Research report
E-tool for Vaginal Complaints


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Summary

Introduction: In the Netherlands the incidence of vaginal complaints is about 40-50 per 1000 female patients per year of which half of them are between 20-30 years old. In approximately 30 per cent of the cases presented at the GP, no microbiological cause for the complaints are found. Simultaneously, not all women with complaints seek the medical help they need. Since the health costs in the Netherlands are rising, it is important to investigate the possibilities to make diagnosis and treatment of vaginal complaints more effective. In order to suppress the rising costs of healthcare, e-health could potentially contribute to make diagnosis and treatment of vaginal complaints more efficient.

Objective: In order to make the diagnosis of the cause for vaginal discharge more efficient, the aim of this study is to evaluate an e-health tool designed to help patients from the Student Health Services of the University of Amsterdam with vaginal complaints self-diagnose and choose an appropriate treatment. Therefore, the corresponding research question is: To what extent does the e-tool satisfactory contribute to self-diagnose and self-treatment of women with vaginal complaints?

Methods: Ten women with vaginal complaints were interviewed on their expectations and perceptions on the quality of a decision aid for vaginal complaints. Semi-structured interviews were performed, combined with ‘think-a-loud’ method. Hereby structure for the interviews was given, while letting room for elaboration on significant subjects.

Results: Ten women between 21 and 57 years old were interviewed. All participants were educated at UAS or U level. Seven participants were students, while three participants were working. The quality expectations of decision aid on the subset content and effectiveness were met in the perceptions of the participants, leading to confirmation and patient satisfaction. The expectations on the subset development process were not met as the participants would find the language level in the decision aid to high for the general population. Additionally, participants expected more medical trained people to be involved in the e-tool than there actually were. Therefore, on the subset development process, the expectations of the participants were not met, leading to disconfirmation and dissatisfaction.

Discussion and conclusion: In general, the decision aid was found to be helpful and convenient by the participants to structure their symptoms and enlarge their knowledge before visiting the GP. However, the decision aid was not found to be a substitute for a consult with the GP. The participants in this research were relatively high educated and noted the language level might be too high for the general population. It would be interesting to extend this research with input from lower educated participants. Additionally, it is recommended to involve a gynaecologist in the development of the tool in order to increase the perceived credibility of the decision aid and improve patient satisfaction. In general, the decision aid has high potential to satisfactory help patients structure their symptoms and choose the appropriate action to take.
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Abbreviations

BV  Bacterial vaginosis
CV  Vaginal candidiasis
GP  General practitioner
IPDAS  International Patient Decision Aid Standard
NHG  Dutch General Practitioner ’s Society (Nederlands Huisartsen Genootschap)
STD  Sexual transmittable disease
STI  Sexual transmittable infection
U  University
UAS  University of Applied Sciences
UvA  University of Amsterdam
VU  VU University Amsterdam
1. Introduction
At the general practitioners (GP) vaginal complaints are commonly presented. The incidence of vaginal complaints in the Netherlands is 40-50 per 1000 female patients per year, of which half of them are between 20 to 30 years old (Dekker et al., 2009). Vaginal complaints occur when women would classify their vaginal discharge as more extensive or alternative than usual or experience pain or itchiness in the vaginal area.

The causes for vaginal complaints may be physiological or pathological. Women with vaginal complaints often visit their GP to screen for sexual transmittable diseases (STDs), even though the presence of vaginal complaints poorly predicts infection with a STD (Mitchel, 2004). In fact, in approximately a third of the cases presented at the GP, no microbiological cause for the vaginal complaints is found and the vaginal complaints are likely to spontaneously disappear (Dekker et al., 2009). However, untreated vaginal infections can have severe consequences that might eventually lead to infertility. Therefore, the symptoms should not be ignored (Pellati 2008).

Additionally, a substantial number of women experiencing vaginal complaints self-treat their symptoms and do not seek medical help (Theroux, 2005). Although it is important to be examined when vaginal complaints are experienced, the stigma’s associated with STDs might keep young women from seeking the medical help they need (Van Bergen, 2001). Simultaneously, unnecessary visit for vaginal discharge occur. Since the costs of healthcare increase in the Netherlands (RIVM, 2014), it is important to investigate the possibilities to create more efficient ways to provide care while not compromising the patients’ health.

To reduce healthcare costs by increasing the efficiency of healthcare, electronic health (e-health) is increasingly deployed. According to Eysenbach (2001), e-health could ‘avoid duplicative or unnecessary diagnostics or therapeutic interventions, through enhanced communication possibilities between health care establishments and though patient involvement’. E-health could contribute to patient empowerment, which, according to Aujoulat, d’Hoore, and Deccache (2007), ‘has been acknowledged as an alternative to compliance in order to guide the provider–patient relationship’. In their article, they stated that in contrast to the traditional approach towards healthcare where patients were only seen as the recipients of medical decisions, in the empowerment- oriented approach patients are seen as responsible for their choices and the consequences of these choices (Aujoulat, d’Hoore and Deccache, 2007).

At the Student Health Service of the University of Amsterdam (UvA), Ten Velden (2016) previously evaluated an e-health tool for reoccurrence urine infections. The conclusion of this evaluation was highly positive. Patients rated the e-service an 8.4 on a scale from 1-10 with 10 as very satisfying. This implicates the development of e-health tools for the Student Health Service of the UvA to be promising.

Vaginal complaints could potentially be treated more efficiently with the use of e-health. In about 30 per cent of the cases presented at the GP no microbiological cause for the vaginal complaints is found, while at the same time not all women seek medical help for their symptoms. An e-health tool could help the patient consider the nature of their complaints by structuring their symptoms and give both the practitioner and the patient more insight into the symptoms. Moreover, it might be less confronting for the patient to give intimate information via an e-health tool. Even women who
would not have gone to the GP might experience a lower threshold to search medical help for their symptoms when they could use an e-service.

In order to make the diagnosis of vaginal complaints more efficient, the aim of this study is to evaluate an e-health tool designed to help patients from the Student Health Service of the UvA vaginal complaints self-diagnose and choose an appropriate action. Therefore, the corresponding research question is: To what extent does the e-tool satisfactorily contribute to self-diagnose and self-treatment of women with vaginal complaints?
2. Contextual background
This section elaborates on how vaginal complaints are defined and what the most common causes are. Thereafter, the concepts of e-health, patient empowerment and how decision-making aids are discussed. At last, it is discussed how decision-making aids could contribute to self-diagnosis and treatment decisions for vaginal complaints.

2.1 Vaginal complaints
Under vaginal complaints not only abnormal vaginal discharge is meant, but also symptoms as itchiness and pain in the vaginal area. Abnormal vaginal complaints could have different pathological causes. The most frequent pathological causes found for vaginal complaints are vaginal candidiasis (CV), bacterial vaginitis (BV) or a STD.

The most common cause for vaginal complaints is a candida infection. About 75 per cent of the women experience a yeast infection at some point of their lives, with 40-50 per cent experiencing two or more episodes in a lifetime (Mitchel, 2004). Symptoms reported for candidiasis vaginitis are often thick quark-like white discharge and itch in or around the genitals (NHG-werkgroep Fluor Vaginalis, 2016). While infection may be passed by intercourse, candidiasis vaginitis is not considered an STD. Treatment of candidiasis vaginitis involves most of the time anti-fungal treatment which could be both oral as vaginal (NHG-werkgroep Fluor Vaginalis, 2016).

In the normal vaginal flora, lactobacilli maintain a low pH that prevent bacterial overgrowth (Donders, 2007). When there is a decrease in the lactobacilli, there is a chance for anaerobic bacteria to growth in the vagina (Nugent, 1991). Many women are not aware of having the condition since only in a few cases symptoms occur. If symptoms do occur, watery discharge and an amine or fishy odour are the most common symptoms (NHG-werkgroep Fluor Vaginalis, 2016). It is not yet understood how this bacterial in balance can occur and the cause could not be associated with one single agent but rather with a group of genital microorganisms. Therefor BV is considered a clinical syndrome and is defined by Amsel et al. (1983) by the following clinical signs: pH of the vagina is >4,5, presence of white vaginal discharge, detection of clue cells and the presence of an amine odour after the addition of KOH. Laboratory research includes culture for Gardanella virginals, direct Gram stain of vaginal discharge and biochemical tests for metabolic by-products of vaginal bacteria (NHG-werkgroep Fluor Vaginalis, 2016).

