Patient Education and Counseling xxx (xxxx) xxx–xxx

Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pec

To what extent do decision aids for prenatal screening and diagnosis address involvement of partners in decision-making? - An environmental scan

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ARTICLE INFO

Article history:
Received 6 January 2021
Received in revised form 18 March 2021
Accepted 10 April 2021
Available online xxxx

Keywords:
Prenatal screening
Decision aid (DA)
Partner involvement
Informed decision-making

ABSTRACT

Objective: Numerous decision aids (DAs) have been developed to inform pregnant people about prenatal screening as the decision whether or not to accept the prenatal screening offer may be difficult. Currently, little is known about the role of the decisional partner of the pregnant people in this decision-making process and to what extent DAs involve and engage the partner.
Methods: A broad search was conducted to identify publicly available DAs in English and/or Dutch regarding prenatal screening and diagnosis. These DAs were analysed on aspects of partner involvement.
Results: Ten of the 19 identified DAs (52.6%) contained at least one aspect of partner involvement. Several DAs acknowledged that both partners should be involved in the decision (n = 7). The content that was least likely to contain aspects of partner involvement in the DA was value clarification content (n = 2) and only one DA contained content with plural addressing.
Conclusion: Just over half of the included DAs included some aspect(s) of partner involvement.
Practical implications: More research is needed to determine to what extent, and how, the partner should be involved in the decision-making process as expectant people consider the input of their partner as important.

1. Introduction

In the last few decades, the number of infants dying of congenital anomalies during their first year of life has declined sharply in the Netherlands [1]. Congenital birth defects refer to conditions that an infant is born with and they can range from mild to severe, causing mental or physical disabilities [2]. This decrease is mainly due to prenatal screening; more pregnancies are terminated and therefore less infants with congenital trisomies are born [1,3]. Prenatal screening is offered to expectant people to determine whether the foetus has an increased risk of a genetic condition or birth defect. In the Netherlands, several prenatal screening programs exist [4]. In 2007, a genetic screening called the combined test (CT), was introduced to calculate the risk for Down syndrome (trisomy 21). The CT consist of a blood test and a measurement of the nuchal translucency through ultrasound. This screening was extended in 2010 to detect Patau- and Edwards syndrome (trisomy 13 and 18). Another genetic screening, The Non Invasive Prenatal Test (NIPT), a maternal blood test, is available for all pregnant people since 2017 and is a more accurate screening test for these trisomies [5,6]. Compared to the CT, the sensitivity and specificity of the NIPT are high [7]. In addition, pregnant people can choose for a second trimester ultrasound anomaly scan to examine the foetus for physical abnormalities [1]. These non-invasive screening tests do not pose any risks to the child or the pregnant person [8].

The results of prenatal screening provide a risk estimate and no definite diagnosis [6]. Pregnant people who receive a positive result after screening, meaning that the foetus is at higher risk of having the disorder, will be offered prenatal diagnosis to obtain more

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https://doi.org/10.1016/j.pec.2021.04.009
0738-3991/

certainty regarding the health of their foetus. The two available methods to obtain fetal material are chorionic villus sampling (CVS) and amniocentesis. They are both invasive and carry a small procedure related risk of miscarriage [9]. Definitive unfavourable results may induce uncertainty and prospective parents may be confronted with a difficult decision whether to continue or terminate the pregnancy [4]. Additionally, the moral acceptability of prenatal screening, diagnosis and the possibility of a pregnancy termination may vary between people and thus may influence the decision [10].

Most research is solely focused on whether or not the pregnant person is making an informed choice in the context of prenatal screening and diagnosis [11–14]. The role of the pregnant person's partner in decision-making is often overlooked by health professionals [15]. Nevertheless, it is important that both decisional partners, most often the pregnant person's life partner or someone close who contributes to decision, understand the decision that needs to be made and are involved in the decision-making process to an extent that he/she aspires, as this could reduce the burden of decision-making for the pregnant person. Although the question may arise whether this involvement infringes the pregnant person's right to autonomy and self-determination, partner involvement could facilitate the decision-process while respecting the autonomy of the pregnant person [16–18]. Previous research has for instance shown that pregnant people find it important that they, and their partners, have the same view about the prenatal screening decision and that they should decide together [8,19]. Some pregnant people even reported that their partner is the most important person in this decision-making process and that they need their support [20].

While the difficult nature of the decision regarding prenatal tests is evident, decisional conflict - which can be described as the uncertainty experienced when making a decision between two or more options - could be reduced and decisional satisfaction may be higher when the decision is informed and well-considered [11]. Counselling can contribute to informed decision-making (IDM) of pregnant people deciding whether or not they will participate in prenatal screening. Previous research states that an informed decision is made if someone has sufficient knowledge and if the attitude towards the screening program is in line with the actual participation [21–23]. The goal of providing information during counselling is not to maximise participation in prenatal screening but to promote the autonomy of partners in their reproductive choice and choice of care, encompassing both preconception care and counselling to understand and weigh the risks and benefits of various genetic screening tests [24–26]. Even though research has explored the topic of IDM regarding prenatal testing, the involvement of (decisional) partners in this decision-making process is largely under investigated.

As decision-making concerning prenatal testing can be difficult, numerous decision aids (DAs) have been developed to support IDM about prenatal screening and diagnosis. Previous research concluded that DAs significantly contributed to the decision-making process by enhancing knowledge and decreasing decisional conflict and anxiety among pregnant people [27]. However, most studies focused on pregnant people and it is currently not known to what extent these DAs address aspects of partner involvement and in which way partners are addressed. As the involvement of partners is important, the aim of this research is to explore if and how these DAs involve and target decisional partners of pregnant people.

