Free Online Decision Tools to Support Parents Making Decisions About Their Children's Chronic Health Condition: An Environmental Scan

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ABSTRACT

BACKGROUND: Medical decisions parents make on their children's behalf can be challenging. Free online decision support tools are created to help parents faced with these decisions.

OBJECTIVE: We used an environmental scan to identify free, online tools that support parents in making decisions about their children's chronic health condition. We described the tools and assessed their potential to harm, content, development process, readability, and whether their use changed decision makers' knowledge and alignment of their preferences with their final decision.

DATA SOURCES AND ELIGIBILITY: Decision aid repositories, Google searches, and key informants identified decision support tools. Eligible tools were freely available online and for parents of children with chronic health conditions.

APPRAISAL METHODS: Two reviewers independently assessed the tools' quality based on the International Patient Decision Aid Standards (IPDAS). Tool readability was assessed using the Flesch Reading Ease test.

RESULTS: From 21 free, online decision support tools, 14 (67%) provided sufficient detail for making a specific decision (IPDAS qualifying criteria). None sufficiently met IPDAS certification criteria necessary to reduce the possibility of patient harms when using the tool. Three (14%) were fairly easy or easy to read. Of those evaluated by developers (n = 6), 2 improved knowledge and 4 improved alignment of preferences with the available options.

LIMITATIONS: Google searches and key informant sources are not replicable.

CONCLUSIONS: Free, online decision support tools for parents of children with chronic health conditions are of variable quality, most are difficult to read, and there is limited evidence their use achieves intended outcomes.

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KEYWORDS: chronic disease; decision making; decision support techniques; parents

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WHAT THIS REVIEW Adds

There is evidence that decision support tools improve patient decision making in adult health care. Comparatively less is known about the availability and outcomes of the use of decision support tools in pediatric and adolescent health care.

We found that tools for parents making decisions about their child's chronic health condition are difficult to read and many do not meet international standards for quality.

HOW TO USE THIS REVIEW

Clinicians could use our central list of identified decision support tools with parents of children with chronic health conditions. Future research is indicated to develop decision support tools that are more accessible and could be used with children.

AN INCREASING NUMBER of decision support tools are being developed to facilitate medical decision making.[1] In adult health care, decision support tools have shown

to improve the decision maker's knowledge, decrease decision regret and enable decisions consistent with the decision maker's values and goals.[2] Comparatively less is known about the existence and outcomes of the use of these tools in child and adolescent health care.

Parents of children with chronic health conditions (eg, neurodevelopmental conditions, cerebral palsy, cancer) frequently make decisions about the care of their child.[3] Health decisions can be difficult when they involve more than one option, uncertain outcomes or outcomes that people value differently.[4] The requirement for parents to engage with challenging, preference-sensitive decisions can negatively impact their psychological wellbeing.[5] Decision regret has been documented among parents making health decisions for their children.[6,7]

Decision support tools assist individuals in making difficult decisions by providing information about different options and helping them to define their core values.[8] These tools have been proven to be effective in helping adults make health decisions.[1] A decision support tool for patients at higher risk of cardiovascular disease was found to enhance decision making and statin adherence.[9] However, the existence and quality of free online tools designed for parents making decisions on their children's behalf are not known.

Often, the types of decisions for which decision support tools are created could result in critical health-related outcomes (including morbidity and mortality). As such, it is important that the information decision support tools provide is unbiased and up-to-date to ensure their safe use in health care.

Assessing the quality of available decision support tools and identifying gaps will help determine the resources needed for parents and areas where current tools fail to meet their needs. Documenting what decision support tools exist will also serve as a resource for parents or health professionals engaged with decisions for children with chronic health conditions. Dissemination and implementation have been recognized as key limitations to widespread decision support tool use.[10]

We aimed to:

1. Identify (aim 1a) and describe (aim 1b) free, online decision support tools designed for parents to use while making decisions for their children with chronic health conditions
2. Assess the quality of the tools in terms of their: potential to reduce harm (aim 2a), content (aim 2b), development process (aim 2c) and readability (aim 2d)
3. Investigate whether the tools were evaluated by the developers (aim 3a) and if so, whether the literature demonstrates evidence of change in decision makers' knowledge and alignment of their preferences with their final decision through use of the decision support tool (aim 3b).

METHODS

DESIGN

We conducted an environmental scan to identify free, online decision support tools that are designed for parents to use while making decisions for their children with chronic health conditions. This methodology, which is widely used to identify decision support tools, has been recommended by decision-making experts to understand tools available to patients.[11,12] Google searches were conducted to mimic the user experience. The Google searches were supplemented by searching decision support tool repositories and contacting key informants to identify decision support tools that may be recommended by health professionals.

We used the International Patient Decision Aid Standards (IPDASi v4.0) checklist, an internationally accepted set of standards to assess the quality of decision support tools. This checklist examines factors such as the tool's development, the information and options presented, associated probabilities, the exploration of patient values, whether the evidence is up-to-date, and whether the tool has been evaluated in a scientific study.[13]

STUDY INCLUSION/EXCLUSION CRITERIA

Tools were included if they: i) targeted parents of patients aged <18 years[14] making medical decisions about their children with a chronic condition[15]; ii) were freely available online, including those reported in open access peer-reviewed literature; iii) in any language.