Some sexual transmittable diseases are known to cause vaginal complaints. The most prevalent STDs in The Netherlands are chlamydia and gonorrhoea. When patients are at risk of a STD, a test needs to be done to confirm the diagnosis (NHG-werkgroep Fluor Vaginalis, 2016). Symptoms of Chlamydia include increased vaginal discharge and vaginal contact bleedings. Gonorrhoea is characterised by a yellow-green vaginal discharge (NHG-werkgroep Fluor Vaginalis, 2016). However, vaginal complaints are found to be a poor predictor of the presence of STD’s (Mitchel, 2004).

2.2 E-health
The healthcare sector has been influenced by the electronic developments over the last decades. To cover the description of this influence, the term ‘e-health’ has been introduced. The use of e-health in the healthcare sector created new challenges and opportunities in communication and care for both patients and institutions, for example the possibilities for patients to interact with the
Institutions systems, for institutions to share more data with other institutions and for patients to interact with other patients online (Eysenbach, 2001). Since e-health therefore is not only ‘electronic health’ but comes with a whole new view on healthcare and a new range of possibilities as a consequence of its influence, Eysenbach (2001) defined e-health as follows:

\textit{In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology.}

With this definition Eysenbach (2001) implicit that since e-health is not only a technical development, but a state of mind. Ball (2001) underlines the idea that e-health requires a different way of thinking where patient involvement and empowerment is increasingly important compared to the traditional way of thinking.

### 2.3 Patient empowerment

As described in the section above, the growing use of e-health seems to go hand in hand with patient empowerment. Though different definitions of empowerment have been given, empowerment in general can be described as “a process by which people gain mastery over their lives” (Rappaport 1987). For patient empowerment, this involves the autonomous participation of the patient in decision-making regarding his or her health by taking a more active role and increased responsibility (Schulz & Nakamoto 2013). Schulz & Nakamoto (2013) discussed the underlying thoughts of the appeal of patient empowerment in modern health care. Three reasons for this increased appeal in modern health care were given. First, they identified the ethical grounds on which patient empowerment rests; patient should have increased autonomy in decision making towards their health. Second, the view that patients should be more active and take responsibility for their health in order to reduce healthcare costs is increasingly popular. Third, patient empowerment has been found to improve health outcomes and therefore is beneficial to implement in healthcare. As the increased involvement of patients in health decision-making is a major part of patient empowerment, healthcare providers should facilitate patients in this decision-making process.

### 2.4 Decision-making aids

In line with the trend of growing patient empowerment and as an application of e-health, electronic patient decision-making aids are increasingly used. Decision making aids are designed to support patients to make informed choices. For example, Elwyn et al. (2006) stated that “decision aids are superior to standard counselling in improving patient’s knowledge and realistic expectations about the results of treatments and other procedures”. Decisions-making aids are defined by Elwyn et al. (20015) as “a specific subset of patient decisions, mostly surgical, that are ‘preference sensitive’”. This preference sensitivity means that the decisions made by the patients are based on their specific preferences for the outcomes. For example, when different treatments have the same outcome in terms of expected mortality, the choice for one of them is influenced by the personal preferences of the patient. For the preferences of the patients, the profile of side effects and expected health outcomes of a treatment are important.
2.5 Self-diagnosis of vaginal complaints

Recently, self-medication has become increasingly important in healthcare (Hughes, McElnay & Fleming 2001). According to Hughes et al. (2001) “self-medication moves patients towards greater independence in making decisions about management of minor illnesses, thereby promoting empowerment”. In the Netherlands, more and more over-the-counter drugs are available. For vaginal complaints, this is not different. Since April 2012 the anti-fungal drug clotrimazol has been freely available in Dutch drugstores under the brand name Canesten Gyno. The increase of freely available drugs also initiates the need to self-diagnose. Shivo et al. (2000) states this self-diagnosis raises concerns in the healthcare sector since the information given in the advertisements of over-the-counter drugs might influence women to buy treatments they do not necessarily need. For instance, on the website of Canesten Gyno, a self-test for vaginal candida infection is available. Though multiple possible treatments for this condition do exist, the website only advises the use of their own product and could influence women in to buying their product. Studies showed most women are not able to self-diagnose their vaginal complaints accurately, and more information should be provided by doctors and physicians and pharmacy personnel to help women self-diagnose their complaints better (Sihvo, Ahonen, Mikander & Hemminki 2000).
3 Conceptual background
In this section, the theoretical basis of this study is described. First is described how the quality of a decision-making tool can be assessed by the IPDAS criteria from Elwyn et al (2006). Secondly a framework is explained about satisfaction towards a service and its quality by De Ruyter et al (1997). Thirdly, a combination of both frameworks applied on an e-health tool by Hooiveld (2016) will be explained that is used for the evaluation of the patient satisfaction with the e-tool for vaginal complaints.

3.1 Decision-making aid quality criteria
As a consequence of the trend of patient empowerment, decision-making aids in health care in are increasing. More than 500 decision-making aids are available worldwide, but not all give reliable health information and it is hard for patients to check whether a decision tool is reliable (Elwyn et al., 2006). Elwyn et al (2006) developed the International Patient Decision Aid Standard (IPDAS) to fill in this gap. These standard is presented as a checklist of quality criteria available for both users as developers of decisions aids and aims to generate an internationally supported quality framework for decision aids. Therefore, the IPDAS criteria can be used by developers as a checklist in the development process, but also for the evaluation of an existing decision-making aid by for example users. Based on their study, Elwyn et al. (2006) distinguished three subsets in the quality assessment: content, development process and effectiveness. The first subset, content, refers to the reliability of the information and the available options that are specific for the condition the decision aid is about. This subset elaborates on whether the decision aid gives information in sufficient detail to base a decision on, presents information in an unbiased and understandable way, includes methods for clarifying patient values and included a structured guidance in to making a decision. The second subset, the development process, refers to criteria of the presentation of the information. This subset is used to estimate whether the decision aid presents information in a balanced way, uses scientific evidence, and discloses conflicts of interest of the parties involved. Additionally the second subset targets the understandability of the language used in the decision aid. The third subset, effectiveness, refers to the process of decision-making and whether the decision aids accurately helps to make high quality decisions based on the input of the patients. Thus, whether the match between the chosen treatment option and patient values is improved.

Although the IPDAS quality framework is widely used to assess the quality of patient decision-making aids, Bekker (2010) expressed critics on the use of the standard. The main critic is that the use of the IPDAS quality criteria assumes investigators have the knowledge to critically appraise the intervention, evaluation and implementation. Bekker (2010) described three reasons why this critical appraisal might be challenging. First, the checklists have 47 criteria to fulfil and it is implied that all criteria are equally important for the quality of the decision-making aid. Second, Bekker (2010) argues that the criteria “require significant expertise from the decision science to operationalize”. This need for expertise is required since the criteria state for example ‘provide steps to make a decision’ but it is not explained how steps to make a decision can be provided. Third, the evidence-based domain to base the IPDAS criteria on was weak. The checklist therefore is based on the opinions of experts and has no evidence to indicate which criteria lead to better decision-making. Durant et.al (2015) endorse the challenges of the IPDAS criteria. However, it is argued by Durant et al. (2015) that although further theoretical and empirical support for quality measures of decision-making aids is needed, the use of the IPDAS quality framework is beneficial since at the moment, it is
the only quality control that is available for the increasing amount of patient decision-making aids. Therefore, it is important to take these critics in account when using the IPDAS quality criteria.

3.2 Patient satisfaction

To test whether the decision aid is actually satisfying women with vaginal complaints, the concept of patient satisfaction regarding a decision-making tool has to be understood. De Ruyter, Bloemer & Peeters (1997) developed a framework that merges the quality of a service with satisfaction. In this framework patient satisfaction is based on three key concepts; expectation, perception and confirmation. Ruyter et al., (1997) argue that before using a service, costumers have expectations of the service and these expectations are the standard against which the costumers will judge the service. Perceptions imply the perceived performance of the service. When these expectations are compared to the perceptions of the service, this will lead to a degree of confirmation or disconfirmation. Confirmation will occur when the service meets precisely the needs of the expectation of the costumers. Disconfirmation can lead to both satisfaction as well as dissatisfaction. Ruyter et al., (1997) predict that satisfaction is likely to occur when the perceived performance exceeds the expectations of the costumer. While dissatisfaction is likely to occur when the prior expectations exceed the performance of the service (Ruyter et al. 1997). This means that the degree of satisfaction is influenced by perceived performance and expectations by degree confirmation, but also by perceived performance of a service directly. De Ruyter et al. (2012) argued that perceived quality of a service and patient satisfaction influence each other in a non-recursive positive relationship.

