing field of digital health offers to people with chronic pain, where aspects such as proceeding from official and public health care combined with end-user experiences were considered believable and trustful [31–33].

This is supported by other studies arguing for cocreation between health professionals and end-users of digital health solutions targeted people with chronic pain [31, 32, 34]. This way, the website will be tailored to meets the users' special challenges. In our study aspects such as the language and length of the written information as well as the visual and auditory effects on the site were emphasized as advantageous. These customized features may meet some of the challenges people with high-impact chronic pain experience such as tiredness, lack of concentration and light sensitivity [35].

The addressed challenges concerned the unknown update frequency of the website, information consisting of mostly text and many links, lack of material to improve selfmanagement and too general information on the website. According to Hurley-Wallace and colleagues, people with chronic pain often seek for novel information about treatment options and applicable self-management solutions online [32]. These aspects may influence the usability of Smerteinfo and require frequent updates with new evidence and expansion of the toolbox, which interview participants found too superficial. Our results indicated that navigating on the website could be a challenge, which may impede the immediate usefulness of the website for people with highimpact chronic pain. Other studies points to the importance of having time to get to know the digital health solution [36–38]. This is supported by the quantitative results in our study, where having the opportunity to be acquainted with the website over a longer period of time did improve some users understanding of and coping with pain in everyday life. In our study, concern was raised regarding the website being too general. Since the website is non-interactive and addressed to people with chronic pain in general it might be

difficult to capture the personal needs of people with specific pain problems. This is similar to the study of Hurley-Wallace and colleagues [32] where young people stated that they diverted away from the website authored by the National Health Service because it was lacking detailed information on chronic pain and only provided treatment options they considered basic or generic. Fernandes and colleagues pointed at impersonal and disengaging websites as barriers to user-engagement [37]. Interestingly, we found that the majority of participants, who had visited the website, at least somewhat could recognize themselves and their challenges in the information provided on Smerteinfo. Concerns about the website may explain why less than 25 % of the persons, who had visited Smerteinfo reported that it is very likely that they would visit the site again, and less than a third were very likely to recommend the site to others. This correspond to the calculated NPS of -6.1 which is low in user-satisfaction indicating that the website still needs some improvements to be valuable for more people with high-impact chronic pain. However, the NPS can be used as a benchmark in evaluation of the website in the future [39].

Our study showed promising results on what digitally provided information can achieve. Half of the people, who had visited the website, reported that they had improved their understanding of pain after reading on Smerteinfo. More than a third described that they at least somewhat had become better in managing their pain. Finally, more than half of the people, who had visited the site had made at least a little change in their everyday life subsequently. The beneficial effects of digital health solutions among people with chronic pain has been confirmed in recent systematic reviews [19, 40]. The ability to access information and guidance about pain-management being at home in a wellknown environment in a personal place may empower people with chronic pain and enhance their self-efficacy in everyday life [31, 32, 36, 37]. Digital health as Smerteinfo may be a low-cost way to promote support and knowledge in a

clinical area with few specialists and long waiting lists for consultations in specialized Pain centers. In Denmark, 97 % of families have access to digital media by smartphone or computer [41]. This provides good opportunities for disseminating knowledge of the website among people with chronic pain. Especially introducing the site at an earlier stage in the illness trajectory was highlighted in this study. This is supported by the study of Ma and colleagues exploring primary health care providers' perceptions of applying digital therapeutics for Chronic Pain. Here, digital solutions to support, educate and help people manage their pain were found to be a promising alternative in primary care [42]. Even though almost everyone in Denmark has personal access to the internet, only providing digital information and support may exclude people with chronic pain who have lessened health literacy or are too challenged to apply digital self-help and thereby increase inequality in health [43].

# Strengths and limitations

A strength in this study is the mixed-method approach applying a triangulation of methods capturing both numerical and detailed descriptions from people with high-impact chronic pain concerning their experiences, perceived usability and challenges with the website Smerteinfo. This corresponds to the overall aim of mixed method studies, where qualitative and quantitative methods mutually inform each other to develop a more comprehensive understanding [44].

Another strength is the long and comprehensive individual interviews combined with observations in the qualitative part enabling the participant to think aloud while visiting the website, which enhanced information power of the study [23]. On the other hand these long interviews with both talking about and going through the website could have been too exhausting for the participants, since they were all suffering from high-impact chronic pain which often is accompanied with cognitive impairment [35]. This could have affected the participants' ability to navigate the site and thereby influenced the challenges mentioned in the results.

