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Do online decision aids reflect new prenatal screening and testing options? An environmental scan and content analysis

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ABSTRACT

Objective: Decision aids have been developed to help prospective parents make informed, shared decisions about medical tests, but these options are rapidly changing. This study aimed to identify and evaluate publicly available decision aids written in English for prospective parents seeking prenatal test information.
Methods: A systematic review process was followed using 3 sources: known decision aid repositories, fetal medicine organisations and Google. The search, screening process, quality assessment, and data extraction was performed by two independent researchers. The quality assessment of the decision aids was based on the International Patient Decision Aids Standards (IPDAS v.4.0).
Results: We identified 13 decision aids, which varied in the screening and diagnostic tests that they discussed. No decision aid met all the IPDAS v.4.0. criteria and no decision aid reported updated risk of miscarriage for amniocentesis and chorionic villus sampling (CVS). There was a lack of decision aids for some common decisions in the prenatal context.
Conclusion: We identified outdated content in current prenatal decision aids. The findings will inform healthcare professionals of the quality of current prenatal decision aids, which may facilitate their patients' informed decision-making about prenatal tests.
Innovation: Considerations for improving future decision aids are outlined.

1. Introduction

1.1. Testing in the prenatal context

Since prenatal screening and testing options have become widely routinised for prospective parents in developed countries, it has enabled prospective parents to assess whether their pregnancy has an increased chance of a fetal abnormality [1-3]. Prenatal screening programs involve a combined first trimester screen (cFTS) (a combination of maternal blood test and ultrasound including nuchal transclucency scan), and second trimester maternal serum screen (MSS). Screening programs have generally targeted aneuploidies including trisomy 21 (Down syndrome), trisomy 18 (Edwards syndrome) and trisomy 13 (Patau syndrome), because their incidence increases with maternal age and they contribute to perinatal morbidity and spontaneous pregnancy loss [4,5]. MSS detects the three aneuploidies at a lower sensitivity but is also able to identify neural tube defects i.e., spina bifida, in the pregnancy [6]. These tests may also be combined in various ways according to the screening programs offered in different countries, e.g. serum integrated prenatal screen (SIPS) involves the first trimester blood test combined with the second trimester MSS, with a screening result determined after the second blood test. Integrated prenatal screening (IPS) adds a nuchal transclucency scan to the SIPS protocol [7]. The more recent introduction of non-invasive prenatal screening (NIPS, also referred to as NIPT) has provided the chance to screen earlier in pregnancy, broaden the scope of the screen including the optional testing for sex chromosome aneuploidies, microdeletion and microduplication syndromes, and increases the sensitivity when testing for Down syndrome (99.3%), Patau syndrome (97.4%), and Edwards syndrome (97.4%) [8] compared to cFTS (85-90%) [9] and MSS.

If prospective parents receive an increased chance result from prenatal screening, it is standard practice that they are offered a discussion about the result, its implications, and further options (i.e., diagnostic testing) with a health professional such as a genetic counsellor or obstetrician [10]. Currently, invasive testing by chorionic villus sampling (CVS) or amniocentesis is the only method to diagnose genetic conditions in fetuses. These tests are associated with a small risk of miscarriage. Current professional guidelines for prenatal screening and diagnosis estimate the procedure-related risk of miscarriage attributed to invasive diagnostic

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tests as likely to be <0.5% [11], with procedure-specific rates of 0.1% (1 in 1000) for amniocentesis and 0.2% (1 in 500) for CVS [12,13] based on a 2015 meta-analysis [14]. The same study also reports that the risk of miscarriage is not significantly different for women who choose not to undergo invasive testing at the same gestation [14]. An updated meta-analysis in 2019 found that the weighted procedure-related risk of miscarriage following amniocentesis or CVS was 0.3% and 0.2% respectively. However, when risks were compared between invasive-procedure and control groups with similar background risks for chromosomal abnormalities, there was no significant increase in risk above the background risk level for women undergoing invasive procedures and there was no evidence that CVS is less safe than amniocentesis [15].