3.3 Framework and research questions

In order to assess the quality of this decision-making aid for vaginal complaints in regard of patient satisfaction, both frameworks can be combined. Hooiveld (2016) combined these two frameworks to assess patient satisfaction of a contraceptive aid. The model of Ruyter (1997) was used and in the perceived quality domain of his original model, the IPDAS quality criteria domains were inserted to represent the concept of perceived quality in the case of a decision-making aid. This quality criteria could be used for the perceived quality since the IPDAS criteria are fit to be used to evaluate an existing decision-making aid. An adaption of the combined framework by Hooiveld (2016) is shown in figure 1. Expectations and perceptions on the quality of the decision tool both lead via a degree of (dis)confirmation between them to a certain degree patient (dis-)satisfaction as shown in the figure.
The aim of this study is to evaluate an e-tool for women with vaginal complaints. Based on the framework described above, sub questions are derived. In order to evaluate the e-tool, the framework shown in figure 1 will be used to assess the patient satisfaction on the quality of the e-tool. According to the framework, both the expectations of the quality as the perceived quality need to be assessed based on the IPDAS subsets of criteria. This leads to the following research questions.

Main Research question: To what extent does the e-tool satisfactory contribute to self-diagnose and self-treatment of women with vaginal complaints?

Sub questions:
1. **Content**
   - What do the users expect from the content of the decision-making aid?
   - Does the decision-making aid meet these expectations in the user’s experience?
   - Does the decision-making aid...
     - Provide information about options in sufficient detail for decision making?
     - Present probabilities of outcomes in an unbiased and understandable way?
     - Include methods for clarifying and expressing patient’s values?
     - Include structured guidance in deliberation and communication?
2. **Development Process**
   - What do the users expect from the information sources and parties involved in the decision-making aid?
   - Are these expectations met according to the users?
   - Does the decision-making aid...
     - Present information in a balanced manner?
     - Have a systematic development process?
     - Use up to date scientific evidence that is cited in a reference section or technical document?
     - Disclose conflicts of interest?
     - Use understandable language?

3. **Effectiveness**
   - What do the users expect from the effectiveness of the decision aid?
   - Does the decision-making aid meet these expectations according to the users?
   - Does the decision-making aid ensure decision-making is informed and values based?
4. Methodology

In this section elaborates on the study procedures of the current study. The development of the e-tool is explained followed by the procedures and analysis of the semi-structured and ‘think-aloud’ interviews.

4.1 Study design

This study will be carried out amongst the patient population of Student Health Service of the UvA/GP Oude Turfmarkt located in Amsterdam, The Netherlands. Student Health Service of the UvA is a GP specialised in student health care, but also non-student inhabitants of Amsterdam are assigned to the practice.

The study was conducted over a 20-week period between February and July 2017. In order to address the main research question, an in depth understanding of the expectations and perceptions of the users of the e-tool is needed. In this line, a qualitative study design will be appropriate as it allows patients to elaborate on their answers and help gain a deeper insight in the expectations of the quality and perceived quality of the e-service. First, the decision-aid was developed taken in account the IPDAS quality criteria and the need assessment of Dutch female students towards a decision-aid by Molenaar (2014), since a large part of the patient population of the Student Health Service of the UvA is student. Second, in order to answer the research question, qualitative data was gathered using semi-structured and cognitive interviews (Gray, 2014).

4.2 Development of the e-tool for vaginal complaints

In the first part of the study, an online self-diagnosis and decision-making aid for vaginal complaints was developed by the researcher of this study. The aid was developed in the form of an online questionnaire available on a website. The aid was commissioned by the Student health service of the UvA. The first part of the aid aims to help women with vaginal complaints self-diagnose more accurately, while the second part of the aid aims to direct women with vaginal complaints to a treatment/action that is most appropriate and in line with the patient’s preference. Besides, the decision aid, the website will exist of informative pages of causes for vaginal complaints and treatment options in order to help women be more informed about vaginal complaints.

The content of these informative pages is based on literature research, the NHG-standard for vaginal complaints, expert information of Peter Vonk (GP at the Student Health Service of the UvA) and the outcomes of the need assessment by Molenaar et al. (2014). Molenaar et al. (2014) found in a research on the need assessment of Dutch female students towards a contraceptive decision aid that Dutch female students found it important to have an extensive explanation of the proposed contraceptive. Additionally, the design and look of the questionnaire was important for Dutch female students. While the current e-tool for vaginal complaints not only focusses on Dutch female students, but on Dutch women at the GP’s generally, it could be argued that this critical attitude towards information about the explanation of treatment possibilities and design is also applicable on the population of high educated modern women in the centre of Amsterdam. After the gathering of information for the aid and developing the structure, the content was discussed with GP Peter Vonk and Dr. Claudia van der Heijde. Thereafter, web design agency Baas Interactive developed a website with this questionnaire and the informative pages. The designed prototype was then shown to the supervisors of this study and after approval the interviews to evaluate the e-tool began.
4.3 Study population and sampling
Since the Student Health Service of the UvA is specialized in student health care, the study population will be existing mainly, but not only, of young women living and or studying in Amsterdam. Patients assigned to the General Practisers’ with current or previous vaginal complaints were selected based their medical information available in the patient files. The participants were contacted to be participate in the research personally by e-mail. This e-mail is available in appendix 2.

4.4 Data collection
The qualitative part of this study was conducted by face-to-face semi-structured interviews and ‘think-aloud’ interviews. The semi-structured interviews enabled the researcher to guide the interview on the basis of the theoretical framework explained in the conceptual background section in order to gain deeper insight in the expectations and perception of the participants (Gray, 2014). ‘Think-aloud’ interviews were used in order to gain insight in the participant’s opinions on the use of the e-tool while using the tool. Interviews using the ‘think-aloud’ method, have an open structure. This method enables participants to speak out loud all their thoughts and remarks while performing a task, in this case while using the e-service. This method generates inductive data that can be used to improve aspects of the e-tool (Someren et al., 1994). The two methods will be integrated during the interview of which the procedure is explained below.

The interviews were conducted face-to-face at a location that enabled the researcher and participant to talk out loud freely over the privacy sensitive subject vaginal complaints. The location was chosen in consultation with the participant. At the start of the interview, an introduction will be given that explains the purpose of the interview. The participants were asked for permission for audio recording of the interview. The records were used only for data analysis. Thereafter, the participants were asked to give some general information about their age and education. Followed by the first part of the semi-structured interview, that contains question regarding their expectations of the participants towards the quality of the e-tool. Then, the ‘think-aloud’ part of the interview took place in which participants were asked to use the e-tool and report every thought they had out loud. After this, the semi-structured interview resumed in which was asked whether the e-tool met their expectations towards the quality criteria. The interview guide used during the interviews can be found in appendix 3.

4.5 Data analysis
After data collection, the interviews were transcribed and analysed using three types of coding (Gray, 2014). First open coding will be performed. Hereby relevant fragments of the transcripts will be labelled. Then, axial coding took place whereby the labels where sorted and categorised. In the last phase of the coding selective coding was performed where codes were linked to concepts and sub concepts of the conceptual framework. Additionally, the remarks that could be suggestions for improvement of the decision-aid in the ‘think-aloud’ part of the interviews, will be taken in account for the revising of the e-tool.
5. **Results**

In this chapter the results of the study are discussed. First, an overview of the characteristics of the study population is given. Second, the results of the expectations, perceptions leading to (dis-)confirmation per subset of the IPDAS quality criteria are discussed.

5.1 **General characteristics**

In total 10 women who previously or currently experienced vaginal complaints were interviewed. The age of the respondents ranged from 21 to 57 years old. All respondents were educated at University or University of Applied Sciences level. Seven of the respondents were still studying, while three respondents were in the working phase.

Table 1 An overview of the age, educational level and occupation of the study population

<table>
<thead>
<tr>
<th>Respondent</th>
<th>Age</th>
<th>Level of education</th>
<th>Occupation</th>
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<tbody>
<tr>
<td>R1</td>
<td>33</td>
<td>U</td>
<td>Working</td>
</tr>
<tr>
<td>R2</td>
<td>38</td>
<td>UAS</td>
<td>Student</td>
</tr>
<tr>
<td>R3</td>
<td>33</td>
<td>U</td>
<td>Working</td>
</tr>
<tr>
<td>R4</td>
<td>23</td>
<td>U</td>
<td>Student</td>
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<tr>
<td>R5</td>
<td>24</td>
<td>UAS</td>
<td>Student</td>
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<tr>
<td>R6</td>
<td>22</td>
<td>U</td>
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<td>R7</td>
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<td>R9</td>
<td>23</td>
<td>U</td>
<td>Student</td>
</tr>
<tr>
<td>R10</td>
<td>57</td>
<td>UAS</td>
<td>Working</td>
</tr>
</tbody>
</table>

5.2. **Content**

This paragraphs elaborates on the content subset of the IPDAS criteria. The information need, expectations and perceptions of the respondents towards the content of the decision aid will be discussed. First will be discussed how respondents search for information about their complaints and how they distinguish between information sources. Second, the expectations towards the content of the decision tool prior to using it be discussed. Third, perceptions of the respondents on the content after the use of the e-service will be treated and how these expectation’s and perceptions (dis-)confirm each other.