The sequential mixed-method design has some limitations. Firstly, the participants were recruited on different stages in their referral to the Pain Center. The participants in the qualitative part of the study were recruited after they had been in touch with the Pain Center and most of them only had a chance to get a short glance at the site before the interview. This way, the site was rather unfamiliar. This is different from the participants in the survey, as they got access to the site while they were on a waiting list to a consultation in the Pain center. This group was introduced to the site three months before the survey. This implied, that they had more time to get to know the site and immerse in the information and try out the initiatives mentioned in the toolbox. These different timeframes getting acquainted with the website could explain some of the differences stated in the result section. Secondly, during the time between the qualitative and the quantitative parts of the study, some changes inspired by the interviews were made on the Smerteinfo website (e.g. improved toolbox and more videos added). This way, the participants in the two parts of the study did not visit the exact same website. This could explain some of the differences in the results, where participants in the qualitative part expressed concern with the superficial toolbox. This is contrary to the participants in the quantitative part, were the majority of the persons had made at least small changes in everyday life and even a little improvement in understanding their pain after visiting the site.

We only explored the usability of the website for persons, who were on a waiting list or already seen in a single consultation in the Pain Center. However, the promising results for some persons prior to their consultation in the Pain Center, could be an argument for recommending the website to persons with high-impact chronic pain in general.

# **Conclusion and implications**

In conclusion, this study demonstrated that Smerteinfo is a valuable and useful Danish digital website to support knowledge distribution and self-management to improve living and coping with pain in everyday life among people with high-impact chronic pain. Some people with chronic pain may be empowered and improve their understanding of pain or even make changes in everyday life based on the knowledge and guidance on the website.

Implications of this study implies attention towards spreading knowledge of the website to general practitioners, who could introduce the site to people with chronic pain in an earlier stage of their illness. Furthermore, Smerteinfo needs to find a balance between general and customized information about chronic pain to support familiarity and preserve the interest of the potential users. Continuously improving the site and expand the applicable tools based on scientific evidence and in collaboration with end-users are crucial to ensure the usability of the website in the future.

**Research ethics:** The Danish Data Protection Agency approved the data collection (ref. no. 21/55999), and the conduct of this study complied with the Declaration of Helsinki. As treatment was not affected by participation in the study, under Danish law, this study did not need ethics approval (Act on Research Ethics Review of Health Research Projects, October 2013, Section 14.2).

Informed consent: Written informed consent was obtained from all participants included in this study.

Author contributions: All authors discussed the results and commented on the manuscript. All the authors have accepted responsibility for the entire content of this manuscript and approved its submission.

Competing interests: There are no actual or potential competing interests for any of the authors.

Research funding: The development of smerteinfo.dk was supported by The Philantropic Foundation TrygFonden and The Danish Ministry of Higher Education and Science. No funding was received for this study.

Data availability: Anonymised data is available on reasonable request.

