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### Shared decision-making in maternity care

*Health literate-sensitive support for healthcare professionals and clients*

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## Chapter 5

# How do current digital patient decision aids in maternity care align with the health literacy skills and needs of clients in maternity care?: a think aloud study

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## Abstract

**Background:** Patient decision aids (PDAs) have shown to be effective in facilitating shared decision-making (SDM) in maternity care. However, many PDAs are difficult to use for clients because of high cognitive demand.

**Objective:** This study aimed to explore how current digital PDAs support clients' health literacy skills (understanding, appraising, and applying information) and fit their needs for support in SDM in maternity care.

**Methods:** Clients (n=21) in Dutch maternity care were invited to use five PDAs during think aloud interviews. The interviews were transcribed verbatim, coded with open and axial coding, and analysed using thematic analysis. A framework of health literacy skills for SDM was used to categorize the themes.

**Results:** Clients reported a need for support to appraise and understand the purpose of PDAs. Most clients adequately used both benefit/harm information about available options and available Value Clarification Methods (VCM), indicating that these main PDA elements supported them to actively process this information in their decision-making process. However, these elements were only appreciated and adequately used when clients understood the pregnancy- and labour related terminology used. A lack of balanced probability information about outcomes of options for mother and child hindered further information use. VCM were only used when presented attributes were relevant for clients.

**Conclusions:** Clients were in general able to process and use information presented in PDAs in maternity care tested in this study, thus PDAs were aligned with health literacy skills. Adequate understanding of terminology and perceived relevance of specific information elements were important preconditions.

**Keywords:** Think aloud; Health literacy; Maternity care; Patient decision aids; Shared decision-making

## Introduction

Adequate information provision and decision-support are considered a priority in maternity care in Western countries. Clients are nowadays encouraged to inform themselves about available options (e.g. pain relieving options during labour or breech mode of labour) beforehand and to express (provisional) preferences to their healthcare professional. This participation in decision-making (also called Shared Decision-Making (SDM) requires health literacy (HL) skills, including accessing, appraising, understanding and applying information to make informed decisions, as well as communicating effectively and exchanging information with maternity care professionals (1). We previously specified HL skills needed to make decisions during pregnancy and labour (see Table 1) based on a framework of HL and SDM of McCaffery and colleagues. The framework by McCaffery and colleagues supports researchers to consider demands of SDM as applied to low literate adults (2, 3).

Patient decision aids (PDAs) are tools (e.g. audio booklets, pamphlets or web-based tools) that are used in parallel with SDM to offer decision-support (4, 5). A typical PDA includes elements about options, probabilities, value clarification methods (VCM), guidance in the deliberation process and communication, and information about the evidence used (6). These elements could support clients in applying HL skills during the decision-making stages mentioned in table 1. A systematic review in obstetrics and gynaecology reported evidence supporting the use of PDAs to facilitate SDM (7). For example, individuals who use PDAs tend to report reduced decisional conflict (7) and being better informed to make decisions (5, 8). Despite the overall beneficial effects of PDAs, there are challenges to their use in practice; many PDAs have been designed for independent use at home or in waiting rooms, and subsequent decision-making in the consultation may not be shared (9). Another challenge is that PDA content is not optimally designed to meet the needs of clients who have difficulty using such information, often (but not necessarily) reflected by basic HL (i.e. basic reading, understand and processing levels) (10). Specifically for the maternity context, clients also need to take into account the provisional nature of preferences, since acute medical/labour-related circumstances may change the actual possibilities as well as clients' preferences.

PDAs are often digital tools, which require digital HL skills, i.e. the ability to appraise and apply health information from electronic sources to address or solve a health-related problem (11). A review of PDAs in maternity care, reported that only 11 out of 27 identified PDAs well-suited lower HL clients (9). The reading level and cognitive demand are generally too high, and many PDAs do not meet thresholds

for comprehension or ability to take actions (12). Despite greater attention to the issue of HL in PDAs, we still lack knowledge about the way clients interact with PDAs in maternity care, and what makes the PDAs potentially cognitive demanding for them. Individuals with lower basic HL seem to be in greater need of decision-support, given their higher levels of uncertainty (3), decisional regret, and lower level of involvement in decision-making (13). Specifically for maternity care, more insight is needed into how PDAs support clients to process and apply information in their decision-making process (i.e. health literacy skills). Therefore, this study aimed to explore how (elements of) current digital PDAs support a diverse range of HL skills and how they fit clients' needs for support in decision-making in maternity care.