With the increase in tests available and the differences in information they provide, prospective parents often experience the challenge of making decisions about the appropriate test for them, what information they would like to gain from testing, and next steps if they receive an increased chance result or diagnosis [16-18]. These challenges coupled with the unexpected event of an increased chance result from screening, diagnosis of a condition, and the time pressure to make decisions, can be distressing and place a decisional burden on prospective parents [19].

1.2. Utility of decision aids in the prenatal context

Decision aids (DAs) have been acknowledged as effective tools that facilitate the communication of benefits and risks involved in decisions related to health [20,21]. DAs integrate unbiased and evidence-based information about procedures so that patients can make informed decisions based on having an accurate perception of the risks involved in the procedures and the expectations of the outcome [20]. Many studies have been published supporting the use of DAs in the prenatal context as they facilitate informed decision-making, value-consistency, and deliberation [22-25]. In the prenatal context, DAs have a role in improving knowledge about each screening and diagnostic test option [26,27] which can potentially reduce the anxiety or pressure that patients may feel when faced with decision-making [28]. The International Patient Decision Aid Standards (IPDAS) Collaboration is a group of professionals that have developed frameworks to help produce quality patient DAs based on a set of criteria to assess the quality and effectiveness of patient DAs, which at the time of this study was version 4.0. (IPDAS v.4.0.) [29,30].

1.3. Role of the internet as a resource for prenatal information

The Internet has a growing role as a resource for health information and health awareness [31]. A recent review identified that the Internet was the most used resource for primary care patients, followed by physicians, television, then family and friends [32]. The study also reported that help-seekers often used Internet resources to supplement advice received from health professionals rather than to seek a second opinion [32]. One Australian study found that 89% of women identified the Internet as their first source of pregnancy-related information [33]. Thus, it is important to ensure that the available resources for prospective parents are proficient in informing them of the prenatal screening and testing options and the benefits and risks that are involved with each test.

It is important to consider the quality and accessibility of patient DAs that are publicly available online. It is unclear what DAs are currently available online for prospective parents seeking aids to help with decision-making in the prenatal context. A previous environmental scan published in 2015 found 20 decision aids [34], none of which were found to meet all 16 IPDAS minimum standards, with a median score of 10/16, and only one of which discussed NIPS. NIPS became commercially available in 2012, and has become increasingly popular over the past decade; in most Australian and American states, NIPS is conducted in 25-50% of pregnancies [35]. This study aimed to update the 2015 review to include decision aids about newer tests such as NIPS, and evaluate content against the latest estimates for diagnostic test outcomes.

2. Methods

2.1. Study design

Following the method of an earlier review [34], an environmental scan was conducted to identify publicly available prenatal DAs on the Internet [36]. The search strategy was guided by the principles of the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) [37].

2.2. Search strategy

The research team identified three main sources of DAs related to prenatal screening and/or prenatal diagnostic tests to conduct our searches. These were: (i) known DA repositories (Appendix A; Table A.1), (ii) known fetal medicine and/or prenatal genetics organisations or support groups (Appendix A; Table A.2), and (iii) Google Australia. The list of known DA repositories was compiled in consultation with an expert in decision-making and risk communication (C.B.). The list of known organisations and support groups for fetal medicine or prenatal genetics was considered a valuable source of information for patients seeking information and was compiled in consultation with a genetic counsellor (L.F.). As we were sourcing materials that reflected the consumer perspective, we did not search for patient DAs in the scientific literature.

A systematic search was performed on Google Australia to identify publicly available patient DAs. The search terms (Appendix A; Table A.3) were developed in consultation with a genetic counsellor (L.F.), an expert in decision-making (C.B.) and a librarian. A previous environmental scan [38] advised that search terms which performed well were specific prenatal procedure terms and “decision aid”. We piloted additional terms before the 16 search terms were finalised.

Before performing all searches, the browsing data, cookies, and caches were cleared on the Google Chrome web browser to minimise search engine optimisation affecting the results. The plugin SEOQuake was used to export the search results to Microsoft Excel. The SEOQuake plugin was set to export the first 70 search results as the remainder were unlikely to meet the inclusion criteria. The URL results, search terms used, date and time were recorded.