5.2.1 **Searching for information**

Most of the respondents reported to search for information when experiencing vaginal complaints. All of them mentioned to use the internet to google their symptoms. None of them mentioned to search in books or magazines. The respondents argued to distinguish between reliable and not so reliable sources. Respondents found it hard to value whether a source was reliable, although most of the time they would not search for the writers of the source. Most respondents would use multiple sources to double check the advises they previously found. This searching of multiple sources was not found to be a problem.
But I don’t really mind to look in to multiple sources. Just to quickly look at five websites or something I don’t mind. You will arrive at the website of gyno crème very quickly for example, but they just want you to buy their product. So, I will check that on another website as well.  

Forums with patient experiences were specifically noted as unreliable sources, however some respondents did find them useful to check a certain treatment found in another source. Thuisarts.nl was often referred to by the respondents as a useful and reliable source because it was written by GPs. The involvement of medical education persons in the information given in a source was found to be very important for the respondents. Although respondents found there was a lot of information about symptoms and treatments available on the internet, it was found hard to distinguish which symptoms would be applicable to them. Respondents also mentioned to use their friends as source of information, they would discuss their experiences with symptoms and possible treatments with them. Respondents who did not search for information about their symptoms gave as main reason that they already recognized their symptoms and knew how to act up on them, therefore they did not need to search for information.

5.1.2 Expectations on content
When asked about their expectations of the content of a decision aid for vaginal complaints, most respondents answered to expect an informative webpage with mostly information about vaginal candida infections. Some respondents also mentioned to expect information about bacterial vaginosis and only one respondent also mentioned spotting between periods and vaginism. The respondents expected the aid to guide them through the symptoms they experienced and to give them information about what caused their symptoms, but also about the actions they needed to take to treat their symptoms.

Yes I would think it would be a sort of roadmap that starts with what are your symptoms. Maybe you will start with multiple categories and that you can refine until you end with a solution.  

Multiple respondents mentioned they would expect the aid to help them distinguish when to visit the GP and when to self-treat their symptoms. It was especially mentioned by respondents with reoccurring vaginal candida infections that they would like the aid to tell them how often they could use the over-the-counter products and whether they would be harmful to use on a regular basis. Also, respondents mentioned they would like the decision aid to give information about the prevention of reoccurring symptoms.

5.1.3 Perceptions on the content
After the respondents went through the decision aid, they gave their perceptions on the content of the aid. In general, respondents found that the aid was convenient and gave a clear advice. Especially

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1 Je maar ik vind het zelf ook niet zo erg om meerdere dingen te kijken. Gewoon even snel 5 sites lezen ofzo dat maakt me niet uit. Je komt al heel snel op zo’n site van bijvoorbeeld gyno crème ofzo maar zij willen natuurlijk gewoon dat je dat koopt. Dus dan check ik dat ook wel op andere websites.

2 Ja, ik zou denken dat het een.. Eh.. Soort stappenplan is waar je mee begint van wat is je klacht. Misschien dat je begint met een aantal categorieën en dat je het telkens kan verifiën tot je bij een oplossing komt.
the information about the natural treatment options, even though these are not scientifically proven, were found to be very interesting by the respondents.

*Well, I think it is convenient that it is explained what considerations were made for a certain something. And also, as with the tampon, that there is information given that you can just give a try. That is very nice.*

However, it was mentioned that some the descriptions of some of the symptoms were subjective. The respondents suggested this subjectivity could possibly be solved by the addition of visible support to the description. Also, the respondents had to choose from one of the symptoms, while one respondent mentioned that in her situation all symptoms occurred at the same time.

*It is very subjective. If it states like discharge is lumpy, what is actually lumpy? Actually, you would want to know how it looks like. A picture or something.*

Additionally, most respondents mentioned that the decision tool gave enough information to help them decide which action to take. The considerations to choose different treatment options were found to be clear to the respondents. Although, one respondent noted she would have wanted to have more information about for example the exact side effects of certain over-the-counter and prescription drugs. That was in contrast to a respondent who mentioned more detailed information would only rise confusion and not contribute to her make a better decision.

*No I would not want to know that actually, it would only raise questions like why do this side effects occur and how often and why would I have them or not?*

A respondent who argued the information was detailed enough for her to make a decision suggested that women who would like to know more about the suggested treatment could always search the web for more information. In general, the respondents found the content of the aid to be informative and to enlarge their current knowledge on treatment options.

### 5.1.4 Confirmation on content

In general, the expectations of the respondents on the content of the decision aid were met. In line with the expectations on the content, the decision aid was a road map that would lead to an advice. Respondents mentioned to be satisfied with the content and did not miss vital information about the diagnosis and treatment options. However, when discussing the perceptions on the content it was mentioned on several occasions that visual support would be wanted.
5.2 Development process
The development process subset of criteria targets whether or not the decision aid would present information in a balanced manner, uses up to date scientific information, discloses conflicts of interest and uses understandable language and what parties are involved in the decision aid. In this paragraph the subset development process is discussed. The expectations on the development process will be described followed by the perceptions of this after using the decision aid. At last, the (dis-) confirmation between the expectations and perceptions of the respondents on the development process subset will be treated.

5.2.1 Expectations on development process
Parties expected to be involved in the development of the decision aid were, GPs, gynecologists, scientists, web designers and pharmacists and the municipality. Especially the involvement of medically trained persons was mentioned to be very important to the respondents. On several occasions respondents said to hope no pharmaceutical company would be involved as this would negatively influences the credibility of the e-tool.

Well, they just want to sell their product so I would think that would influence the outcome. If for example you would get money for every patient you would prescribe their drug, yes that would be bad.6

Respondents expected the information given on the website to be based on the experiences of medically trained persons such as general practitioners and gynecologists. The information shown in the e-tool would not necessarily need be scientifically proven as most respondents claim to trust the judgement of medical trained persons. Although, multiple respondents did mention scientific evidence would be an asset to the tool.

It is always nice if it has been scientifically proven, that gives... assurance, handhold.7

The tool was not expected to use references in the text to underline the scientific basis. Instead, respondents expected a short overview somewhere on the website of the literature used in the decision aid. One respondent mentioned to hope to see a reference to the NHG-standard in the sources list.

On the language of the tool the respondents expected the tool to be understandable for all people. Medical terminology was found to avoided as this was expected to reduce the understandability. On the other hand, respondents mentioned the decision aid should not be in too simple language if this would make them feel childish and not taken seriously.

5.2.2 Perceptions on development process
The information shown in the decision tool was found to balanced and unprivileged by all respondents. None of the respondents had the feeling one of the outcomes or treatment methods had preference above another without an explanation of the pro’s and con’s. The respondents mentioned the involvement of a GP in the decision aid to be very positive. However, a few

6 Nou, zij willen gewoon hun product verkopen dus ik zou denken dat dat wel de uitkomst beïnvloedt. Als je bijvoorbeeld geld krijgt voor iedere patiënt die je hun medicijn zou voorschrijven. Ja, dat zou slecht zijn.

7 Het is altijd fijn als dingen wetenschappelijk bewezen zijn, dat geeft... zekerheid, houvast,"
mentioned they would have expected a gynecologist to be involved and found it a bit disappointing that there was not one involved.

Where the information on the website was based on, was clear to the respondents. Multiple respondents mentioned it was clear to them the natural treatment options were not based on scientific evidence, however the respondents found these options to be an interesting supplement to the evidence based information. In the judgement of the respondents the sources listed in the reference list were found to be convincing. As one respondent stated:

*Let’s see... I see NHG standard, pharma therapeutic compass... some English sources. Looks good. Also ‘water as medicine’, no idea what that is. It looks reliable.*

The language used in the decision aid was found to be understandable by the majority of the respondents. However, some respondents mentioned the use of medical terminology which they did not understand. Also, some critics on the readability of the text arose. Multiple respondents mentioned the text of some questions was too long and therefore not understandable to everybody. In general, the respondents found the text understandable to themselves, but had doubts on whether the general population would understand the text of the decision aid.