2. Methods

2.1. Study design

An environmental scan was conducted to search for publicly available DAs on prenatal screening and diagnosis. An environmental scan is an efficient, organised method to collect information about the external environment and to study real-world interventions (e.g. DAs) [28–31]. In this environmental scan, we will identify information about if, and how, freely available and accessible DAs target and involve the decisional partners of pregnant people. Since DAs are mostly not found in scientific literature, a broad range of sources including grey literature was used for this purpose.

2.2. Eligibility criteria

To guide the identification and quality appraisal of a patient DA, the six qualifying criteria of the IPDAS v4.0 minimal criteria were used, which a DA must fulfil to be considered a DA [32]. These criteria prescribe that the DA should describe the health condition or problem for which the index is required, it should explicitly state the decision that needs to be considered, describe the available options for the index decision, describe the positive and negative features of each option and describe the experience of the consequences of the options [32]. Furthermore, to be included in the analysis, 1) the DA must be aimed at pregnant people and/or their partners, 2) the DA must concern a decision about prenatal screening (ultrasound examination or maternal blood sample including NIPT or combination test) and/or diagnosis (offered after positive screening test, CVS and amniocentesis), 3) the DA must be available in English and/or Dutch and 4) the DA must be publicly available. A DA was considered publicly available when it could be freely accessed, with or without registering.

2.3. Data sources and search strategy

Several data sources were searched to obtain a complete overview of publicly available DAs. Firstly, the Decision Aid Library Inventory (DALI) of the Ottawa Patient Decision Aids Research Group [19], a database with a collection of DAs that all meet the IPDAS qualifying criteria, and the Option Grid database [20], a database with DAs developed by the Option Grid collaborative, were searched for any DAs relating to prenatal screening and diagnosis on April 22, 2020. Secondly, a search in Google was conducted on April 27, 2020 using the following search entries in English: 'prenatal screening decision aid', 'prenatal test decision aid', 'prenatal diagnosis decision aid', 'prenatal screening decision support', 'prenatal test decision support' and 'prenatal diagnosis decision support'. On April 30, 2020 a second search was conducted in Google using the corresponding Dutch search entries: 'prenatale screening keuzehulp', 'prenatale test keuzehulp', 'prenatale diagnose keuzehulp', 'prenatale screening beslishulp', 'prenatale test beslishulp' and 'prenatale diagnose beslishulp'. Both searches were conducted within the incognito mode in the browser Opera to minimize external influence. Of every search entry, the first 100 URLS were screened for eligibility, with exception of the last two Dutch entries, which yielded 99 and 78 results, respectively. Thirdly, on April 30 2020, a search was conducted in three scientific databases: Pubmed, PsycInfo and Web of Science using the search terms displayed in Table 1.

The databases and search terms were chosen in consultation with an expert in systematic literature reviews, and experts on the topic of shared or IDM. The searches were limited to the last 10 years, because it was likely that DAs created before this time would not be up to date in light of the rapid developments in the field of non-invasive prenatal screening tests in particular. When articles were found that were thought to have used or produced an eligible DA, the authors were contacted by email with the request to share (access to) this DA. When the authors did not reply, a second email was sent after two weeks. When they did not reply to this either, the article was excluded from the selection. As a fourth data source, the reference lists of relevant articles on this topic were examined. Based on the results from these strategies, a preliminary list of DAs was created and was, as a fifth strategy, submitted to several

Table 1
Search terms used for retrieval of relevant items in scientific databases.

Pubmed	((((pregnant[tiab]) AND (couples[tiab] OR women[tiab] OR men[tiab] OR partner*[tiab] OR significant other[tiab] OR husband[tiab] OR wife[tiab] OR wives[tiab] OR mother[tiab] OR father[tiab]))) AND ((((prenatal[tiab] OR antenatal[tiab] OR intrauterine[tiab]) AND (care[tiab] OR screening[tiab] OR diagnosis[tiab] OR testing[tiab])))) OR ((fetal abnormalities[tiab] OR down syndrome[tiab] OR trisomy[tiab] OR ultrasound[tiab] OR amniocentesis[tiab] OR chorionic villus sampling[tiab] OR CVS [tiab] OR NIPT[tiab] OR non-invasive prenatal testing[tiab] OR genetic testing)))) AND ((decision*[tiab] OR choice*[tiab]) AND (aid*[tiab] OR support[tiab] OR support tool [tiab] OR support technique*[tiab])) Filters: published in the last 10 years
PsycInfo	((decision OR choice) AND (aid* OR support* OR support tool OR support technique)) AND (pregnant AND (women OR men OR partner* OR significant other OR husband OR wife OR wives OR mother OR father)) AND (((prenatal OR antenatal OR intrauterine) AND (care OR screening OR diagnosis OR testing)) OR fetal abnormalities OR Down Syndrome OR amniocentesis OR trisomy OR ultrasound OR chorionic villus sampling OR CVS OR NIPT OR Non-invasive prenatal testing OR genetic testing))
Web of Science	(((decision OR choice) AND (aid* OR support* OR support tool OR support technique)) AND (pregnant AND (women OR men OR partner* OR significant other OR husband OR wife OR wives OR mother OR father)) AND (((prenatal OR antenatal OR intrauterine) AND (care OR screening OR diagnosis OR testing)) OR fetal abnormalities OR Down Syndrome OR amniocentesis OR trisomy OR ultrasound OR chorionic villus sampling OR CVS OR NIPT OR Non-invasive prenatal testing OR genetic testing))

international experts on the topic of shared or IDM to check whether they had any additions to the list.