2.3. Patient decision aid inclusion and exclusion criteria

Items were included if they: (i) met six eligibility criteria from IPDAS v.4.0. [30] (Box 1), (ii) contained educational material or a tool designed to help with decision-making for the prenatal screening and testing context. One DA that had been superseded by an updated version was included on the basis that it was still freely accessible to consumers via internet search.

Items were excluded if they: (i) did not meet six eligibility criteria in IPDAS v.4.0 [30] (Box 1); (ii) were not related to prenatal screening and/or diagnostic testing; (iii) were aimed to be used by health professionals i.e., academic literature; (iv) were not available in English; and (v) needed to be purchased.

The search strategy and inclusion criteria were designed to create a homogenous sample for this study, which specifically aimed to assess the quality of patient DAs. It is important to note that the search and inclusion strategies used may not reflect search strategies used by members of the

Box 1
IPDAS v4.0 eligibility criteria used in this study [30].

1. The decision aid describes the condition (health or other) related to the decision
2. The decision aid describes the decision that needs to be considered
3. The decision aid identifies the target audience
4. The decision aid lists the options (health care or other)
5. The decision aid has information about the positive features of the options (e.g. benefits, advantages)
6. The decision aid has information about the negative features of the options (e.g. harms, side effects, disadvantages)

public to find and appraise information about prenatal screening and diagnosis.

2.4. Data extraction and evaluation

All three sources were independently searched, compiled, and screened by two reviewers (J.L. and S.M.). There were no discrepancies with the final list of search results.

The following characteristics were extracted for the included DAs: title, name of developer, date of publication, and source. Two independent reviewers (J.L. and S.M.) assessed the included DAs against the remaining sections of the IPDAS v.4.0. checklist, certification criteria and quality criteria (Appendix C). Certification criteria (n = 10) are those deemed essential to avoid bias, and include criteria related to the balanced presentation of options, the evidence synthesis process, presence of citations, and disclosure of funding sources. Quality criteria (n = 28) are those considered desirable but not essential to avoid bias, including criteria related to the presence and presentation of outcome probabilities, values clarification, the DA development process, and the presence of information related to test sensitivity and specificity [30]. The IPDAS v.4.0. checklist used a 4-point Likert scale to score if a criterion was met or not, the options were strongly disagree (1), disagree (2), agree (3), and strongly agree (4). A total score was recorded for each DA out of 152. Scoring discrepancies were resolved by consensus. All criteria were marked based only on the information provided in the DA itself. Materials describing DA development were not considered.

A data extraction tool (Table 2) was created based on literature that identified issues and knowledge that is needed to inform patients when considering prenatal genetic testing [39]. The data extraction tool was also informed by experts in the research team (L.F) and reviewed by a clinical midwife consultant, a clinical epidemiologist, a bioethicist, and an expert in health technology decision-making.

2.5. Data synthesis

The data was presented in tabular format capturing characteristics and written information from the data extraction tool and the numerical data from the IPDAS v.4.0. checklist. The analysis compared the two sets of extracted data against the research questions to determine key findings and themes which were summarised through narrative synthesis.

3. Results

The search was conducted across four known DA repositories, 29 known organisations and support groups, and Google Australia and yielded 446 records (see Fig. 1). A total of 13 records met the inclusion criteria for quality assessment and data extraction (Table 1).

3.1. Ease of access to decision aids

All DAs were from high income countries including the United States of America (USA) ($n = 6$); Canada ($n = 3$); Australia ($n = 3$) and the United Kingdom (UK) ($n = 1$). Most DAs ($n = 12$) were published or updated after 2012, when NIPS was publicly available. The remaining DA was published in 2004, and while the publisher has since released an updated DA, the 2004 version is still freely available via Google search. All DAs were available through Google Australia, except for four DAs from Healthwise (USA). However, they were accessible through the Decision Aid Library Inventory (see Table 1).

3.2. Decision aid evaluation

The DAs ($n = 13$) presented the benefits and harms of testing options equally (i.e., same fonts, no portrayal of one option over another), included information about what the tests were designed to identify, and all mentioned options for next steps if a condition was diagnosed or detected at an increased risk when assessed against the certification criteria from IPDAS v.4.0. (see Appendix C). One DA met all of the relevant certification criteria. Nine DAs mentioned considerations for next steps if a condition was not detected; four DAs did not include this information.