**Table 1.** Framework for decision-making stages and health literacy skills in maternity care(3)

<b>Stage 1: Understanding Pregnancy Stages and the Procedures of Labour</b>	<b>Stage 2: Understanding the Consequences: Risks, Limitations, Benefits and Uncertainties</b>	<b>Stage 3: Identifying Preferences and Combining Utilities with Probabilities</b>	<b>Stage 4: Participate in Decision-Making with Maternity Care Professional</b>	<b>Stage 5: Make a Decision</b>
(a) Find sources of information about pregnancy and labour	(a) Understand different harms and benefits of options	(a) Anticipate health states during labour or after birth	(a) Understand that involvement and choice is possible	(a) Self-efficacy
(b) Select and appraise (online) information -Decide when to stop looking for information	(b) Understand the likelihood of these occurring to mother and/or baby—carry out basic calculations	(b) Identify preferences for different outcomes	(b) Articulate and discuss preference to maternity care professional	(b) Taking responsibility for mother's and child's health
(c) Interpret written or spoken pregnancy-related terminology	(c) Interpret probabilities of harms occurring to mother and/or child	(c) Combine preferences with probabilistic information	(c) Ask questions to maternity care professional	(c) Cope with practical barriers of options and costs
	(d) Compare options against each other	(d) Share and communicate values to: -Significant others (e.g., friends, mother) -Peers -Partner		
		(e) Use own knowledge and previous pregnancy and birth experiences		

## Methods

In a think-aloud study clients were exposed to elements of five existing digital PDAs in Dutch maternity care. This allowed us to observe interactions with and reactions to the PDAs. We focused on a diverse range of HL skills (see table 1) needed to make decisions while using PDAs. The specific HL skill 'Accessing information' was excluded from the analysis, since we provided the PDA ourselves to participants. Communicative skills were also excluded, since we did not test the PDAs during interactions with professionals.

Participants were recruited between November 2019 and March 2021. According to Dutch law, this study was waived from requiring medical ethical approval (W18\_307). We guaranteed the anonymity of participants and ensured that written or oral informed consent was obtained prior to conducting the interviews. Initially, interviews were held at participants' home and written informed consent was obtained. Due to COVID-19 restrictions from March 2020, interviews were held by video calls and oral informed consent was obtained at the start of the interview.

### Recruitment

Clients pregnant for at least 25 weeks and women who had given birth in the period between the interview and maximally eight months previously were included. Purposive sampling was conducted to achieve a representative sample by screening clients' basic HL level prior to the interview (see Procedure). Clients were recruited via social media and at primary and secondary care practices in the Netherlands. Clients were approached by the first author (LM) during childbirth classes and in the waiting rooms of a hospital and child health clinics. Furthermore, we used snowball sampling in which participants invited other clients to participate. Participants received a €10,- gift voucher.

## Materials

### PDA's

Relevant PDA's for this study were selected in three rounds. First, an overview was made of available Dutch online tools/information websites that could be potentially decision-supporting in maternity care ( $n=28$ ) and of which the content met the definition of PDA's: tools that support clients to make decisions about their pregnancy or labour by informing them about their options and helping them clarify their preferences. In a second round, we used the International Patient Decision Aids Standards (IPDAS) to estimate the quality of PDA's (6). IPDAS and additional criteria (e.g., relevance of decision for a sufficient number of clients) were discussed among an expert panel. We finally selected five PDA's based on aforementioned criteria and the presence of strategies that support clients with low basis HL, such as use of videos or plain language (see table 2 for a description of PDA's).