2.4. Data extraction

Firstly, general data was extracted from the DAs regarding name, author, year of last update, country/language and form/type of medium used. Furthermore, the aim and focus, as defined in the DA and its content (the general structure of the DA) were noted. This is based on the previous environmental scan by Portocarrero [35]**.** For detailed analysis regarding partner involvement, a data extraction sheet was developed together with experts on the topic of shared decision-making (Appendix A). The development of the data extraction sheet was guided by the main concepts of IDM as defined by Marteau et al. [21] and Van den Berg et al. [22]. Main aspects extracted pertained to the mentioning/addressing of the partner in the text accompanying the DA and in the aim and target (when described) of the DA, mentioning/addressing of the partner in the DA itself, as well as involvement of the partner in the (use of) the DA and more specifically in deliberation and value clarification methods (when present). Other main aspects that were analysed in the DAs were form of addressing (plural or singular), graphics and pictures (are there pictures present that portray the partner as well) and, if available, data about development and evaluation of the DA (whether partners were involved in development and/or evaluations of the decision aid). With the term 'partner', the romantic (life) partner is meant in this analysis. Five DAs were coded in duplicate by the authors (HL) and (YS). Afterwards, Cohens' kappa was calculated to assess inter-rater reliability.

2.5. Quality appraisal

To assess the selected DAs for their quality, the qualifying and certifying criteria of the IPDASi4.0 minimal criteria were used [32]. The qualifying criteria are commonly used to assess whether or not a decision support tool qualifies as a DA. Additionally, the certification criteria are used to judge whether the information in a DA is presented in a biased way. Similar to the data extraction, quality appraisal was done in duplicate for the same five DAs by two researchers (HL and YS). Cohen's kappa was calculated again separately for assessing inter-rater reliability.

3. Results

3.1. Selection of DAs

In Fig. 1, the selection process of the DAs is illustrated. Ultimately, nineteen DAs fulfilled the eligibility criteria. When two versions of the same DA were found, only the most recent version was included. Furthermore, a DA was excluded if it wasn't fully accessible or fully functional anymore. None of the included decision aids were produced by for-profit companies.

3.2. Characteristics of the DAs

The information regarding the characteristics of the included DAs is displayed in Table 2. The DAs are heterogeneous in terms of screening methods and tests covered. Of the selected DAs, most were for prenatal screening only (n = 9), some were for prenatal diagnosis only (n = 3) and the remaining were for both prenatal screening and diagnosis (n = 7). The DAs were developed in the United States (n = 10), the Netherlands (n = 4), Canada (n = 3) and Australia (n = 2). Nine DAs were (partly) interactive, meaning that the input that is given is processed to result in a score, summary or other outcome measure.

3.3. Quality analysis

The included DAs were quality-appraised using the qualifying and certifying criteria of the IPDAS v4.0 minimal criteria [32]. Cohen's kappa was 0.96, indicating an almost perfect inter-rater reliability. The remaining DAs were analysed by one researcher (HL). The results of the quality appraisal are presented in Table 3. All DAs met the qualifying IPDAS criteria. With regard to the certifying criteria, only 2 DAs met all these criteria.

3.4. Aspects of partner involvement in the DA

Data was extracted from the included DAs on ten main categories. These categories are displayed in Table 4. Cohen's kappa for the five DAs that were analysed in duplicate was 0.92, indicating a very good inter-rater reliability. The remaining fourteen DAs were analysed by one researcher (HL). In total, ten of the nineteen DAs (52.6%) contained some aspect(s) of partner involvement and nine DAs did not involve the partner at all. The degree of partner involvement per aspect will be explained in the following paragraphs.

3.5. Accompanying text acknowledges/mentions involvement of the partner in the decision/DA

Text that gave a description of the DA and/or instructions on how to use the DA, whether this was accompanying the DA or included in the DA itself, was considered as accompanying text. In five DAs, the accompanying text mentioned involvement in one or more ways of the partner in the decision. This varied from recommendations to share the decision with the partner (n = 3), to assumptions that the decision would be shared with the partner if present (n = 1), to mentioning the partner in the aim and target of the DA (n = 2) (see next section). In four of these five DAs involvement of the partner in the use of the DA was also mentioned in the accompanying text. This varied from encouragement to share the DA with a partner (n = 1) to suggestions for the partner to also complete (a part of) the DA (n = 2) to mentioning the partner in the aim and target of the DA (n = 1). In one DA it was mentioned that even though they would address the reader in singular form for the sake of readability, it would be possible to go through the DA together.