The quality criteria in IPDAS v.4.0. were split into three further criteria for consideration: information on outcome probabilities, developmental process of DA, and information on the test's sensitivity and specificity. All DAs ($n = 13$) included a comparison of the benefits and harms of each test option, and they all encouraged patients to choose the option that was in concordance with their values and beliefs with consideration of the beneficial and harmful outcomes. Almost all DAs provided sections that support

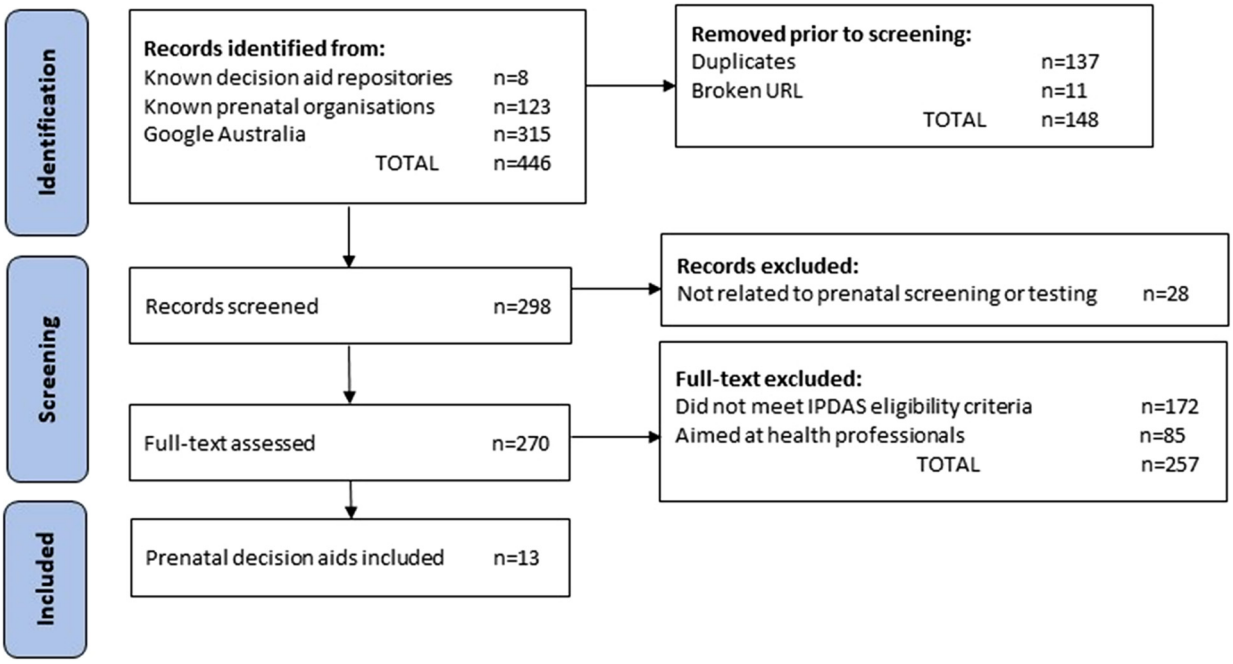

Fig. 1. Search strategy and results.

Table 1
Eligible decision aids (n = 13).