*Well, maybe it is understandable, but I think there are a lot of people who would not want to read so much text. That would be a hooking point. If you are scientifically educated, it would not be a problem. I don’t know whether is fits with people who are not. If I think of my carpenter friends, it would be a lot to them.*

5.2.3 (dis)confirmation on development process

There was some disconfirmation between the expectations and perceptions on the development process subset. Respondents expected more medical trained people to be involved in the development of the decision aid than there actually were. On this point, the expectations of the respondents were not met in the perception. Even so, respondents claimed the aid would be as reliable as expected since the initiative of developing the aid was taken by a GP and they would trust their GP.

*That is because it is at my GPs. That is why you would think this would just be good.*

Additionally, the scientific basis of the decision aid did meet the expectations of the respondents. On this point the perception of the respondents confirmed their expectations.

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8 Even kijken... Ik zie NHG-standaard, farmaco therapeutisch kompas... Paar Engelstalige bronnen. Ziet er goed uit. Ook water als medicijn, geen idee wat dat is. Het ziet er wel betrouwbaar uit.

9 Nou het misschien wel begrijpelijk maar ik denk dat er wel veel mensen zijn die niet zoveel tekst willen lezen. Dat zou wel ene afhaak punt zijn. Als je wetenschappelijk opgeleid bent, zal dat geen probleem zijn. Ik weet niet of het goed aansluit voor mensen die dat niet zijn. Als ik denk aan vrienden die timmerman zijn, dan is het voor hun wel veel.

10 Dat heeft er dus mee te maken dat het bij mijn huisarts is. Daarom denk je van dit moet gewoon goed zijn.
The language of the tool was not found to be as plain as expected, what caused disconfirmation at this point of the subset. This was mostly caused by the lengthiness of the text of some questions. Therefore, the text would not be understandable to the whole population as the respondents did expect.

5.3 Effectiveness

This paragraph elaborates on the subset effectiveness. This subset describes the process leading to actual decision-making and the quality of the decision. First, the expectations towards the effectiveness are explained. Second, the perception of the respondents on the effectiveness will be discussed. Third, the compliance between the expectations and perception of the respondents on the effectiveness will be treated.

5.3.1 Expectations on effectiveness

The influence of the decision aid on decision-making was expected to be big. Most respondents argued they would follow the advice of the decision-aid. Respondents hoped to tool would clarify to them when to seek medical help and when to wait and see how symptoms develop. Respondents mentioned they would not expect the decision aid to substitute a consult with a GP, but it would rather help them think about their symptoms and possible treatment options before going into a consult. This was expected to positively influence their consult with the GP as they would be more informed and aware of their possible diagnosis and treatment options.

5.3.2 Perceptions on effectiveness

Respondents found the tool helpful in helping them diagnose and make a decision towards the action they needed to take. As one respondent described:

*That you are just being led precisely towards the diagnose and the extra tips and background information given, I find it very convenient. All that information in one place, so you don’t have to search different sites. And that you are able to ...eh... sort of self-diagnose but that it is based on the GP so that it would be reliable.*

The tool was found to be very helpful in distinguishing when to visit a GP and when to wait and see how symptoms develop. Respondents argued that the reason for this was that the tool explained how symptoms may disappear by themselves but also gave information about natural treatment options. These options were found to be a convenient possibility to try out while awaiting the symptoms. Therefore, the tool would stimulate women in taken the action needed.

*I think it would help women to take action sooner. Sooner to be like ok, I need to take action because the website shows me this is going on with me. Or like, I don’t have to stress because it is not as bad as I thought. I just need to go to the drugstore and take a little pill and it is done.*

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11 Dat je gewoon precies geleid wordt tot die diagnose en dat er wat extra tips en achtergrondinformatie bij staat vind ik handig. Dat die informatie op 1 plek staat en dat je dus niet allemaal sites af hoeft te gaan en toch... eh... Toch een soort zelf diagnose die toch gebaseerd is op de huisarts op iets wat gewoon klopt.

12 Ik denk dat het vrouwen om het zo te noemen sneller tot actie overzet. Sneller van oké ik moet wat doen want de website laat zien van dit is gaande bij mij. Of van ik hoef niet te stressen want dit is niet zo erg als ik denk ik moet gewoon even naar de drogist een pilletje nemen en dan is het klaar.
However, some remarks towards the decision aid were made. Some respondents mentioned that when you would choose the option of having had unsafe sex and the aid would immediately and recommend to test for an STD, that outcome was disappointing. Since, this result would pop-up after just one question, they would not feel heard. In that case, they would be triggered to disregard the test or redo it and fill in they would not have had unsafe sex. Therefore, that part of the decision tool would not be effective in decision-making.

5.3.3 (Dis-) confirmation on the effectiveness
The expectations and perceptions on the effectiveness on the tool leaded to confirmation according to the respondents. As expected by the respondents, the tool was not found to be a replacement for a consult with the GP. However, the respondents did find the tool to be helpful in order to help differentiate which action to take as they expected the tool to be. All respondents claimed to recommend using the tool to their friends who experienced vaginal complaints.
6. **Discussion**

In this chapter the main findings of the study are discussed and put in perspective. The limitations and strengths of this study are treated and recommendations for further research are given. At last, the clinical implications are given.

6.1 **Main findings**

The aim of this study was to evaluate an online decision aid for women with vaginal complaints in order to make diagnose and treatment more efficient. Therefor the corresponding research question was: To what extent does the decision aid satisfactorily contribute to the self-diagnose and self-treatment of women with vaginal complaints. In order to investigate the patient satisfaction with the quality of the e-tool, ten female patients of the Student Health Service of the UvA / GP Oude Turfmarkt in Amsterdam were interviewed.

As described in conceptual framework, patient satisfaction with the quality was measured based on the (dis-)confirmation between expectations and perceptions of the patients on the quality of the decision aid. The measurement of the quality of the decision aid was based on the IPDAS quality criteria. These criteria existed of three subsets: content, development process and effectiveness. The subset content referred to whether the aid provided the right information to base a decision on. With development process was meant whether or not the e-tool presented information in a balanced manner, used up to date scientific information, disclosed conflicts of interest and used understandable language. The last subset, effectiveness described the process leading to actual decision-making and the quality of the decision.

On the content subset, the expectations of the respondents were met in their perception leading to confirmation and patient satisfaction with the e-tool. The tool was, as expected, found to be a roadmap leading to an advice. The respondents mentioned to found the information detailed enough, but did suggest visual support in order to make the interpretation of the symptoms less subjective. This part about the decision-aid is particularly hard since two patients might nog describe their symptoms the same way. While in order to make a decision, some sort of description should be given. Wulff (1999) described how doctor should ask themselves how the patient feels, but will only be able to understand a patient to a certain extent since feelings and experiences are personal and therefor subject to subjectivity.

The expectations on the development process subset were not met on all points leading to some disconfirmation and dissatisfaction. The decision aid was expected to be developed by multiple medical trained people, while in reality one GP was involved. Even though this did not meet the expectations of the participants, the participants did found the decision aid reliable since they would fully trust their GP. In 2002, Andreassen et al., found how important this trust relationship between doctor and patient is in e-mediated communication. They stated that on the base of effective e-mediated communication, there must be trust between patients and doctors. Therefore, the trust in the GP reported by the participants of the current study is an interesting factor contributing to the perception of reliability of the decision aid.

Another aspect of the development process that did not cover the expectations of the participants, was the understandability of the language used in the decision aid. Respondents claimed to find the aid readable for themselves, but did not expect the whole general population to understand the...
In line with the expectations of the development process, no pharmaceutical companies were involved in the development of the e-tool. This aspect was found to be very positive by the respondents and was found to increase the credibility of the decision aid. Also, the presentation of different treatments options was found to be balanced and unbiased. This reported balanced and unbiased presentation of information perceived by the respondents could be tricky in assessing the actual balance of information according to Barry (2002). Barry (2002) explained that people leaning to a certain decision before using a decision aid often find that decision tool referencing their decision as well.

On the subset effectiveness, the expectations of the patients were met leading to confirmation and satisfaction. Beforehand, the respondents claimed to not expect the decision aid to substitute a consult with a GP, but to help them distinguish whether or not to visit the GP. The respondents reported the tool to be helpful in guiding them towards a decision to make on which action to take. Additionally, the tool was found to help patients gain insight in their symptoms and enlarge their knowledge on treatment options. Therefore, respondents found the tool to improve the efficiency of their consult with a GP.