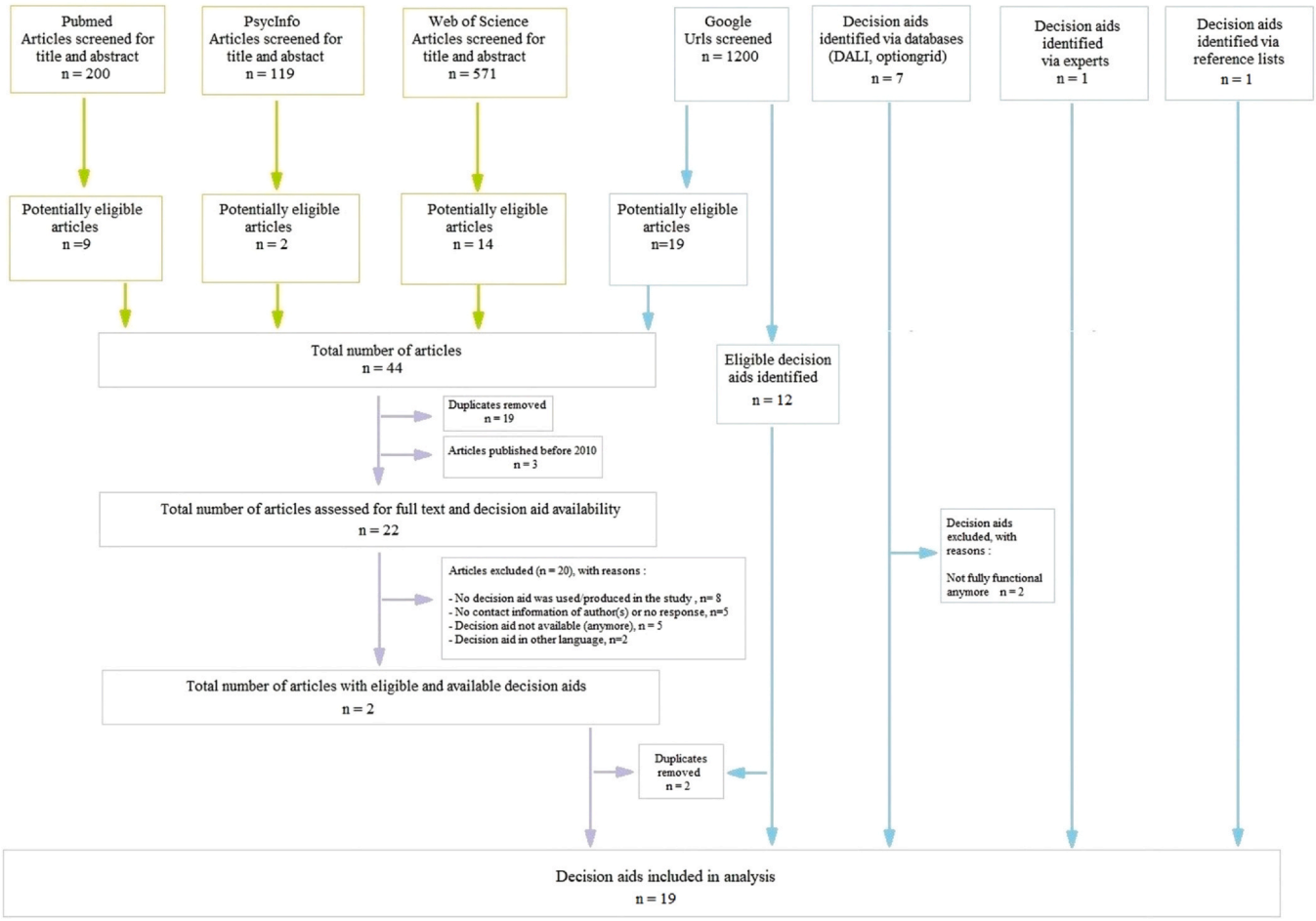

Fig. 1. Flow diagram of DAs selection.

3.6. Target and aim of the DA

The target and aim was not described in every DA. When described, it was often only mentioned in the accompanying text. In only two DAs, the partner was mentioned in the aim. In one of these, it was described as a tool to help pregnant people and their partners decide. In the other, involvement in the decision was not explicitly described, but it was mentioned that the DA was meant as a helpful tool for couples.

3.7. Involvement of the partner in the decision

In seven of the nineteen included DAs it was acknowledged or mentioned in varying ways that the partner is involved in the decision. In most of these DAs, it was suggested (n = 5) to the pregnant person to talk to their partner, as this could make the decision easier. In one DA, an informational video was presented, in which couples talked about their experiences.

with the decision and having a child with a disability. Even though the video was aimed at pregnant people (this was described in the aim), the partner was given room to talk about their experiences in making this decision and the pregnant person sometimes referred to the decision in a way that suggested it was made together, for example by using the word 'we'. Four of these seven DAs also acknowledged or mentioned that both the pregnant person and the partner are involved in the DA.

3.8. Graphics and pictures

Four of the included DAs contained pictures or graphics of couples suggesting involvement of both partners in decision making, represented by sitting together at a health counsellor's office, thinking together or talking together. These graphic representations may suggest that both partners (displayed as opposite gender-couples) may visit a health counsellor and deliberate and discuss the decision regarding prenatal screening together.

3.9. Parts of the DA are also directed at the partner (forms of addressing)

Only in one DA, the partner was addressed directly in some parts trough use of plurals.

3.10. Involvement of the partner in deliberation

In four DAs, the partner was mentioned in the deliberation exercises in relation to prenatal testing. In most of these cases, the partner was mentioned in the personal experience stories of other pregnant people (n = 3). One DA specifically instructed the partner to participate in deliberation exercises. In these DAs, the partner was mentioned in text that described the decision that would have to be made if the result of the screening revealed a high risk estimate or if the result of the diagnostic test revealed abnormalities. In another DA, this was the only mention of the partner in deliberation exercises ($^{*}_{1}$, Table 4).

Table 2
Characteristics of included DAs.