# References

- 1. Breivik H, Collett B, Ventafridda V, Cohen R, Gallacher D. Survey of chronic pain in Europe: prevalence, impact on daily life, and treatment. Eur J Pain 2006;10:287-333.
- 2. Eriksen J, Sjøgren P, Ekholm O, Rasmussen NK. Health care utilisation among individuals reporting long-term pain: an epidemiological study based on Danish National Health Surveys. Eur J Pain 2004;8:517-23.
- 3. Flachs E, Eriksen L, Koch M, Ryd J, Dibba E, Skov-Ettrup L, et al. In: Sundhedsstyrelsen, editor. The Disease Burden in Denmark. Copenhagen: Statens Institut for Folkesundhed, Syddansk Universitet: 2015, vol 2.
- 4. Sundhedsstyrelsen. Afdækning af smerteområdet; 2020. https://www. sst.dk/-/media/Udgivelser/2020/Smerteomr%C3%A5det/Afdaekningaf-smerteomraadet.ashx?la=da& hash=96E2233A389E7711787A43736D68AC3E30420C9C [Accessed 1
- 5. Todd A, McNamara CL, Balaj M, Huijts T, Akhter N, Thomson K, et al. The European epidemic: pain prevalence and socioeconomic inequalities in pain across 19 European countries. Eur J Pain 2019;23:1425-36.
- 6. Meints SM, Edwards RR. Evaluating psychosocial contributions to chronic pain outcomes. Prog Neuropsychopharmacol Biol Psychiatry 2018;87:168-82.
- 7. Chou R, Huffman LH. Nonpharmacologic therapies for acute and chronic low back pain: a review of the evidence for an American Pain Society/American College of Physicians clinical practice guideline. Ann Intern Med 2007:147:492-504.
- 8. Oliveira CB, Maher CG, Pinto RZ, Traeger AC, Lin CC, Chenot JF, et al. Clinical practice guidelines for the management of non-specific low back pain in primary care: an updated overview. Eur Spine J 2018;27: 2791-803.
- 9. Vaegter HB, Christoffersen LO, Enggaard TP, Holdggard DEM, Lefevre TN, Eltved R, et al. Socio-demographics, pain characteristics, quality of life and treatment values before and after specialized interdisciplinary pain treatment: results from the Danish Clinical Pain Registry (PainData). J Pain Res 2021;14:1215-30.
- 10. Sondergard S, Vaegter HB, Erlangsen A, Stenager E. Ten-year prevalence of mental disorders in patients presenting with chronic pain in secondary care: a register linkage cohort study. Eur J Pain 2018;22: 346-54.

- 11. Eriksen J, Sjøgren P, Bruera E, Ekholm O, Rasmussen NK. Critical issues on opioids in chronic non-cancer pain: an epidemiological study. Pain 2006;125:172-9.
- 12. Dahlhamer J, Lucas J, Zelaya C, Nahin R, Mackey S, DeBar L, et al. Prevalence of chronic pain and high-impact chronic pain among adults -United States, 2016. MMWR Morb Mortal Wkly Rep 2018;67:1001-6.
- 13. Fashler SR, Cooper LK, Oosenbrug ED, Burns LC, Razavi S, Goldberg L, et al. Systematic review of multidisciplinary chronic pain treatment facilities. Pain Res Manag 2016;2016:5960987.
- 14. Lynch ME, Campbell F, Clark AJ, Dunbar MJ, Goldstein D, Peng P, et al. A systematic review of the effect of waiting for treatment for chronic pain. Pain 2008;136:97-116.
- 15. Lin I, Wiles L, Waller R, Goucke R, Nagree Y, Gibberd M, et al. What does best practice care for musculoskeletal pain look like? Eleven consistent recommendations from high-quality clinical practice guidelines: systematic review. Br J Sports Med 2020;54:79-86.
- 16. Bülow K, Lindberg K, Vaegter HB, Juhl CB. Effectiveness of pain neurophysiology education on musculoskeletal pain: a systematic review and meta-analysis. Pain Med 2021;22:891-904.
- 17. Deslauriers S, Roy JS, Bernatsky S, Blanchard N, Feldman DE, Pinard AM, et al. The burden of waiting to access pain clinic services: perceptions and experiences of patients with rheumatic conditions. BMC Health Serv Res 2021;21:160.
- 18. Goode J, Voices N. Improving our understanding of the experience of waiting for elective care; 2020. Available from: https://www. nationalvoices.org.uk/sites/default/files/public/publications/national\_ voices\_desk\_research\_improving\_our\_understanding\_of\_the\_ experience\_of\_waiting\_for\_care\_february\_2020.pdf.
- 19. de Oliveira Lima L, Saragiotto BT, Costa LOP, Nogueira LC, Meziat-Filho N, Reis FJJ. Self-guided web-based pain education for people with musculoskeletal pain: a systematic review and meta-analysis. Phys Ther 2021;101:pzab167.
- 20. Creswell JW. Research design: qualitative, quantitative and mixed methods approaches, 4th ed. Thousand Oaks, CA: Sage; 2014.
- 21. Creswell JW, Plano Clark VL. Designing and conducting mixed methods research, 2nd ed. Los Angeles, CA: Sage: 2011.
- 22. 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;19:349-57.
- 23. Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: guided by information power. Qual Health Res 2015; 26:1753-60.
- 24. O'Cathain A, Murphy E, Nicholl J. The quality of mixed methods studies in health services research. J Health Serv Res Policy 2008;13:92-8.
- 25. Charters E. The use of think-aloud methods in qualitative research an introduction to think-aloud methods. Brock Educ J 2003;12:68-82.
- 26. Spradley JP. Participant observation. Fort Worth: Harcourt Brace College Publishers; 1980. xi, 195 s., illustreret.
- 27. Sjetne IS, Bjertnaes OA, Olsen RV, Iversen HH, Bukholm G. The generic short patient experiences questionnaire (GS-PEQ): identification of core items from a survey in Norway. BMC Health Serv Res 2011:11:88.
- 28. Krol MW, de Boer D, Delnoij DM, Rademakers JJ. The Net Promoter Score-an asset to patient experience surveys? Health Expect 2015;18:
- 29. Braun V, Clarke V. Thematic analysis: a practical guide. Los Angeles: SAGE; 2022. xxxiv, 338 s.
- 30. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006;3:77-101.