6.2 Strengths and limitations

Some limitations need to be taken in account when assessing the findings of this study. The IPDAS quality criteria for decision aids are developed for both developers of decision-aids as for users (Elwyn, 2006). Even though some criteria mentioned in the IPDAS implicate deep understanding and knowledge of decision-making processes and therefore it can be doubted whether the IPDAS can be applied by users to examine the quality of a decision-aid. In this study, this limitation was restricted by not using all criteria named in the IPDAS, but select the ones that were applicable.

Another point of discussion is that the IPDAS is designed to assess the quality of decision-aids for situations where the health outcomes of the possible treatments are the same for all outcomes of the decision aid (Elwyn, 2006). This means that no matter what the treatment outcome of the decision aid is, it would have equal effects on the health outcome of the patient. The designed decision aid for vaginal complaints actually consists of two parts. The first part is a self-diagnosis aid. In this part is does matter what the outcome is for the eventual health outcome, since treatment would not resolve if a patient is treated for the wrong diagnosis. However, the second part of the decision aid is an actual decision aid since all treatments had as outcome to treat the diagnosis, it can be questioned whether the IPDAS would be applicable for the first part of the decision-aid.

Additionally, it needs to be taken in account that there might be some bias in the selection of the study population. Patients from the Student Health Service were asked to participate in the research. Out of the fifty approached women, fifteen interviews were planned. Five interviews were cancelled by participants on the last minute. This could implicate that the women interviewed in this study found it important to participate in a research for vaginal complaints. Therefore, it could be that they...
would have high interest in the subject due to personal experiences with vaginal complaints. This could have influenced their perception on the decision aid as they might be more satisfied with or more critical on the existence of a decision aid than women who would not have found research to vaginal complaints important. Moreover, the women participating in this research reported to have experienced vaginal complaints on several occasions and indicated that the diagnostic part of the tool might be more helpful for women who would experience their complaints for the first time. It might be interesting to test the decision-aid on patients who present themselves at the GP with vaginal complaints for the first time in order to gain insight in how satisfying the decision-aid is to these women.

As mentioned above, all participants were educated on U or UAS level. This might be explained because at Student Health Service / GP Oude Turfmarkt more highly educated women are registered, but also because these highly educated women are more interested in research. The relatively high education level of the participants compromises the generalizability of the results for the general Dutch female population.

The age distribution of the participating women is strength of this research. The women interviewed in this study were between 21 and 57 years old. Therefore, the results are not only applicable for students but give information about women of different age groups. This wide spread of age in the participants increases the generalizability of the results.

6.3 Implications for further research

During the interviews, multiple respondents mentioned to experience a gap in the medical help for women with recurrent vaginal candida infections. They present themselves at the GP on a regular basis with symptoms of candida infections and are treated for their symptoms every time. However, this solution is not structural. The women need to go to the GP every time and feel like there is no real solution for their complaints, symptoms reoccur after treatment. These women also mentioned the need for more attention to the psychological effects of the symptoms as it would affect their personal sex lives as well. As one women stated:

*There have been times, I had it so often. Than I did not want to have sex. You feel dirty. For a time, I have washed my bed every day. I thought, maybe that is the reason.*

Therefore it could be interesting to investigate the needs and treatment possibilities of women with recurrent vaginal infections in order to develop a protocol for GPs on how to support this group both physically and psychologically.

Another implication for further research is the educational level of the participants. As the educational level of the participants is relatively high, it would be interesting to reproduce this research with women from different educational levels. This could give more insight in whether the decision-aid need adaptations to be useful to the general female population in the Netherlands. Not only on the textual understandability or readability, but also to gain insight in the issues this part of the population have on vaginal complaints.
6.4 Recommendations and clinical implications
In conclusion, it can be said that the decision-aid has high potential to help women with vaginal complaints structure their symptoms and choose appropriate treatment satisfactorily. The tool is not implicated to substitute a consult with the GP, but could potentially help women structure their symptoms and enlarge their knowledge before visiting the GP. This could contribute to more effective diagnosis and treatment of women with vaginal complaints when the tool is made before visiting the GP. Therefore, doctor assistants of the practice should be involved in the promotion of the tool under the patients so that patients would do the tool before visiting their GP. However, some adaptations need to be made in order to make the tool more satisfying for the patients. The language use in the e-tool should be reconsidered and some visual support needs to be added in order to reduce the subjectivity of the symptoms as much as possible. Additionally, it is recommended to involve a gynecologist in the development of the tool in order to increase the perceived credibility of the decision aid as this would satisfy the users.
7. References


Appendix 1: IPDAS criteria

**IPDAS 2005: Criteria for Judging the Quality of Patient Decision Aids**

**Steering Committee:** A O'Connor (CA) & G Chyn (UK) (co-leaders) with A Barrett (AU), M Berry (US), A Coulter (UK), M Holmes-Rovner (US), G Moodie (UK), I Llewellyn-Thomas (US), M O’Kane (US), A Thomson (UK), D Stacey (CA), T Whelan (CA)  
**Methods Group:** G Chyn (Leader) UK with S McOwen (US), T Shekelle (US), R Thompson (UK), I Volk (US)  
**Stakeholder Leader:** A Coulter (UK)  
**Quality Criteria Panels:** A O'Connor (CA) & I Llewellyn-Thomas (US) editors with J Audisier (UK), A Barrett (AU), M Berry (US), G Moodie (UK), J Rennie (US), C Bradshaw (UK), P Butow (AU), E Chan (US), A Chvatl (Switz), A Clarke (UK), J Davison (CA), J Dolan (US), A Edwards (UK), V Entwistle (UK), A Fagerlin (US), D Feldman-Stewart (CA), J Fowlke (US), D Frosch (US), P Hawke (UK), M Holmes-Rovner (US), T Hope (US), M Jacobsen (CA), A Kennedy (Switz), S Knight (US), M Kuperman (US), B Ling (US), T Marteau (UK), K McCaffery (AU), N Mourjides (RU), A Mulley (US), M O'Connor (US), E O’Grady (US), C Pare (CA), P Pare (US), R Riboli (US), C Ross (NC), L Schwartz (US), K Spivak (US), S Stirling (US), S Statkoff (UK), D Stolar (CA), D Stowell (US), V Tal (CA), D Timmermans (NL), T Teixeira (AU), T Whelan (CA), C Wells (US), S Woloshynowych (US), Z Zielinski (UK)

**What are patient decision aids and why are they needed?**

Patient decision aids are tools to help people participate in their health decisions in ways they prefer. They are used when there is more than one medically reasonable option to diagnose or treat a health problem. Each of the options has good and bad features that people value differently. Even when two people are in the same situation, what is important for one person may be different for another person. Therefore, there is no clear answer that applies to everyone. The best choice involves matching which features matter most to a person with the option that has these features. To make a good decision, you need an expert on the facts (e.g., a health practitioner) and an expert on which features matter most (e.g., the patient) and a way to share their views with each other in ways they prefer.

Patient decision aids aim to do three things to support people for decision making. They provide facts about a person’s condition, the options and their features. They help people to clarify their values (the features that matter most to them). They help people to share their values with their health care practitioner and others, so a course of action can be planned that matches their values. Patient decision aids do not advise people to choose one option over another. They do not replace counseling from a health care practitioner. Instead, they prepare people to discuss the options with their health care practitioner.

An international group of researchers, known as the ‘Cochrane Review Team of Patient Decision Aids’ is compiling decision aids and summarizing the results of research trials. The latest review of 24 studies shows that patients and practitioners who use patient decision aids make better decisions. Patients participate more, know more, and have more realistic expectations of what might happen. They are more likely to receive an option with features that are valued by both the patient and the practitioner.

The **International Patient Decision Aid Standards (IPDAS) Collaboration** is a group of researchers, practitioners and stakeholders from around the world. The goal is to establish an internationally approved set of criteria to determine the quality of patient decision aids. These criteria will be helpful to a wide variety of individuals and organizations that use and/or develop patient decision aids.

**Why are standards needed?**

There are over 500 patient decision aids available or being developed by many different individuals and groups around the world. However, people have difficulty knowing whether or not a decision aid is a source of reliable health information that can help in decision making.

**How were the standards obtained?**

There was a 2-stage evidence-informed Delphi consensus process:

- **Participants Included:** 122 people from 14 countries and 4 stakeholder groups [researchers/developers; health professionals/patient/consumers; policy makers/health plan administrators]
- **A voting document was developed from a series of background papers on 12 quality domains.** [The experts who wrote these papers are listed above.] Before voting on the importance of each criterion in judging the quality of a patient decision aid, voters reviewed: definition of decision aid; definition of criterion; theoretical link between criterion and decision quality; and empirical evidence supporting or not supporting its use in decision aids. Evidence was derived from fundamental studies and a Cochrane Collaboration systematic review of randomized trials of patient decision aids.