	Title of DA *(developer)*	Country and language	Year of last update	Aim/focus	Form/media	Summary of content of the DA
1	Pregnancy – Should I Have Amniocentesis? *(Healthwise)*	United States English	2020	Making a choice whether to undergo **amniocentesis** or not (prenatal diagnosis)	Web-based, interactive	- Information in written text - Option grid with pros and cons - Value-clarification methods - Worksheet to note down questions - Summary of filled out questions All four Healthwise DAs have the same features, only with different information.
2	Pregnancy – Should I Have an early fetal ultrasound? *(Healthwise)*	United States English	2020	Making a choice whether to undergo an **early fetal ultrasound** or not (prenatal screening)	Web-based, interactive	
3	Pregnancy – Should I have CVS (Chorionic Villus Sampling)? *(Healthwise)*	United States English	2020	Making a choice whether to undergo **chorionic villus sampling** or not (prenatal diagnosis)	Web-based, interactive	
4	Pregnancy – Should I have screening tests for birth defects? *(Healthwise)*	United States English	2020	Making a choice whether to undergo a screening test **(blood test or ultrasound)**	Web-based, interactive	
5	What are my options regarding prenatal screening tests? *(Université Laval)*	Canada English, French	2017	Making a choice whether and which screening test to undergo **(SIPS, IPS, NIPT, or none)**	Paper based (PDF), not interactive	- Information in written text - Graphics with information - Option grid with pros and cons - Value clarification methods
6	Should I take the SIPS/IPS test to screen for Trisomy 21 (Down Syndrome)? *(BC Prenatal Genetic Screening Program)*	Canada English	2019	Making a choice whether to undergo the **SIPS, IPS** or no test (prenatal screening)	Paper based (PDF), not interactive	- Information in written text - Tables with information - Option grid with pros and cons - Value clarification methods
7	An Aid to Decision-Making for Prenatal Screening *(Yukon)*	Canada English	2019	Making a choice whether to undergo the **SIPS/NIPT test** or no test (prenatal screening)	Paper based (PDF), not interactive	- Information in written text - Tables with information - Option grid with pros and cons - Value clarification methods - Question prompt sheet - Worksheet to note down questions
8	Your choice: Prenatal Screening tests in pregnancy *(Murdoch Childrens Research Institute)*	Australia English	2018	Making a choice whether to undergo any type of prenatal screening **(NIPT, cFTS, 2TMSS, cfDNA, ultrasound)** or not. A very small part of the information booklet is dedicated to prenatal diagnostic tests.	Information booklet (PDF) (not interactive) and a web-based tool (interactive)	Booklet: - Information in written text - Graphics and tables with information - Pros and cons listed in text Web-tool: - Two worksheets with value clarification methods - Conclusion and advice - Option grid with test characteristics as a summary
9	Making decisions about screening for Down Syndrome in Pregnancy *(Smith* et al.*)*	Australia English	2014	Making a choice whether to undergo prenatal screening and/or prenatal diagnosis or not **(blood test, ultrasound, NIPT, CVS, amniocentesis)**	Paper based (PDF), not interactive	- Information in written text - Graphics and tables - Value clarification methods - Question prompt sheet - Worksheet to note down questions - List of terms
10	Considering Your Options For Prenatal Genetic Testing *(AllinaHealth)*	United States English	2019	Making a choice whether to undergo prenatal screening and/or prenatal diagnosis or not **(blood draw, ultrasound, sequential or integrated screening, cell free DNA screening, CVS, amniocentesis)**	Paper based (PDF), not interactive	- Information in written text - Graphics - Option grid with pros and cons - Worksheet with value clarification methods - Question prompt sheet - Worksheet to note down questions
11	Prenatal Screening tests *(Genetic Support Foundation)*	United States English	2019	Making a choice whether to undergo prenatal screening or not and which test to take **(ultrasound, blood draw, quad screen, sequential screening, cell-free DNA/NIPT, genetic carrier screening)**	Web-based, not interactive	- Information in written text for each subject (heading) - Pros and cons described in the information text - An explanatory video for some tests - Drop-down boxes with information about interpretation of the results

(*continued on next page*)

Table 2 (*continued*)

	Title of DA *(developer)*	Country and language	Year of last update	Aim/focus	Form/media	Summary of content of the DA
12	Prenatal Diagnostic tests *(Genetic Support Foundation)*	United States English	2019	Making a choice whether to undergo prenatal diagnosis or not and which test to take **(CVS, amniocentesis, fluorescence in-situ hybridization, traditional chromosome analysis, chromosomal microarray)**	Web-based, not interactive	- Information in written text for each subject (heading) - Pros and cons described in the information text - Drop-down boxes with information about interpretation of the results
13	Prenatal Testing Options *(Michigan Medicine)*	United States English	2018	Making a choice whether to undergo prenatal testing or not **(screening through blood work or ultrasound, CVS, amniocentesis)**	Video-based, not interactive	- Narrative information with clarifying graphics - Pros and cons are described
14	Screening for Down's, Edwards' and Patau's syndromes *(RIVM)*	The Netherlands Dutch	Unknown	Making a choice to undergo prenatal screening **(NIPT or combination test)** or not	Web-based (not interactive) and a questionnaire + worksheet (interactive)	Web-page: - Information in written text - Option grid with characteristics of the tests - Question prompt sheet Questionnaire + worksheet: - Value clarification methods - Worksheet for discussion with partner - Summary
15	Twenty-week ultrasound *(RIVM)*	The Netherlands Dutch	Unknown	Making a choice to undergo prenatal screening **(20-weeks ultrasound)** or not	Web-based (not interactive) and a questionnaire + worksheet (interactive)	Web-page: - Information in written text - Option grid with characteristics of the tests - Question prompt sheet Questionnaire + worksheet: - Value clarification methods - Worksheet for discussion with partner - Summary
16	Patient+ decision aid: Prenatal testing *(Beulen* et al.*)*	The Netherlands Dutch	2016	Making a choice to undergo prenatal screening and/or testing, or not **(NIPT, amniocentesis, CVS)**	Web-based, interactive	- Information in written text - Graphics and tables - Option grid with characteristics of the tests - Value clarification methods - Self-check questions - Summary
17	Prenatal testing: is it right for you? *(Mayo clinic)*	United States English	2018	Making a choice to undergo prenatal screening and/or testing, or not **(blood test, ultrasound, nuchal translucency, quad screen, prenatal cell-free DNA screening)**	Web-based, not interactive	- Information in written text - Pros and cons described in the information text - Question prompt sheet
18	Prenatal screening: is it right for you? *(Darthmouth – Hitchcock)*	United States English	2013	Making a choice to undergo prenatal screening and/or testing, or not **(targeted fetal anatomy ultrasound, NIPT, CVS, amniocentesis)**	Paper based (PDF), not interactive + video-based, not interactive	- Information in written text - Graphics and tables - Value clarification methods - Pros and cons described in the information text - An additional video with information and personal stories of other couples
19	Twenty-week ultrasound *(NPV zorg)*	The Netherlands Dutch	Unknown	Making a choice to undergo prenatal screening **(20 weeks ultrasound) or not**	Web-based, interactive.	- Information in written text - Graphics, tables and videos - Pros and cons described in the information text - Personal stories and various value clarification methods