ID	Title	Developer	Year Published/Last Updated	Source
a.	What are my options regarding prenatal screening tests?	Université Laval, Canada	2017	Known DA Repositories, Google Australia
b.	A Decision Aid - Testing in pregnancy for fetal abnormalities*	Murdoch Children's Research Institute (MCRI), Australia	2004	Google Australia
c.	Making decisions about screening for Down syndrome in pregnancy	Psychosocial Research Group, Prince of Wales Clinical School, Australia	2017	Known Organisations, Google Australia
d.	Should I take the SIPS /IPS test to screen for Trisomy 21 (Down syndrome)?	Perinatal Services BC, Canada	2019	Known Organisations, Google Australia
e.	Pregnancy: Should I Have Screening Tests for Birth Defects?	Healthwise, USA	2013/2020	Known DA Repositories
f.	An Aid to Decision-Making for Prenatal Screening	Congenital Anomalies Support Yukon, Canada	2019	Google Australia
g.	Your Choice – Prenatal Screening Tests in Pregnancy & Screening Choices tool	MCRI, Australia	2018	Known Organisations, Google Australia
h.	Down syndrome screening test: yes or no?	Option Grid Collaborative, Dartmouth, USA	2015	Known DA Repositories, Google Australia
i.	Pregnancy: Should I Have Amniocentesis?	Healthwise, USA	2012/2020	Known DA Repositories
j.	Pregnancy: Should I Have CVS (Chorionic Villus Sampling)?	Healthwise, USA	2012/2020	Known DA Repositories
k.	Shared Decision Making – Down's, Edwards', and Patau's Syndromes	National Health Service (NHS), England	2017	Google Australia
l.	Pregnancy: Should I have an early fetal ultrasound?	Healthwise, USA	2012/2020	Known Decision Aid Repositories
m.	Amniocentesis test: yes or no?	Option Grid Collaborative, Dartmouth, USA	2015	Known DA Repositories, Google Australia

* This DA (ID-b) has been superseded by ID-g, but is still accessible online to consumers via Google search results

patient involvement in their decision-making, such as worksheets or lists of questions for healthcare providers ($n = 12$) (Table 2); and provided a comprehensive step-by-step process to aid in decision-making (n = 11). Less than half of the DAs ($n = 5$) provided more than one way of viewing outcome probabilities (i.e., numerical, bar graphs, icon arrays).

Seven DAs included details about the chances of true positives, false positives, and false negatives for the specific prenatal test. Five DAs detailed statistics of true negative results for the prenatal tests that they discussed, and eight DAs did not include information about true negatives. One DA specified the chance of detecting Down syndrome with and without the use of prenatal screening tests (i.e. explicitly specified that without prenatal screening, a person's individual chance of having a baby with Down Syndrome is unknown).

The highest scoring DA scored 106, and the lowest scoring DA scored 62, out of the highest possible total of 152. The median score was 97 out of 152. Table 3 summarises the mean and standard deviation of the certification and quality criteria scores for each DA.

3.3. Decision aid content

Table 2 summarises the content and main focus of the DAs, including information about which screening and/or diagnostic test options were presented, and which conditions being screened/tested for were mentioned in the DA. While all prenatal DAs mentioned the option of ultrasound scans as a screening test and amniocentesis as a diagnostic option after receiving an increased chance screening result, all the DAs except one focused on either only screening or only diagnostic tests. While 12/13 DAs were published after NIPS became available, 4 of those 12 do not mention NIPS. None of the DAs presented NIPS as a non-invasive alternative to diagnostic testing after a high-chance cFTS. The DAs produced in Canada (n = 3) are the only ones that mention SIPS and IPS as screening options. Down syndrome was the most commonly mentioned condition (n = 13), followed by Edwards syndrome (n = 9), Patau syndrome (n = 8) and neural tube defects (n = 8). Less than half of the DAs (n = 6) described a spectrum of phenotypes for one or more of the conditions mentioned in the DA.

3.4. Risks and implications of screening and diagnostic tests

All 13 DAs provided at least one description of a physical implication including: discomfort from diagnostic tests, possibility of miscarriage, or a description of the procedure. Ten DAs mentioned at least one psychosocial implication, including: feelings of anxiety when waiting for results, social or familial pressure, stress around making difficult decisions, and feeling reassured by negative results.

The potential risks associated with prenatal screening tests were the emotional distress around true positive, false positive, and false negative results. The potential risk that was commonly noted in association with prenatal diagnostic tests was the risk of miscarriage due to the procedure. The statistical risk of miscarriage due to amniocentesis provided by the DAs ranged from "1 in 100" to "1 in 1000" to "small" (Table 2). The statistical risk of miscarriage due to CVS was reported from "1-2 in 100" to "1 in 1000" to "higher than amniocentesis" and "small". Seven DAs reported risks of miscarriage for both amniocentesis and CVS; three reported the same statistical risk of miscarriage for both procedures and four reported that CVS had a slightly higher statistical risk of miscarriage compared to amniocentesis.