The standards are summarized in a users’ checklist on the next page.  
For more information and to obtain copies of the IPDAS documents visit our website at [www.ipdas.ohri.ca](http://www.ipdas.ohri.ca)
Table 3. IPDAS Patient Decision Aid Checklist for Users

I. Content: Does the patient decision aid ...

Provide information about options in sufficient detail for decision making?
- list the options [2.1]
- list the option of doing nothing [2.2]
- describe the natural course without options [2.3]
- describe procedures [2.4]
- describe positive features [benefits] [2.6]
- describe negative features of options [harms / side effects / disadvantages] [2.7]
- include chances of positive / negative outcomes [2.8]

Additional items for tests
- describe what test is designed to measure [2.9]
- include chances of true positive, true negative, false positive, false negative test results [2.10]
- describe possible next steps based on test result [2.11]
- include chances the disease is found with / without screening [2.12]
- describe detection / treatment that would never have caused problems if one was not screened [2.13]

Present probabilities of outcomes in an unbiased and understandable way?
- use event rates specifying the population and time period [3.1]
- compare outcome probabilities using the same denominator, time period, scale [3.2, 3.3, 3.6]
- describe uncertainty around probabilities [3.4]
- use visual diagrams [3.5]
- use multiple methods to view probabilities [words, numbers, diagrams] [3.7]

Include methods for clarifying and expressing patients' values?
- describe the procedures and outcomes to help patients imagine what it is like to experience their physical, emotional, social effects [3.1]
- ask patients to consider which positive and negative features matter most [4.2]
- suggest ways for patients to share what matters most with others [4.3]

Include structured guidance in deliberation and communication?
- provide steps to make a decision [6.1]
- suggest ways to talk about the decision with a health professional [6.2]
- include tools [worksheet, question list] to discuss options with others [6.3]

II. Development Process: Does the patient decision aid ...

Present information in a balanced manner?
- able to compare positive / negative features of options [6.1]
- shows negative / positive features with equal detail [fonts, order, display of statistics] [6.2]

Have a systematic development process?
- includes developers' credentials / qualifications [1.1]
- finds out what users [patients, practitioners] need to discuss options [1.2, 1.3]
- has peer review by patient / professional experts not involved in development and field testing [1.4, 1.5]
- is field tested with users [patients facing the decision; practitioners presenting options] [1.6, 1.7]

Use up to date scientific evidence that is cited in a reference section or technical document?
- provides references to evidence used [11.1]
- report steps to find, appraise, summarise evidence [11.2]
- report date of last update [11.3]
- report how often patient decision aid is updated [11.4]

Disclose conflicts of interest?
- report source of funding to develop and distribute the patient decision aid [11.5]
- report whether authors or their affiliations stand to gain or lose by choices patients make after using the patient decision aid [11.6]

Use plain language?
- is written at a level that can be understood by the majority of patients in the target group [10.1]
- is written at a grade 8 equivalent level or less according to readability score [SMOG or FRY] [10.4]
- provides ways to help patients understand information other than reading [audio, video, in-person discussion] [10.5]
### Table 3. IPDAS Patient Decision Aid Checklist for Users

<table>
<thead>
<tr>
<th>Meet additional criteria if the patient decision aid is Internet based</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ provide a step-by-step way to move through the web pages 8.1</td>
</tr>
<tr>
<td>□ allow patients to search for key words 8.2</td>
</tr>
<tr>
<td>□ provide feedback on personal health information that is entered into the patient decision aid 8.3</td>
</tr>
<tr>
<td>□ provides security for personal health information entered into the decision aid 8.4</td>
</tr>
<tr>
<td>□ make it easy for patients to return to the decision aid after linking to other web pages 8.5</td>
</tr>
<tr>
<td>□ permit printing as a single document 8.6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Meet additional criteria if stories are used in the patient decision aid</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ use stories that represent a range of positive and negative experiences 9.1</td>
</tr>
<tr>
<td>□ reports if there was a financial or other reason why patients decided to share their story 9.2</td>
</tr>
<tr>
<td>□ state in an accessible document that the patient gave informed consent to use their stories 9.3</td>
</tr>
</tbody>
</table>

### III. Effectiveness: Does the patient decision aid ensure decision making is informed and values based?

- **Decision processes leading to decision quality.** The patient decision aid helps patients to...
  - □ recognise a decision needs to be made 12.1
  - □ know options and their features 12.2, 12.3
  - □ understand that values affect decision 12.4
  - □ be clear about option features that matter most 12.5
  - □ discuss values with their practitioner 12.6
  - □ become involved in preferred ways 12.7

- **Decision quality.** The patient decision aid...
  - □ improves the match between the chosen option and the features that matter most to the informed patient 12.8

Note: numbers behind items correspond to endorsed criteria in Table 2.
Appendix 2: Respondent recruitment letter

Beste patiënt,

Op dit moment is de afdeling Onderzoek en Preventie van Bureau Studentenartsen bezig met het ontwikkelen van een online keuzehulp voor vrouwen met vaginale klachten om hen te helpen met het structuren van hun klachten en een keuze te maken in de mogelijke behandelmethoden. Uit een steekproef is jouw naam gekomen. We heel graag jou interviewen over wat je vindt van deze online keuzehulp.

Een interview zal ongeveer 1,5 uur in beslag nemen en plaatsvinden in de periode van 29 mei tot 16 juni. Exacte tijdstip en plaats van het interview zal in overleg worden bepaald. Deelname zal worden beloond met een H&M-bon ter waarde van €20!

Heb jij interesse om ons te helpen?! Neem dan voor 25 mei contact op met Merel Hoek via m.h.hoek@student.vu.nl !

We horen graag van je!

Vriendelijke groeten

Merel Hoek,

Wetenschappelijke stagiaire Huisartsen Oude Turfmarkt | Studentenartsen
Appendix 3: Interview Guide


1. Heb je hier bezwaar tegen?

Voordat we beginnen met de vragen over de keuzehulp, zou ik graag wat achtergrondinformatie over jou willen die we gebruiken voor de beschrijving van de onderzoeksgroep

2. Wat is je leeftijd
3. Werk/ studeer je? In welke branche?

Voor het gebruik van de keuzehulp

Ik zou je wat willen vragen over jouw verwachtingen van een keuzehulp voor vaginale klachten en jouw informatiebehoefte.

4. Bij het ervaren van vaginale klachten, welke informatiebronnen gebruik je om informatie over je klachten op te zoeken?
5. Wat zijn je overwegingen om deze bronnen te gebruiken?
6. Wat vind je van de beschikbare informatie? Is er genoeg informatie beschikbaar?
7. Hoe speelt deze beschikbare informatie een rol bij jouw keuze voor een behandeling?
8. Welke persoonlijke factoren spelen een rol bij jouw keuze voor een behandeling van de vaginale klachten?

Bij Bureau Studentenartsen hebben wij nu een keuzehulp ontwikkelt voor vaginale klachten.

9. Wat verwacht je van de inhoud van een keuzehulp voor vaginale klachten? Waarom?
10. Wat verwacht je van de vorm van de keuzehulp voor vaginale klachten? Waarom?
11. Welke partijen verwacht je dat betrokken zijn bij de ontwikkeling van de keuzehulp?
   a. Hoe denk je dat dit een invloed zou kunnen hebben op de manier waarop de keuzehulp een bepaald advies uitbrengt?
   b. Waar verwacht je dat de informatie van de keuzehulp op is gebaseerd en hoe verwacht je dit te zien?
12. Wat verwacht je van de effectiviteit van de keuzehulp? Hoe verwacht je dat de keuzehulp jouw behandelmethode gaat beïnvloeden?
   a. Welke stappen verwacht je dat nodig zijn om een goede keuze te maken in de behandeling van jouw vaginale klachten?
   b. Hoe draagt de keuzehulp bij aan jouw uiteindelijke keuze voor een behandeling? (bijv. Advies, maar zoek andere info ect ect)
      i. Wat vind je er van als er meerdere keuzes qua behandeling over zouden blijven voor jou?
      ii. Zou je het advies van een keuzehulp opvolgen? Waar ligt dat denk je aan?
      iii. Als de keuzehulp jou een ander advies geeft dan de behandelmethode die jij in eerste instantie zelf in gedachten al had, wat zou dat met je doen?
Gebruik van de keuzehulp

Nu vraag ik je de keuzehulp te bekijken en in te vullen terwijl gebruik te maken van de hard op denkmethode. Dit betekent dat je alles wat je denkt hard op uitspreekt. Dit mag echt alles zijn, op- en aanmerkingen, of je iets verwarrend of helder vindt, of juist over de lay-out.