Table 3
Quality appraisal of included DAs.

IPDASi v4 criteria	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19
DA describes health condition or problem for which the index decision is required	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
DA explicitly states the decision that needs to be considered	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
DA describes the options available for the index decision	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
DA describes the positive features of each option	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
DA describes the negative features of each option	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
DA describes what it is like to experience the consequences of the options (physical, psychological, social)	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
DA shows the negative and positive features of options in equal detail	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
DA provides citations to the evidence selected	√	√	√	√	√	√	√			√							√	√	
DA provides a production or a publication date	√	√	√	√	√	√	√		√	√	√	√	√			√	√	√	
DA provides information about the update policy					√														
DA provides information about the levels of uncertainty around event or outcome probabilities				√	√	√		√	√	√	√					√			
DA provides information about the funding source used for development					√	√	√		√										
DA describes what the test is designed to measure	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
DA describes the next steps typically taken if the test detects the condition or problem	√	√	√	√	√	√	√	√	√		√	√		√	√	√		√	
DA describes the next steps if the condition or problem is not detected				√	√	√		√	√		√	√		√	√	√			
DA has information about the consequences of detecting the condition or disease that would never have occurred if screening had not been done (lead time bias)					√	√	√	√											√
Total quality score (out or 16)	11	11	11	13	16	16	13	12	13	11	12	11	9	10	10	12	10	11	9

3.11. Involvement of the partner in value clarification

In two DAs, it was suggested that the partner could complete their own questionnaire (as part of a value clarification method). These were the only two DAs with explicit involvement of the partner in value clarification (n = 2). In one of these DAs, there is a white space where the pregnant people can fill out how their partner thinks about the subject and on what points they agree or disagree. Two other DAs implicitly involved the doctor, family or the partner in the value clarification (n = 2). In one DA (*2, Table 4), it was suggested to share the thoughts with the doctor and/or family directly below the value clarification methods. In one DA (*3, Table 4), it was explained in the introduction that sometimes, for the sake of readability, the instructions would be given in singular form but the partner could also complete the exercises. However, the involvement of the partner in the value clarification methods was therefore not explicitly present.

3.12. Providing advice/support for making a decision together

In three DAs, advice or support is provided for making a decision together. In two DAs, some suggestions are provided for talking together about the results of the exercises. In one DA, a telephone number is provided that can be called for support if it is not possible to come to a decision together.

3.13. Development and evaluation of the DA

Information about the development process was available only for one DA. In the development process of this DA, only women had been involved. Evaluation details were available for two DAs. In both cases, only women were involved in the evaluation.

4. Discussion and conclusion

4.1. Discussion

In this environmental scan, publicly available DAs for prenatal screening and diagnosis were identified and analysed for aspects of partner involvement regarding decision-making. All DAs met the quality criteria as defined by IPDASi4.0. Ten of the nineteen DAs (52.6%) contained some aspect(s) of partner involvement, whereas nine DAs contained no aspect(s) of partner involvement at all. Involvement of the partner in the decision ranged from indirect involvement such as suggesting or advising that the pregnant person could talk to their partner to explicit instructions to discuss and

Table 4
Summary of aspects of partner involvement in included DAs.

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	Total score DAs
Accompanying text acknowledges/mentions involvement of the partner in the decision					√				√					√	√				√	5
Accompanying text acknowledges/mentions involvement of the partner in the DA									√					√	√				√	4
Partner is mentioned in the aim and target of DA (if described)					ND	ND	ND		√	ND	ND	ND	ND	N-D	ND				√	2
DA acknowledges that both the pregnant person and partner are involved in the decision					√	√			√				√	√	√				√	7
DA acknowledges that both the pregnant person and partner are involved in the DA									√					√	√				√	4
Graphics/pictures indicate involvement of the partner in the decision									√					√	√				√	4
Parts of the DA are (also) directed at the partner (forms of addressing)																			√	1
Content focused on deliberation is (also) focused on the partner	*1	√	√	√															√	4
Content focused on value clarification is (also) focused on the partner							*2							√	√				*3	2
Advice/support is provided for making a decision together														√	√				√	3
Total score (out of 10)	0	1	1	1	2	1	0	0	6	0	0	0	1	7	7	0	0	0	9	