Table 2. Description of PDAs

	<b>Professional midwifery website (tested by 7 clients)</b>	<b>GPinfo.nl (tested by 5 clients)</b>	<b>PatientPlus (tested by 10 clients)</b>	<b>Amsterdam UMC (tested by 7 clients)</b>	<b>Flyer infant feeding (tested by 7 clients)</b>
<b>Developer</b>	Royal Dutch organisation of midwives (KNOV)	Dutch College of General Practitioners	PatientPlus (professional PDA company)	Amsterdam UMC	Royal Dutch organisation of midwives (KNOV)
<b>Introduction of decision</b>	Introduction about pain relief during labour	Introduction about pain relief during labour	Introduction about birth after C-section	Introduction about birth after C-section	n/a
<b>Presentation formats for options</b>	Table of content	Table of content	Table of content	Table of content	n/a
<b>Benefits and harms information</b>	<ul style="list-style-type: none"> <li>Presented in videos (including procedures of options)</li> <li>List of benefits and harms</li> <li>Presented through anecdotes of peers</li> </ul>	<ul style="list-style-type: none"> <li>Presented in text</li> <li>List of benefits and harms</li> </ul>	<ul style="list-style-type: none"> <li>Presented in text</li> <li>Table of benefits and harms for all options (i.e. option grid)</li> </ul>	<ul style="list-style-type: none"> <li>Presented in videos (including procedures of options)</li> <li>Presented in text</li> <li>Option grid</li> </ul>	<ul style="list-style-type: none"> <li>Presented in text about breast- and artificial feeding</li> </ul>
<b>Videos and pictures</b>	Videos about procedures of pain relief options and their benefits and harms	n/a	n/a	Two videos about vaginal birth and the procedure of C-section, including icon arrays	<ul style="list-style-type: none"> <li>Pictures of baby bottles</li> <li>Breastfeeding positions</li> <li>Capacity of a newborn's stomach</li> </ul>
<b>Anecdotes of peers</b>	Anecdotes explaining benefits and harms of options	n/a	n/a	n/a	n/a
<b>Presentation formats of probabilistic information</b>	Numerator/denominator	n/a	<ul style="list-style-type: none"> <li>Icon arrays</li> <li>Numerator/denominator</li> </ul>	<ul style="list-style-type: none"> <li>Percentages</li> <li>Icon arrays</li> </ul>	n/a
<b>Value clarification method</b>	n/a	Ratings of pain relief options on a scale from 1 to 10	Ratings of attributes to identify preferences on a scale of importance	Rating attributes to identify preferences on a scale of importance	n/a
<b>Comprehension test</b>	n/a	n/a	Multiple choice questions	True or false questions	n/a

## **Procedure**

Before the interview, participants provided background characteristics. After the interview, we orally assessed clients' basic HL level using the Short Assessment of Health Literacy-Dutch (SAHL-D) and the Newest Vital Sign-Dutch (NVS-D). A SAHL-D score lower than 9 and a NVS-D score lower than 4 were considered as low basic HL (14, 15).

Participants were told to imagine to be in a scenario that suited the PDA's purpose, e.g. that they previously had a C-section. They were asked to use the PDA as if they would do at home when making a decision, and to think aloud while viewing and using the PDA. Additionally, probing questions were asked to let participants further elaborate. To investigate whether participants could apply the range of HL skills mentioned in table 1, we also asked specific open-ended questions, e.g. "How would you appraise this website?", "What are your options, according to this information?" and "What are the benefits and harms of the two options?" Finally, they were asked to identify and explain their preference based on the VCM.

## **Data analysis**

All interviews were recorded, transcribed literally, and coded by the first author (LM) (i.e. open and axial coding) using thematic analysis (16). Two interviews were independently coded by a second coder (AR). Differences in coding were discussed and consensus was reached. Data-saturation was reached when no new codes arose from the data. Open coding was first applied on the data. Axial coding was used to connect different codes reflecting the same topic, resulting in provisional themes. Next, we categorized the themes according to the stages from the existing framework of HL skills needed for SDM. The themes were discussed in regular meetings of LM, MF and OD, until consensus was reached.

## **Results**

### **Background characteristics**

In total, 21 participants evaluated one or two PDAs, depending on the interview's duration. We did not observe difficulties in participants' ability to use computers or to complete tasks. Table 3 displays background characteristics.

**Table 3.** Background characteristics of interview participants (n =21)

	<b>n (%)</b>	<b>Mean (SD; Range)</b>
<b>Age</b>		33 (4; 25-43)
<b>Educational level</b>		
Low	1 (5%)	
Middle	6 (29%)	
High	14 (67%)	
<b>Ethnic background</b>		
Dutch	18 (86%)	
Non-Dutch: Western	2 (10%)	
Non-Dutch: Non-Western	1 (5%)	
<b>Marital status</b>		
Married/ living together with partner	21 (100%)	
<b>Basic HL level</b>		
SAHL-D		10 (3; 1-13) <sup>1</sup>
NVS-D		5 (1; 4-6) <sup>2</sup>
Low basic HL level	6 (29%) <sup>3</sup>	
<b>Parity</b>		
Primiparous	4 (19%)	
Multiparous	4 (19%)	
Primigravida	6 (29%)	
Multigravida	7 (33%)	
<b>Number of weeks after birth</b>		19 (12; 4-34)
<b>Number of weeks pregnant</b>		(6; 20-39)

<sup>1</sup>For the SAHL-D, individuals with <9 out of 13 correct responses were considered low reading and understanding skills.

<sup>2</sup>For the NVS-D, individuals with <4 out of 6 correct responses were considered calculating skills.