4. Discussion and conclusion

4.1. Discussion

4.1.1. Main findings

This environmental scan retrieved 13 prenatal testing DAs that were publicly available, accessible through the Internet and met IPDAS v.4.0. eligibility criteria [30]. Key issues raised from the analysis include: (1) lack of high-quality prenatal DAs (i.e. DAs that meet IPDAS certification and quality criteria), (2) inconsistencies between current evidence and information given in DAs particularly in regards to procedural risks that may lead to confusion and decrease trust, (3) lack of DAs for some common decisions in the prenatal context, (e.g. DAs presenting the choice between CVS and amniocentesis after a high-chance screening result, or presenting NIPS as a non-invasive option after a high-chance cFTS result).

4.1.2. Risk communication for prenatal diagnostic testing

The DAs identified that the main risk associated with diagnostic tests was procedure-related risks of miscarriage. Out of the DAs that produced a numerical statistic for the procedure-related risks of miscarriage (n = 10), no DAs had an up-to-date statistic for the procedure-related risk of miscarriage. While several of the DAs reflected the estimated rates of procedure-related risks of miscarriage from the 2015 meta-analysis

Table 2
Data extraction tool noting specific characteristics of eligible decision aids (n = 13).

Characteristics	Decision aids (n = 13)												
	a.	b.	c.	d.	e.	f.	g.	h.	i.	j.	k.	l.	m.
Tests mentioned:													
Ultrasound/Anomaly scan	✓		✓	✓	✓	✓	*✓	✓	✓	✓	✓	*✓	✓
cFTS		*✓	*✓		*✓		*✓	*✓					
MSS		✓	*✓		*✓		*✓	*✓					
NIPS	*✓		*✓	✓	*✓	*✓	*✓	*✓					✓
IPS	*✓			*✓									
SIPS	*✓			*✓		*✓							
Amniocentesis	✓	*✓	✓	✓	✓	✓	✓	✓	*✓	✓	*✓	✓	*✓
CVS		*✓	✓		✓		✓	✓	✓	*✓	*✓		✓
Conditions named:													
Down syndrome	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Edwards syndrome	✓	✓	✓	✓	✓	✓	✓				✓		✓
Patau syndrome	✓	✓	✓		✓	✓	✓				✓		✓
Sex chromosome conditions		✓				✓	✓						
Neural tube defects		✓		✓	✓	✓	✓		✓	✓		✓	
Others – specify		Physical abnormalities				Birth defect	Microdeletion syndromes		Cystic fibrosis, sickle cell disease, Huntington's disease	Tay-Sachs disease, haemophilia	Congenital anomalies		
Implications presented:													
Physical	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Psychosocial	✓	✓	✓	✓	✓	✓			✓	✓	✓	✓	
Financial	✓	✓	✓	✓	✓	✓	✓		✓	✓			
Next steps	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Decision-making tools:													
Evaluation of understanding				✓	✓	✓		✓	✓	✓		✓	✓
Value-based questions	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓
Description of spectrum of phenotype/s	✓	✓	✓	✓		✓	✓						
Personal worksheets	✓	✓	✓		✓	✓	✓	✓	✓	✓		✓	
Patient stories		✓			✓				✓	✓		✓	
Reported risk of miscarriage:													
Amniocentesis	1 in 909	0.5% (1 in 200)	1 in 100 – 1 in 1000†		Small risk	1 in 200	1 in 200 – 1 in 1000	Small risk	1 out of 900		1 in 100		<1 in 100
CVS		1% (1 in100)	1 in 100 – 1 in 1000†		Small risk		1 in 100 – 1 in 500	Small risk		1 out of 455	1–2 in 100		Slightly higher than amniocentesis

* Indicates the main screening/diagnostic test(s) discussed in the DA
† Lower risk specified if procedure is performed by experienced doctor

mentioned previously [14], none reflected the most recent (2019) evidence for procedure-related risk associated with amniocentesis (0.3% or 3 in 1000), nor recent findings that there is no significant procedure-related risk associated with CVS [15,40]. Although the procedural risk depends on who performs the procedure [41], the chance of miscarriage is significantly lower than what was reported in most of these DAs. Four DAs that presented CVS and amniocentesis as options gave the impression that CVS is a riskier procedure than amniocentesis in terms of procedure-related pregnancy loss.