- 31. Bostrøm K, Varsi C, Eide H, Børøsund E, Kristjansdottir ÓB, Schreurs KMG, et al. Engaging with EPIO, a digital pain self-management program: a qualitative study. BMC Health Serv Res 2022;22:577.
- 32. Hurley-Wallace A, Kirby S, Bishop F. Trusting in the online 'community': an interview study exploring internet use in young people with chronic pain. Br J Pain 2022;16:341-53.
- 33. Gallardo VI, Alpuente A, Cerda-Company X, Torres-Ferrus M, Sanchez Del Rio M, Lainez JM, et al. The impact of a digital platform on migraine patient-centered outcome research. Evaluation of midolordecabeza.org, a headache website in Spanish. Headache 2021;61: 1403-10.
- 34. Grau LE, Larkin K, Lalloo C, Stinson JN, Zempsky WT, Ball SA, et al. Perspectives on adapting a mobile application for pain selfmanagement in neurofibromatosis type 1: results of online focus group discussions with individuals living with neurofibromatosis type 1 and pain management experts. BMJ Open 2022;12:e056692.
- 35. Hysing EB, Smith L, Thulin M, Karlsten R, Butler S, Gordh T. Identifying characteristics of the most severely impaired chronic pain patients treated at a specialized inpatient pain clinic. Scand J Pain 2017;17:178-85.
- 36. Ranney ML, Duarte C, Baird J, Patry EJ, Green TC. Correlation of digital health use and chronic pain coping strategies. Mhealth 2016;2:35.
- 37. Fernandes LG, Devan H, Fioratti I, Kamper SJ, Williams CM, Saragiotto BT. At my own pace, space, and place: a systematic review of qualitative studies of enablers and barriers to telehealth interventions for people with chronic pain. Pain 2022;163:e165-81.
- 38. Bostrøm K, Børøsund E, Varsi C, Eide H, Flakk Nordang E, Schreurs KM, et al. Digital self-management in support of patients

- living with chronic pain: Feasibility Pilot study. JMIR Form Res 2020; 4:e23893.
- 39. Adams C, Walpola R, Schembri AM, Harrison R. The ultimate question? Evaluating the use of Net Promoter Score in healthcare: a systematic review. Health Expect 2022;25:2328-39.
- 40. Moreno-Ligero M, Moral-Munoz JA, Salazar A, Failde I. mHealth intervention for improving pain, quality of life, and Functional disability in patients with chronic pain: systematic review. JMIR Mhealth Uhealth 2023:11:e40844
- 41. Statistik D. It-anvendelse i befolkningen; 2020. Available from: https:// www.dst.dk/da/Statistik/nyheder-analyser-publ/Publikationer/ VisPub?cid=39431.
- 42. Ma KPK, Stephens KA, Geyer RE, Prado MG, Mollis BL, Zbikowski SM, et al. Developing digital therapeutics for chronic pain in primary care: a qualitative human-centered design study of providers' motivations and challenges. JMIR Form Res 2023;7:e41788.
- 43. Yao R, Zhang W, Evans R, Cao G, Rui T, Shen L. Inequities in health care services caused by the adoption of digital health technologies: scoping review. J Med Internet Res 2022;24:e34144.
- 44. Steinmetz-Wood M, Pluye P, Ross NA. The planning and reporting of mixed methods studies on the built environment and health. Prev Med 2019;126:105752.

Supplementary Material: This article contains supplementary material (https://doi.org/10.1515/sjpain-2023-0044).