<sup>3</sup>Percentage of participants who scored low on either SAHL-D or NVS-D

The identified themes are described for each of the stages of decision-making (marked in bold). The range of HL skills (from table 1) that clients needed in their decision-making process are underlined. Table 4 presents illustrative quotes for each theme.

## **Stage 1: Understanding pregnancy and the procedures of labour**

### ***Theme 1.1: Source of information (e.g. displayed through logos) unclear to appraise PDAs' reliability***

When participants were asked how they would appraise the PDAs, they mainly mentioned to appraise the PDAs as reliable based on the logos, for example of the Royal Dutch organisation of midwives (KNOV). However, most participants who noticed specific logos mentioned that they were unfamiliar with these (Table 4, quote 1). Participants stated that, therefore, it was difficult to appraise the PDA's reliability. Some participants mentioned to look at the profiles of the PDA's developers. Also, some participants mentioned that they would verify information by comparing it to information from other sources.

### ***Theme 1.2: Pregnancy-related terminology complicated understanding the procedures of options***

It appeared to be difficult for participants to initially interpret pregnancy-related terminology used in PDAs (e.g. pethidine, remifentanil or TENS). This specifically hindered comprehension of the procedures related to the options available (e.g. the procedure of applying acupuncture). However, after reading the provided information more closely, most participants were able to roughly explain the procedures of options. Some participants were inclined to focus on terms that they recognised or were already acquainted with based on previous experience, such as breastmilk instead of mother's milk. In case of unfamiliar terms, some participants seemed to stop reading the information. For example, the professional midwifery website also presented chemical names of nitrous oxide, which most participants did not read (Table 4, quote 2).

## **Stage 2: Understanding the consequences: risks, limitations, benefits and uncertainties**

### ***Theme 2.1: Tables of content actively used to understand which options are available***

Participants appeared to use the tables of content actively to understand their options (Table 4, quote 3). All PDAs contained tables of content, except for the flyer about infant feeding. Consequently, for this specific flyer, some participants did not instantly realize that it contained information about artificial feeding in addition to breast-feeding. According to participants, tables of content gave a clear overview of available options. Participants said to prefer a summary chart of options with

accompanying layered information for more details, e.g. when interested in one specific option, instead of all information about the options at once.

***Theme 2.2: Different ways to select options of interest***

Participants selected the options they would want to read more about in three ways. First, some screened all different options displayed and then assessed (un)familiar options. This particularly appeared to happen when the options were presented in a table of content first or when participants had previous experiences with certain options. Some participants scanned the information about options they did not immediately prefer. Second, participants started to read content in the chronological order presented in PatientPlus and Amsterdam UMC's PDAs and in the flyer about infant feeding. PatientPlus and Amsterdam UMC's PDAs were pre-structured in a certain order to be followed; therefore, clients could not miss an option. Third, one participant started with the option she thought she would need at the beginning of labour, i.e. natural pain relief during labour. After selecting the options participants first screened the text to see what type of other information the page provided (Table 4, quote 4).

***Theme 2.3: Probabilistic information overall adequately interpreted, but numbers remained abstract***

**Theme 2.3.1: Probabilistic information in general understood**

While reading the probabilistic information, participants were generally able to understand and interpret the probabilities of benefits or harms occurring (e.g. likely or unlikely to happen), when presented in icon arrays, percentages or with numerator/denominators. Some participants tried to calculate small percentages into numerator/denominators to compare options with each other. Icon arrays were not actively used by participants when probabilistic information was also presented in text numerically (Table 4, quote 5). Others found the icon arrays helpful and mentioned to be able to see the risk of benefits or harms occurring in one glance.

**Theme 2.3.2: Interpretation seemed to depend on presentation format**

Probabilistic information about risks of pain relief options and options for birth after a C-section was used differently depending on the presentation format. When probabilistic information was not given about harms occurring for all options, participants felt that benefit/harm information was framed in a certain direction (Table 4, quote 6). Some participants actively searched for this lacking probabilistic information at other PDA sections. Also, some participants found verbal labels such as 'many' or 'rare' unclear to interpret.

### **Theme 2.3.3: In search for intuitive meaning of abstract numbers**

While using probabilistic information, some participants selected the largest differences between options first before they looked at further content. Participants also indicated to look for contextual information. For example, participants wanted to compare the risks associated with certain options with general population statistics as a frame of reference. They mentioned that they were not able to distinguish whether the probabilistic information provided applied to the general population or to a specific target group (Table 4, quote 7). Finally, participants referred to the difficulty of predicting single events. The probabilistic information only informed them about how many people in some groups are likely to suffer from a particular harm, but women would not know into which category (i.e. group with negative or positive outcome) they would fall into.