There are several issues that can be caused by DAs which report outdated procedure-related risks of miscarriage due to prenatal diagnostic tests. Firstly, many prospective parents base their decisions on the statistical procedure-related risk of miscarriage [17]. An outdated estimate would misinform prospective parents. Secondly, the average procedure-related risk of miscarriage contributes to how pregnant women and couples perceive their risk of miscarriage. However, individual risk is influenced by many other elements including maternal age, ethnic background, inclination to have an invasive diagnostic procedure, previous experience with miscarriage, income, and education [42-45]. The perception of inflated probability estimates (e.g. 1% versus 0.3%) may lead some prospective parents to choose not to undergo diagnostic testing because that risk of miscarriage is too high [45,46]. Thirdly, the DAs inconsistently reported procedure-related risks of miscarriage, which may contradict more updated fig.s provided by healthcare professionals. This may cause patients to lose confidence in the different estimates provided by healthcare professionals and may contribute to a general sense of uncertainty in terms of decision-making [47,48]. Prospective parents may be basing their decisions on inaccurate and outdated statistical risks under the illusion of informed decision-making; their reproductive choices may change if they had known the updated statistical procedure-related risk of miscarriage.

4.1.3. Strengths and limitations

The strengths of this study were that a systematic search, screening process, and data extraction was performed with two independent researchers (J.L. and S.M.) searching within the same time period which resulted in good replication of results. An additional strength was that the study applied stringent IPDAS criteria [30] during screening and data extraction. It is important to note that due to the application of this stringent criteria, this study only represents a small proportion of the information that individuals seeking information on the Internet about prenatal screening and diagnostic tests may find.

Table 3
Certification and quality criteria scores

	Decision Aid ID and Title	Certification Criteria		Certification Total (n/40)[†#]	Quality Criteria		Quality Total (n/112)[‡]	TOTAL (n/152)
		Mean[*]	SD		Mean[*]	SD		
a.	What are my options regarding prenatal screening tests?	3.1	1.0	32	2.6	1.5	74	106
b.	A Decision Aid - Testing in pregnancy for fetal abnormalities	3.1	1.2	31	2.5	1.4	71	102
c.	Making decisions about screening for Down syndrome in pregnancy	3.3	1.3	33	2.5	1.4	69	102
d.	Should I take the SIPS /IPS test to screen for Trisomy 21 (Down syndrome)?	3.0	1.4	30	2.5	1.4	70	100
e.	Pregnancy: Should I Have Screening Tests for Birth Defects?	2.9	1.2	29	2.5	1.5	70	99
f.	An Aid to Decision-Making for Prenatal Screening	2.8	1.3	28	2.5	1.4	70	98
g.	Your Choice – Prenatal Screening Tests in Pregnancy & Screening Choices tool	2.7	1.5	27	2.5	1.5	70	97
h.	Down syndrome screening test: yes or no?	2.3	1.5	23	2.1	1.4	60	83
i.	Pregnancy: Should I Have Amniocentesis?	2.5	1.2	25	2.0	1.3	55	80
j.	Pregnancy: Should I Have CVS (Chorionic Villus Sampling)?	2.5	1.2	25	2.0	1.3	55	80
k.	Shared Decision Making – Down's, Edwards', and Patau's Syndromes	2.5	1.4	25	1.8	1.2	51	76
l.	Pregnancy: Should I have an early fetal ultrasound?	2.6	1.1	26	1.8	1.2	49	75
m.	Amniocentesis test: yes or no?	1.9	1.2	19	1.5	1.0	43	62

[*] All IPDAS certification and quality criteria are scored 1-4 (1 = strongly disagree that criterion is met to 4 = strongly agree that criterion is met).
[#] All criteria were marked based only on the information provided in the DA itself. Materials describing DA development were not considered.
[†] There were ten certification criteria. One certification criterion acknowledged lead time bias which was irrelevant to the prenatal context and all DAs (n = 13) were scored 1 (strongly disagree).
[‡] There were 28 quality criteria. One quality criterion considered whether the DA allowed a user to compare the outcome probabilities across options using the same time period, all DAs (n = 13) scored 4 (strongly agree) with consideration that the time period would be throughout pregnancy