ND = aim and/or target is not described in this DA *1 = partner is mentioned, but not in the context of the decision regarding prenatal screening and/or diagnosis
*2 = it is suggested to share thoughts with family (not explicitly partner) *3 = partner is not mentioned explicitly, but it is mentioned in another part that singular form would be used for the sake of readability

write the thoughts of both partners down in the results. Involvement of the partner in the DA itself ranged from suggesting that the partner could complete a part of the DA to explicitly addressing the partner. Less than a quarter (21%) of DAs on prenatal screening and diagnosis contained six or more aspects of partner involvement, while almost half (47%) contained no aspects of partner involvement at all. It is worth mentioning, that the lowest scores were found for providing advice/support for making a decision together (n = 3), partner involvement in value clarification (n = 2) and for parts of the DA that are specifically directed at the partner (forms of addressing, n = 1). Only about half of the DAs about prenatal screening and diagnosis contained content that stimulated or promoted involvement of the partner in decision-making. Even when the partner was mentioned, he or she was portrayed as someone to talk to and not as an equal decisional partner. In the DAs that mentioned partner involvement, the emphasis was placed on the pregnant person.

The finding that only a few DAS explicitly targeted the (decisional) partner is in line with most studies on reproductive decision-making and prenatal testing as they mainly focus on the perspective of the pregnant person [33]. Even though partners may feel that the final decision should rest with the pregnant person, as they experience the physical burden of pregnancy, couples perceived their reproductive decision-making process as a collaborative process [34]. Women perceive their partner as an important decisional partner and couples feel that deciding about prenatal testing is a very important decision, that should be made collaboratively with limited involvement of individuals outside the couple [8,24]. These findings are not reflected in the extent to which partners are included in the current DAs, as many do not explicitly address both partners. As pregnant people perceive their partner as an important decisional partner, the involvement of partners should be actively supported. Therefore, targeting both partners in DAs may be helpful for couples.

There are some limitations to this study that should be taken into account when interpreting the results. Firstly, the data sources that were used to search for DAs included grey literature, as Google was used to search for DAs. Even though incognito mode was used, the search is not entirely reproducible, meaning that the results can vary depending on location and time of search besides search history. Additionally, only Dutch or English language DAs were included and only publicly available DAs were seen as eligible. However, it is likely that these DAs are a fairly representative sample for publicly available DAs on prenatal screening and diagnosis in Western countries. In non-western countries, the community norms and gender roles in health care decision making might be different making the assumption likely that this is not a representative sample for other cultural backgrounds [17].

4.2. Conclusion

Approximately half of the DAs about prenatal screening and diagnosis contained content that stimulates or promotes partner involvement. In most DAs, little or no attention is payed to the role of the decisional partner and the emphasis is placed on the pregnant person. When the partner is mentioned, this is most often in a way that portrays him/her as someone to talk to, to make the decision easier, but not as a decisional partner. In the few DAs that contained the most content dedicated to involving the partner, the decision still seems to be placed on the pregnant people alone. However, many pregnant people feel that they cannot make the decision alone [17]. They perceive their partner as an important decisional companion and indicate that they need their support [35,36]. The information that is obtained by prenatal testing concerns both parents since they mostly share the responsibility for the child and research has shown that the outcome of a decision, which affects both partners (e.g. reproductive decision), may yield better outcomes when partners deliberate and decide together [8,17]. As male partners tend to be more passive in the decisional process and many partners feel not sufficiently supported by them, efforts should be made to encourage interaction between partners to communicate about prenatal decision-making. These efforts may extend to many more decisions in the context of family planning in which joint informed decisions are made, e.g. contraception use [36–40]. Therefore, it is important that DAs target both partners as this can improve the joint decision-making process [8,38].

4.3. Practice implications

More research is necessary to explore modes of involvement of the partner to an extent that does not infringe the autonomy of, and is positively experienced by the pregnant person [30]. We recommend that future research should investigate the role of the partner in making choices concerning the prenatal period, as pregnant people want their partner to be involved and that the decision is made jointly. Currently, these findings are not reflected in the degree to which the partner is included in decisional support. Future decisional support, by counsellors and in DAs, could benefit from such exploration to better adapt to the needs and wishes of pregnant people and their partners as both partners want to be involved and feel they both should have a say in the decision-making process [41].

Funding

Financial support for this study was provided by ZonMw, The Netherlands (Grant number 543003106). The funding agreement ensured the authors' independence in designing the study, interpreting the data, writing, and publishing the report.

CRediT authorship contribution statement

Yil Severijns: Conceptualization, Investigation, Writing - original draft, Writing - review & editing. **Hanneke van der Linden:** Conceptualization, Investigation, Writing - original draft, Writing - review & editing. **Christine de Die-Smulders:** Conceptualization, Supervision, Writing - review & editing. **Ciska Hoving:** Conceptualization, Supervision, Writing - review & editing. **Jesse Jansen:** Conceptualization, Writing - review & editing. **Liesbeth van Osch:** Conceptualization, Supervision, Writing - review & editing.

Declaration of Competing Interest

The authors declared no potential conflicts of interest with respect to authorship and/or publication of this article.

Acknowledgements

Not applicable.