### ***Theme 2.4: Balanced and clear overview needed in option grids to weigh options***

According to participants, option grids (i.e. options presented in a table) helped to compare the options against each other and to see the most important differences in one overview (Table 4, quote 8). Some participants were able to identify a preference towards vaginal birth or towards C-section and even changed their preferences after reading the information in the option grid, showing that this information was actively used (see theme 2.1). They also emphasized that repetition of information was helpful. One participant found it difficult to understand the option grid, because it contained too much text.

GPinfo.nl presented the benefits and harms of options through plus, minus and '0' symbols, which was complicated for some participants. Others were able to understand the information, for instance they mentioned that natural pain relief options (e.g. bath, relaxation exercises) are better than medical pain relief options, because the uncertainties presented with question marks and minus symbols were not seen for the natural pain relief options.

However, participants explicitly commented that they needed a well-balanced overview about options to compare them. Participants noticed that certain details that they had read in previous sections were not mentioned in the option grid. They also mentioned other benefits and harms experienced in previous pregnancies that were missing in the option grid.

***Theme 2.5: Anecdotes, visuals and comprehension test were used in making sense of the options, when added value was seen***

The professional midwifery website and both PDAs about birth after C-section used videos and pictures to explain options and their benefits and harms. After watching the video about vaginal birth, participants generally understood the reasons why a C-section could still be performed. One participant mentioned to watch the video, because it supported her to remember information. However, participants also gave several reasons why they did not watch videos: because they were already familiar with the option, because they already decided not to want a particular pain relief option or because they did not expect other information than presented in the text.

Participants who read anecdotes of peers said to use these to better understand the benefits and harms of options (Table 4, quote 9), especially when textual information alone was unclear. Other participants neglected this information, because they thought it might be fake, they rather wanted to read factual information, or they preferred to discuss experiences with women they personally knew.

Most participants gave the right answers to the comprehension test. However, some mentioned that they would not answer this, because they did not see added value or because they felt like being tested. In contrast, others mentioned that this element supported them to remember information better, and that they received more information through the explanations given to each test question.

**Stage 3: Identifying preferences and combining utilities with probabilities**

***Theme 3.1: Relevant attributes in value clarification methods used to identify initial preferences***

Participants conveyed their initial preferences and feelings towards the options while working with the VCM, for example, some participants mentioned that they feared a C-section and others mentioned that a feeling of control during labour was important to them. They were also able to apply the VCM to their own situation, and used information previously presented in the PDA and their own experiences to rate the attributes. Not all attributes used were considered important. Also, some participants used previously provided mortality rates of a child for vaginal birth in their trade-off (Table 4, quote 10). Some expected that they would be advised on which option would suit best, based on given answers.

GPinfo.nl presented a table in which clients could rate the pain relief option from 1 to 10. Participants mentioned that it seemed to indicate which option they would certainly or would certainly not choose. It also supported them to indicate which option they would choose in which stage of labour.

***Theme 3.2: Practical information was appreciated and used to anticipate on future health states***

Participants spontaneously expressed positive evaluations of practical information about procedures following an option (e.g. duration of hospital admission after a C-section) provided in the PDAs, which was not necessarily the core decision-relevant information as described by IPDAS. They also used practical information to construct preferences towards options. For example, participants expressed that they considered the duration to recover from a C-section in their decision. Participants also appreciated practical information about alternatives for breastfeeding besides artificial feeding (Table 4, quote 11).

**Stage 4 Participate in decision-making with maternity care professional**

***Theme 4.1: Need for concise introduction to understand involvement in decision-making***

As suggested in stage 1 of the framework, all PDAs introduced the condition (e.g. birth after C-section) and the decision needed to be made, except for the flyer about infant feeding. The lengthy introduction generally did not help to understand the aim and target group of the PDA. Some participants, for example, expected that the PDA would provide an advice on which option to choose (Table 4, quote 12). They did not seem to understand that the PDA's basic idea was to get involved in the decision-making process. Several participants expressed a need for a concise introduction to understand the PDA aim better.

***Theme 4.2: Summary of results in PDA supported to prepare consultation***

PatientPlus was the only PDA that presented a summary of their personal answers in VCM. When participants were asked how they would use the summary, some mentioned that they would keep it for themselves and others would bring it to their consultation to discuss with their professional (Table 4, quote 13). However, some participants were hesitant to provide their e-mail address and would rather see their results on the website instantly.