The principal limitation with this study was conducting a systematic search on Google, a dynamic search engine. The search results obtained in this study are unlikely to be replicable and they would be different depending on the searcher, their geographical location, and the time at which they searched. However, we likely captured the most popular Australian search results at the time, and we did not rely on Google as our only source to locate the DAs. The other limitation is the omitted variable bias, in which we did not consider that different countries have different nomenclature for prenatal screening options. For example, in Canada, SIPS and IPS are provided instead of cFTS and MSS, although the procedures involved are the same. Since these differences were not considered when developing the search terms and during the search, there may be international DAs that were not included.

4.2. Innovation

This study used a novel and dynamic method to identify publicly available DAs that expectant parents may find on the Internet while searching for information on prenatal screening and diagnostic tests. While our search found publicly available DAs covering a wide range of prenatal screening and diagnostic tests, there was a lack of DAs for some common decisions in the prenatal context, raising some important considerations for future DA development in this space. For example, while several DAs were concerned with the decision to have/not have CVS or to have/not have amniocentesis, there were few that presented the decision between having CVS or amniocentesis with equal weight. This is a common decision for expectant parents who have received high chance screening results and wish to have a diagnostic test but must weigh up factors including the timing of the test, the likelihood of an accurate result (amniocentesis is usually recommended over CVS after a high chance NIPS result due to the possibility of confined placental mosaicism) [49], and the options available for termination of pregnancy.

There are two clinical pathways for using NIPS: one as a primary screening test, and the other as a contingent model to support increased risk cFTS results [50]. While the inclusion of NIPS as a primary screening option in DAs has certainly increased (n = 8) since the previously conducted review [34], where only one DA mentioned NIPS, none of the DAs in this present review included NIPS as a non-invasive alternative option to diagnostic testing to increase reproductive confidence after an increased risk cFTS for trisomy 13, 18, and 21 [50]. While NIPS should not be used as a diagnostic test, this option can be useful for expectant parents who decide that the risk of procedure-related miscarriage associated with invasive diagnostic testing is too great. As NIPS is an increasingly relevant screening test, its clinical utility should be comprehensively highlighted in prenatal testing DAs so that pregnant people are able to access the current evidence-based information to support their informed decision-making [51].

4.3. Conclusion

While none of the DAs were found to have met all IPDAS v4.0 certification and quality criteria, this study has identified some DAs to facilitate personal reflection and to guide shared decision-making with prospective parents who are considering their prenatal testing options. While these DAs were all publicly available, how widely they are used and by whom is unknown. Future research could investigate the implementation of prenatal screening and diagnosis DAs in clinical practice, and their sustainability given the rapidly evolving genetic testing landscape. There are benefits for genetic counsellors and other relevant health care professionals to recommend quality prenatal DAs before or after clinical sessions so that expectant parents are left with a trustworthy resource to make an informed decision rather than a consumer-found website that lacks quality and risks misinforming the patient. Given the variations in tests available across countries it would be important to identify the country in which a DA was produced and the year in which it was written as this could influence whether it provides all relevant and updated information for the practicing genetic counsellor or consumer making a choice on prenatal screening.

In the rapidly growing setting of the Internet, resources and information on prenatal screening and testing options have become increasingly available and accessible. The abundance of health information may hinder one's decision-making particularly in a stressful and time-limited situation. This environmental scan identified DAs of varying quality that can be recommended for patients in need of a tool to facilitate decision-making around prenatal screening tests and diagnostic tests. We recommend using a suitable DA for the patient's needs and location; however, healthcare professionals providing one of these DAs needs to be aware of presenting an up-to-date statistical risk of miscarriage due to prenatal diagnostic procedures. Our study highlights the urgent need to update currently available DAs with more accurate risks of miscarriage based on the literature to support informed decision-making and ensure consistency with information provided by health professionals.

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Declaration of Competing Interest

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

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Appendix. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.pecinn.2022.100038.

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