Appendix A. Data extraction sheet

Is there text accompanying the DA that acknowledges or mentions involvement of the partner in the decision in any way?
If yes: choose one of the subquestions
SQ 1: The text suggests involvement of the partner in the decision
If yes: explanation
SQ 2: The text advises involvement of the partner in the decision
If yes: explanation
SQ 3: The text acknowledges or mentions involvement of the partner in another way
If yes: explanation
Is there text accompanying the DA that acknowledges or mentions involvement of the partner in the decision aid in any way?
If yes: choose one of the subquestions
SQ 1: The text suggests involvement of the partner in the decision aid
If yes: explanation
SQ 2: The text advises involvement of the partner in the decision aid
If yes: explanation
SQ 3: The text states that it is required for both partners to be involved with this decision aid
If yes: explanation
SQ 4: The text acknowledges or mentions involvement of the partner in another way
If yes: explanation
Is the partner mentioned in the aim and target of this decision aid (if described)?
If yes: explanation
Does the DA acknowledge/indicate that both the pregnant people and partner are involved in the decision?
If yes: choose one of the subquestions
SQ 1: The DA suggests involvement of the partner in the decision
If yes: explanation
SQ 2: The DA advises involvement of the partner in the decision
If yes: explanation
SQ 3: The DA acknowledges of mentions involvement of the partner in this decision in another way
If yes: explanation
Does the DA acknowledge/indicate that both the pregnant people and partner are involved in the decision aid?
If yes: choose one of the subquestions
SQ 1: The DA suggests involvement of the partner in the decision aid
If yes: explanation
SQ 2: The DA advises involvement of the partner in the decision aid
If yes: explanation
SQ 3: The DA states that it is required for both partners to be involved with this decision aid
If yes: explanation
SQ 4: The DA acknowledges or mentions involvement of the partner in this decision aid in another way
If yes: explanation
Are there pictures/graphics present in the DA that indicate that both the pregnant people and partner are involved in decision making?
If yes: explanation
Are there parts of the decision aid that are (also) directed at the partner? (form of addressing)
If yes: explanation
Are there additional aspects (that are not described above) of the content that are focused on the partner (as well)?
If yes: explanation
Does the DA contain specific questions, exercises of pieces of text that focus on deliberation (mentally visualizing the situation, pros en cons)?
If yes: choose one of the subquestions
SQ 1: This content is focused explicitly on both partners.
If yes: explanation
SQ 2: This content focuses only on the pregnant **people**, but the partner is mentioned.
If yes: explanation
SQ 3: This content focuses only on the pregnant **people**, and the partner is not mentioned.
If yes: explanation
Does the DA contain specific questions, exercises of pieces of text that focus on value clarification (how they feel, what they think)?
If yes: explanation
SQ 1: This content is focused explicitly on both partners.
If yes: explanation
SQ 2: This content focuses only on the pregnant **people**, but the partner is mentioned.
If yes: explanation
SQ 3: This content focuses only on the pregnant **people**, and the partner is not mentioned.
If yes: explanation
Is any advice and/or support provided for making a decision together?
If yes: explanation
Are there any other aspects that have to do with joint decision making that do not fit in these categories?
If yes: explanation
Are both partners involved in the development of the decision aid?
If yes: explanation (to what extent)
Are both partners involved in the evaluation of the decision aid?
If yes: explanation (what concepts are measured?)

Appendix B. Included DAs

1. Pregnancy: Should I Have Amniocentesis? Healthwise; c1995-2020 [updated 2020 Feb 11; accessed 2020 Apr 22]. https://www.healthwise.net/ohridecisionaid/Content/StdDocument.aspx?DOCHWID=aa103080
2. Pregnancy: Should I Have an Early Fetal Ultrasound? Healthwise; c1995-2020 [updated 2020 Feb 11; accessed 2020 Apr 22]. https://www.healthwise.net/ohridecisionaid/Content/StdDocument.aspx?DOCHWID=aa22092

3. Pregnancy: Should I Have CVS (Chorionic Villus Sampling)? Healthwise; c1995-2020 [updated 2020 Feb 11; accessed 2020 Apr 22]. https://www.healthwise.net/ohridecisionaid/Content/StdDocument.aspx?DOCHWID=tb1905
4. Pregnancy: Should I Have Screening Tests for Birth Defects? Healthwise; c1995-2020 [updated 2020 Feb 11; accessed 2020 Apr 22]. https://www.healthwise.net/ohridecisionaid/Content/StdDocument.aspx?DOCHWID=aa21828
5. Decision Box: What are my options regarding prenatal screening tests? Canada: Université Laval; c2017 [accessed 2020 Apr 22]. https://www.boitedecision.ulaval.ca/en/
6. An aid to decision making: Should I take the SIPS/IPS test to screen for Trisomy 21 (Down Syndrome)? Vancouver: BC Prenatal Genetic Screening Program; c2019 [accessed 2020 Apr 27]. http://www.perinatalservicesbc.ca/Documents/Screening/Prenatal-Families/ScreeningDecisionAid.pdf
7. An Aid to Decision-Making for Prenatal Screening. Yukon: Congenital Anomalies Support Yukon; c2019 [accessed 2020 Apr 27]. http://www.hss.gov.yk.ca/pdf/prenatalscreeningguide.pdf
8. Your choice – Prenatal screening tests in pregnancy. Victoria (AUS): Murdoch children's research institute [accessed 2020 Apr 27]. https://www.mcri.edu.au/prenatal-screening
9. Making decisions about screening for Down syndrome in pregnancy. Sydney (AUS): Psychosocial Research Group, Prince of Wales Clinical School; Public Health Genetics, Murdoch children's research institute; Liverpool Hospital, Fetal Medicine Unit; Royal Hospital for Women, Maternal Fetal Medicine; Sydney Medical School, University of Sydney; c2014 [accessed 2020 April 27]. https://askshareknow.com.au/wp-content/uploads/2017/10/Low-literacy-DA-down-syndrome-screening.pdf
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