**Table 4.** Example quotes – skills and needs for support

<b>Stage 1: Understanding pregnancy and the procedures of labour</b>	
Theme 1.1: Source of information (e.g. displayed through logos) unclear to appraise PDA reliability	Quote 1 - ... <i>hmm, PatientPlus does not ring a bell. Never heard anything about it. So, I bet some Big Pharma company is behind it. (high basic HL, 34 weeks pregnant, primigravida)</i>
Theme 1.2: Pregnancy-related terminology complicated understanding the procedures of options	Quote 2 - <i>Yes, I did see something about nitrogen, and oxygen, but because of all those codes around them, I do not really read it. (high basic HL, 25 weeks pregnant, primigravida)</i>
<b>Stage 2: Understanding the consequences: risks, limitations, benefits and uncertainties</b>	
Theme 2.1: Tables of content actively used to understand which options are available	Quote 3 - <i>Now I am clicking on the options, but actually, I only recognise what I have heard before.... Ah, yes, now I do see a warm bath, or shower.... (high basic HL, 25 weeks pregnant, primigravida)</i>
Theme 2.2: Different ways to select options of interest	Quote 4 - <i>Okay. Well yes, then I just check to see what will be on that page. Alternatively, well I just start reading, or looking at the headings. I do that first, because it is actually quite a lot of text. Um, so I just try to scan around a bit to see what catches my eye, like this. (high basic HL, 28 weeks postpartum, primiparous)</i>
Theme 2.3.1: Probabilistic information in general understood	Quote 5 - <i>It was because I read the text. Because otherwise I cannot really figure out from the image that that is what they mean. So I wonder how much extra that adds. (high basic HL, 7 weeks postpartum, multiparous)</i>
Theme 2.3.2: Interpretation seemed to depend on presentation format	Quote 6 - <i>Because you also saw that in the last one, and here again too. Under the Harms, you see little graphs and things and that does make it look weightier. (low basic HL, 20 weeks postpartum, multiparous)</i>
Theme 2.3.3: In search for intuitive meaning of abstract numbers	Quote 7 - <i>I am not so sure how high that is, and how high it is for a normal delivery. Maybe it is like that for a normal delivery too..., and then it would not carry that much weight for me.... But it might still be some help in deciding. (high basic HL, 31 weeks pregnant, primiparous)</i>
Theme 2.4: Balanced and clear overview needed in option grids to weigh options	Quote 8 - <i>And I quite like this, because I can just compare. Because of course, you have text 1 and text 2, and then you have to remember what text 1 says so you can compare that with text 2. (high basic HL, 34 weeks pregnant, primiparous)</i>
Theme 2.5: Anecdotes, visuals and comprehension test were used in making sense of the options, when added value was seen	Quote 9 - ... <i>because actually both of them say the pain still continued undiminished. So for the pain control you do not need to do this. (high basic HL, 25 weeks pregnant, primigravida)</i>
<b>Stage 3: Identifying preferences and combining utilities with probabilities</b>	
Theme 3.1: Relevant attributes in value clarification methods used to identify initial preferences	Quote 10 - <i>Then you just go back a step and think about it further. What did they really say? And then I thought, oh yeah wait a minute. The mortality risk for the baby and the baby's oxygen shortage were actually greater for a vaginal delivery than for a caesarean. (high basic HL, 4 weeks postpartum, primiparous)</i>
Theme 3.2: Practical information was appreciated and used to anticipate on future health states	Quote 11 - <i>Also, like the baby does not want to be breastfeed, then you can also do something with cup feeding. So there is like several options. That is nice to know. (high basic HL, 36 weeks pregnant, primigravida)</i>
<b>Stage 4: Participate in decision-making with maternity care professional</b>	
Theme 4.1: Need for concise introduction to understand involvement in decision-making	Quote 12 - <i>I will be curious to know what it will to do further, the website I mean, or the decision aid.... I expect you can perhaps click on things about what your situation is, for instance, and that it will give you some sort of advice. So I am curious to see if it will provide that, or if it is just something like listing information so you can use that to make a choice, so to speak. (high basic HL, 31 weeks pregnant, primigravida)</i>
Theme 4.2: Summary of results in PDA supported to prepare consultation	Quote 13 - <i>If it is not necessary, then I would not take it with me. But to me it is more about knowing what I am dealing with. (low basic HL, 20 weeks postpartum, multigravida)</i>

## Discussion

This study aimed to explore how (elements of) current digital patient decision aids (PDAs) support clients in understanding, appraising and applying information and fit clients' needs for support in decision-making in maternity care. Clients adequately used both the benefit/harm information about available options and the Value Clarification Methods (VCM), indicating that the main PDA elements supported them in the decision-making process. However, balanced information, for example provided in structured option grids, was needed to compare options easily. Attributes presented in VCMs were only used when they were considered relevant. Clients generally understood the probabilistic information provided, which supported them to interpret the probabilities of benefits and harms occurring and to identify their preferences. However, understanding seemed to depend on the way information was presented and clients often still searched for contextual information. Also, pregnancy and labour-related terminology hindered clients in understanding the purpose of the PDA and sometimes also the options.