Na het gebruik van de keuzehulp

13. Wat is je eerste indruk na het gebruik van de keuzehulp? Over het algemeen, hoe heb je het gebruik van de keuzehulp ervaren?

Inhoud:
14. Wat vond je van de informatie in de keuzehulp over de verschillende behandelmethiden?
   a. Wat vond je van de gedetailleerdheid van de informatie in de keuzehulp?
   b. Hoe werden voor jou de positieve kanten van de verschillende opties duidelijk?
   c. Hoe werden voor jou de negatieve kanten van de verschillende opties duidelijk?
   d. Had je het idee dat sommige opties als voorkeur werden gepresenteerd ten aanzien van andere opties? Als dat zo is, werd er voor jou duidelijk waarom deze opties een voorkeur hadden?

15. Hoe werd voor jou duidelijk waar op het advies aan jou was gebaseerd?

16. Hoe werd voor jou duidelijk of en hoe jouw persoonlijke voorkeuren werden meegenomen in het advies?
   a. Hoe werd voor jou duidelijk welke aspecten jij het belangrijkst vond?
   b. Op welke manier werd voor jou duidelijk welke afwegingen je moest maken voor een geschikte behandelmethode?

17. Hoe denk je dat de inhoud van deze keuzehulp kan bijdragen aan jouw consult met de huisarts?

18. Wat vind je van het stapsgewijs doorlopen van een keuzehulp voor het maken van een behandelkeuze?

Ontwikkelingsproces:
19. Hoe vind je dat de balans tussen positieve en negatieve kenmerken van een behandeling worden gepresenteerd in de keuzehulp?

20. Hoe begrijpelijk gepresenteerd vind je de informatie van de keuzehulp? Bijvoorbeeld het taalgebruik?

21. Hoe is voor jou duidelijk geworden waar de informatie die gepresenteerd wordt in de keuzehulp vandaan is gekomen?

22. Hoe wordt voor jou duidelijk of de informatie wel of niet wetenschappelijk is onderbouwd?

23. Wordt voor jou duidelijk wie financiële belangen hebben bij de keuzehulp en hoe dit mogelijk de adviezen heeft beïnvloed?

Effectiviteit
24. Hoe wordt er voor jou duidelijk dat er een beslissing moet worden gemaakt voor de behandeling van jouw vaginale klachten?
25. Hoe draagt de keuzehulp bij aan jouw kennis over de verschillende behandelopties en hun eigenschappen?
26. Hoe zou de keuzehulp jou helpen in het gesprek met de huisarts over een behandelmethode en welke waarden jij het belangrijkst vindt in relatie tot de behandeling?
27. Hoe vind je dat de optie die de keuzehulp jou geeft aansluit bij wat jij belangrijk vindt in de behandeling van je vaginale klachten?
28. Zijn er aspecten in de keuzehulp die jij graag besproken zou zien worden, maar ontbraken? Welke zijn dat?

**Informatiebehoeften**

29. Over welke onderwerpen zou je na het gebruik van de keuzehulp meer willen weten?
30. Zijn er adviezen gegeven of vragen gesteld die verduidelijking nodig hebben door middel van een stukje tekst?
31. Ben je er weleens tegen aangelopen dat informatie die je zoekt over je vaginale klachten niet te vinden is? Over wat voor soort informatie gaat dit dan?
32. Als er artikelen op de website zouden komen om deze keuzehulp heen, over welke onderwerpen zouden deze dan kunnen gaan?
33. Vind je het bestaan van een keuzehulp als deze een toegevoegde waarde hebben? Waarom?
34. Wat vind je van de lay-out van de keuzehulp? Zijn er aspecten die je lelijk/mooi vindt?
35. Wat vind je van het niveau van de keuzehulp? Hoe zou dit aangepast kunnen worden?
36. Wat vind je van de lengte van de keuzehulp?
37. Wat zou je graag nog willen toewijzen aan deze keuzehulp?
38. Zou je het gebruik van deze keuzehulp aanraden aan anderen in jouw omgeving die vaginale klachten ervaren? Waarom?
### Appendix 4: Coding sheet

<table>
<thead>
<tr>
<th>Codes</th>
<th>Definitions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Personal information</strong></td>
<td></td>
</tr>
<tr>
<td>- Occupation</td>
<td>Statements regarding the current occupation of the participant</td>
</tr>
<tr>
<td>- Educational</td>
<td>Statements regarding the educational level of the participants</td>
</tr>
<tr>
<td>- Age</td>
<td>Age of the participants</td>
</tr>
<tr>
<td><strong>Content</strong></td>
<td></td>
</tr>
<tr>
<td>- Information need</td>
<td>All statements regarding the need to search for information by the participants</td>
</tr>
<tr>
<td>- Expectations on the content</td>
<td>All statements regarding the expectations participants have on the content of the decision aid</td>
</tr>
<tr>
<td>- Perceptions on the content</td>
<td>All statements regarding the participant’s perceptions on the content of the decision aid.</td>
</tr>
<tr>
<td>- Confirmation on content</td>
<td>All notions regarding (dis-)confirmation of expectations and perceptions on the content.</td>
</tr>
<tr>
<td>- Suggestions on content</td>
<td>Notions given by participants to improve or change content of decision aid</td>
</tr>
<tr>
<td><strong>Development process</strong></td>
<td></td>
</tr>
<tr>
<td>- Expectations on development process</td>
<td>All statements given regarding the expectations on the development process of the decision aid.</td>
</tr>
<tr>
<td>1. Expectations parties involved</td>
<td>Subcode expressing notions given about parties that are expected to be involved in development of the decision aid</td>
</tr>
<tr>
<td>2. Expectations on financial disclosure</td>
<td>Subcode that describes what participants expected regarding financial involvement of parties in development of the e-tool</td>
</tr>
<tr>
<td>3. Expectations on scientific evidence</td>
<td>Subcode to describe participant’s expectations on the scientific basis used for the information available in the decision aid.</td>
</tr>
<tr>
<td>4. Expectations on language</td>
<td>Subcode for expectations on the level and readability of the texts in the decision aid</td>
</tr>
<tr>
<td>- Perceptions on development process</td>
<td>All notions regarding the perceptions on the parties involved in the decision aid, language used, financial disclosure, scientific evidence used and understand ability of the tool.</td>
</tr>
<tr>
<td>1. Perception on parties involved</td>
<td>Subcode expressing notions given about parties that are perceived to be involved in development of the decision aid</td>
</tr>
<tr>
<td>2. <strong>Perception on financial disclosure</strong></td>
<td>Subcode that describes the participant’s perception regarding financial involvement of parties in development of the e-tool</td>
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<td>Subcode for perception on the level and readability of the texts in the decision aid.</td>
</tr>
<tr>
<td>- <strong>Confirmation on development process</strong></td>
<td>Notions given regarding the (dis-)confirmation of expectations and perceptions regarding the development process of the tool</td>
</tr>
<tr>
<td>- <strong>Suggestions on development process</strong></td>
<td>All notions given to improve or change aspects of development process</td>
</tr>
</tbody>
</table>

**Effectiveness**

| - **Expectations on the effectiveness** | All notions given about the effectiveness on decision-making of the tool |
| 1. **Expectations on the actual decision-making process** | Subcode describing the expectation of the process of decision-making |
| 2. **Expectations on the decision quality** | Subcode to describe statements regarding the expectations on the quality of the decision based on the decision-aid. |
| 3. **Expectations on the impact of the decision outcome** | Subcode to describe notions of the expectations of the participants regarding the impact of the outcome of the decision-aid on their decision. |
| - **Perceptions on the effectiveness** | All notions regarding the decision-making process and quality of the actual decision. |
| 1. **Perceptions on the decision-making process** | Subcode describing the perception of the process of decision-making |
| 2. **Perceptions on the decision quality** | Subcode to describe statements regarding the perception on the quality of the decision based on the decision-aid. |
| 3. **Perception on decision impact** | Subcode to describe notions of the participant’s perceptions regarding the impact of the outcome of the decision-aid on their decision. |
| - **Confirmation on effectiveness** | All notions given the (dis-)confirmation between the expectations and perceptions of the participant regarding the effectiveness |
| - **Suggestions on effectiveness** | All notions given regarding suggestions to improve or change the effectiveness |