The main elements of the PDAs were generally used adequately, in the sense that the main benefit/harm information was understood and that the VCM attributes were interpreted correctly. However, clients' opinions about the relevance of VCM differed. Previous research also supported the use of VCM to improve decisional outcomes, however how to best present VCM may depend on the setting (17). When a PDA did not contain option grids or VCM, i.e. the flyer about infant feeding, clients only used the information to inform themselves about practical issues rather than to compare options or identify preferences. These findings thus provide support for the idea of using PDAs in the process of Shared Decision-Making (SDM) in maternity care.

In contrast to previous research (18), clients generally seemed to understand and use the probability information provided (e.g. risks of undergoing a C-section) in their trade-off, however they also spontaneously searched for information that provided context to this information. The way the probability information was presented in the PDAs seemed to remain rather abstract for women. Previous research also suggests to put numbers in context, including comparisons to more familiar risks of similar context (19, 20) or to risks of other people (e.g. the average person) and evaluative labels and symbols to improve patient understanding (21).

In line with previous literature about HL and SDM (22), this study showed that pregnancy-related terminology hindered comprehension of options, especially about the procedures related to the options. Our participants also found it difficult to understand the general purpose of the PDAs, because of the lengthy introduction,

and expressed that they would look further to verify the information provided in PDAs. A previous systematic review showed that among accessible PDAs, none met the grade 8 reading level (reading level recommended for an average population sample) (12). In line with our results, previous literature also underlined the importance of supporting pregnant women to appraise online sources, since Internet information of poor quality could have negative implications for women's own and the child's health (23). Professionals could support clients to appraise online sources by guiding them towards certified PDAs.

### **Strengths and limitations**

A strength of our research is that we included clients with varying basic HL levels. We were not able to include the group with lowest digital HL skills or women who do not have access to digital devices, since the interviews were held online because of COVID-19 restrictions. The group with lowest digital HL skills might experience more difficulties in applying the diverse range of skills investigated.

### **Practical and research implications**

When designing and developing PDAs in maternity care, the following recommendations can be made: explain the PDA aim and its idea of client involvement in decision-making, use terminology that is familiar to clients, also in describing the procedures of options, facilitate the recognition of reliability of providers, present benefit/harm information prominently, but in a concise overview with layered options, use value attributes in VCM that are relevant to clients, and provide contextual information to probabilistic information in a careful way, e.g. a comparison of side-effects of one medication to the side-effects of a more familiar medication.

### **Conclusion**

The PDAs tested in our study generally support clients' skills to appraise, understand and actively process and weigh information on benefits and harms of options in maternity care. However, several improvements are still possible, such as summarizing key benefit/harm information in tables and charts, with corresponding contextual information to make sense of probabilistic information.

### **Author contributions**

(1) the conception and design of the study, and acquisition of data (M.P.F; O.C. D.), analysis and interpretation of data (L.M.; A.L.R.; M.P.F; O.C.D.), (2) drafting the article and revising it critically for important intellectual content (L.M.), (3) final approval of the version to be submitted (M.P.F; A.L.R.; E.M.A.S; D.R.M.T.; O.C.D.).

### **Declaration of Competing Interest**

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

## References

1. Sørensen K, Van den Broucke S, Fullam J, Doyle G, Pelikan J, Slonska Z, et al. Health literacy and public health: a systematic review and integration of definitions and models. *BMC public health*. 2012;12(1):80.
2. McCaffery KJ, Smith SK, Wolf MJMDM. The challenge of shared decision making among patients with lower literacy: a framework for research and development. 2010;30(1):35-44.
3. Murugesu L, Damman OC, Derksen ME, Timmermans DR, de Jonge A, Smets E, et al. Women's Participation in Decision-Making in Maternity Care: A Qualitative Exploration of Clients' Health Literacy Skills and Needs for Support. *International Journal of Environmental Research and Public Health*. 2021;18(3):1130.
4. Stevens G, Thompson R, Watson B, Miller YD. Patient decision aids in routine maternity care: benefits, barriers, and new opportunities. *Women and Birth*. 2016;29(1):30-4.
5. Stacey D, Légaré F, Lewis K, Barry MJ, Bennett CL, Eden KB, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane database of systematic reviews*. 2017(4).
6. Joseph-Williams N, Newcombe R, Politi M, Durand M-A, Sivell S, Stacey D, et al. Toward minimum standards for certifying patient decision aids: a modified Delphi consensus process. *Medical Decision Making*. 2014;34(6):699-710.
7. Poprzeczny AJ, Stocking K, Showell M, Duffy JM. Patient decision aids to facilitate shared decision making in obstetrics and gynecology: a systematic review and meta-analysis. *Obstetrics & Gynecology*. 2020;135(2):444-51.
8. Coronado-Vázquez V, Canet-Fajas C, Delgado-Marroquín MT, Magallón-Botaya R, Romero-Martín M, Gómez-Salgado J. Interventions to facilitate shared decision-making using decision aids with patients in Primary Health Care: A systematic review. *Medicine*. 2020;99(32).
9. Kennedy K, Adelson P, Fleet J, Steen M, McKellar L, Eckert M, et al. Shared decision aids in pregnancy care: A scoping review. *Midwifery*. 2020;81:102589.
10. Damman OC, Jani A, de Jong BA, Becker A, Metz MJ, de Bruijne MC, et al. The use of PROMs and shared decision-making in medical encounters with patients: An opportunity to deliver value-based health care to patients. *Journal of evaluation in clinical practice*. 2020;26(2):524-40.
11. Norman CD, Skinner HA. eHealth literacy: essential skills for consumer health in a networked world. *Journal of medical Internet research*. 2006;8(2):e506.
12. Muscat DM, Smith J, Mac O, Cadet T, Giguere A, Housten AJ, et al. Addressing Health Literacy in Patient Decision Aids: An Update from the International Patient Decision Aid Standards. *Medical Decision Making*. 2021:0272989X211011101.
13. McCaffery KJ, Holmes-Rovner M, Smith SK, Rovner D, Nutbeam D, Clayman ML, et al. Addressing health literacy in patient decision aids. *BMC medical informatics and decision making*. 2013;13(2):1-14.
14. Woudstra A, Meppelink C, Maat HP, Oosterhaven J, Fransen M, Dima A. Validation of the short assessment of health literacy (SAHL-D) and short-form development: Rasch analysis. *BMC medical research methodology*. 2019;19(1):122.
15. Fransen MP, Leenaars KE, Rowlands G, Weiss BD, Maat HP, Essink-Bot M-LJPe, et al. International application of health literacy measures: Adaptation and validation of the newest vital sign in The Netherlands. 2014;97(3):403-9.
16. Braun V, Clarke VJQrip. Using thematic analysis in psychology. 2006;3(2):77-101.

17. Witteman HO, Ndjaboue R, Vaissou G, Dansokho SC, Arnold B, Bridges JF, et al. Clarifying values: an updated and expanded systematic review and meta-analysis. *Medical Decision Making*. 2021;41(7):801-20.
18. Usher-Smith JA, Mills KM, Riedinger C, Saunders CL, Helsing LM, Lytvyn L, et al. The impact of information about different absolute benefits and harms on intention to participate in colorectal cancer screening: A think-aloud study and online randomised experiment. *PloS one*. 2021;16(2):e0246991.
19. Keller C, Siegrist M, Visschers V. Effect of risk ladder format on risk perception in high-and low-numerate individuals. *Risk Analysis: An International Journal*. 2009;29(9):1255-64.
20. Freudenburg WR, Rursch JA. The risks of "putting the numbers in context": a cautionary tale. *Risk Analysis*. 1994;14(6):949-58.
21. Bonner C, Patel P, Fajardo MA, Zhuang R, Trevena L. Online decision aids for primary cardiovascular disease prevention: systematic search, evaluation of quality and suitability for low health literacy patients. *BMJ open*. 2019;9(3):e025173.
22. Muscat DM, Shepherd HL, Nutbeam D, Trevena L, McCaffery KJ. Health literacy and shared decision-making: exploring the relationship to enable meaningful patient engagement in healthcare. *Journal of general internal medicine*. 2021;36:521-4.
23. Lagan BM, Sinclair M, George Kernohan W. Internet use in pregnancy informs women's decision making: a web-based survey. *Birth*. 2010;37(2):106-15.