Tools were excluded if they did not meet the above criteria which included tools: a) focused on decisions about antenatal care, acute medical issues (eg, use of antibiotics to treat ear infection) or preventive care (eg, HPV vaccination for healthy children); b) educated or informed the user without engaging them in the decision-making process; c) targeted the child or health professional without incorporating parents in the decision-making process; d) were not freely available to use.

SEARCH METHODS (AIM 1A: IDENTIFY)

To design an effective search strategy, we experimented with various terms and combinations in consultation with an Information Service Librarian from the University of Technology Sydney. The final search terms were chosen to accurately reflect the user's experience and ensure a comprehensive range of results. The search strategy was based on search terms divided into three themes: 1) decision support, 2) child, and 3) health. Synonyms were determined and divided into four search phrases (see supplemental information for search phrases).

Two reviewers (T.W. and A.S.) independently conducted Google searches between July 19 and 25, 2021. The searches were performed in Mozilla Firefox after clearing the cache and cookies. A systematic search of repositories known to contain decision support tools (Table 1) was also conducted on August 9, 2021. All

Table 1. Decision Support Tool Repositories

Organization	Website
Option Grid	http://www.optiongrid.org/
The Decision Aid Library Inventory (DALI)—Ottawa Research Institute	https://decisionaid.ohri.ca/AZlist.html
The Decision Box—Laval University	https://www.boitedecision.ulaval.ca/en/
National Institute for Health and Care Excellence (NICE) Decision Aids	https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making
National Health Service (NHS)	http://sdm.rightcare.nhs.uk/shared-decision-making-sheets/
Agency for Healthcare Research and Quality	http://www.effectivehealthcare.ahrq.gov/tools-and-resources/patient-decision-aids/

decision support tools in repositories were assessed against the inclusion/exclusion criteria.

Each search phrase was applied twice, once in Google Australia and once in Google USA. These countries were selected to represent our locations, with the rationale that the findings of this study will inform development of decision support tools for use in Australia or the USA. URLs for the first 100 search results were exported using the SEOQuake plugin (https://www.seoquake.com/index.html) for Mozilla Firefox. Sources were immediately excluded if they did not include a decision support tool or were obviously irrelevant (eg, nonmedical decisions such as securing funding to send your child to college).

Key informants were contacted on August 19, 2021, to advise about possible repositories or known, free decision support tools. We identified key informants (n = 17) through our professional networks, the reputation of the key informants, and peer-reviewed literature. Key informants were selected to cover a broad range of pediatric subspecialties. We contacted lead developers or authors of decision support tools that were not readily available (eg, described in a research article from the Google search that did not include a copy of the tool) to check if the tool was freely available (n = 8). Key informants and authors were contacted through a personalized email.

Results were combined from each source, duplicates removed, and assessed by the same two independent reviewers against the predefined inclusion/exclusion criteria. Disagreement between authors was resolved by discussion and by a third author (E.T.) where required. Reasons for exclusion were documented.

On selection of our final list of decision support tools, we sought to determine if associated literature was available describing the developers' process of development of the tools (aim 2c: development process) and evaluation (aim 3). This was not intended as a systematic literature review, rather, a focused and thorough search. We used Google Scholar to find any relevant published literature by the authors/developers of the decision support tools, and performed a key word search using decision support tools' titles. The search was conducted on August 27, 2021.

DATA EXTRACTION

T.W. and A.S. independently completed a data extraction form for all decision support tools in the final list. The independent assessments were compared, and

discrepancies were resolved through discussion and consensus between the two reviewers. Any further disagreements were discussed with a third reviewer (E.T.).

AIM 1B: DESCRIBE

We composed a data extraction form that included items relating to the target age of the child for which the parent is deciding, other demographics relating to the target user, name of developer, decision being made and possible outcomes, and components of the tool. We also extracted descriptive items for the tool itself, for example, we recorded inclusion of a knowledge assessment, patient stories, and values-based questions (Table 3 for more detail). Materials were classified according to the condition addressed (neurobehavioral or physical) and target decision context: pharmaceutical management; nonpharmaceutical management; clinical trial; diagnostic test; or general).

AIM 2A−D: ASSESS QUALITY

We assessed the quality of decision support tools using the IPDASi v4.0 checklist[13,16] which includes 44 criteria. Of the 44 criteria, 12 are considered essential for reducing harms to patients when using the decision support tools and 32 are desirable. We used the 12 essential criteria and 11 of the desirable criteria that were relevant to our research aims (Supplemental Table 2 and more detail below).

AIM 2A (POTENTIAL TO REDUCE HARM): QUALIFYING

Six qualifying criteria rated on a binary yes/no scale must be met to ensure the decision support tool provides a sufficient amount of detail for making a specific decision. This included items such as whether the decision support tool "explicitly states the decision that needs to be considered." *Certifying:* Six certifying criteria (scored on a 1, *strongly disagree* to 4, *strongly agree* scale, where a score of 3 or more means the criteria has been met) ensure that patients are making decisions based on the most current evidence and that the features of each option are provided with equal detail.

AIM 2B (CONTENT)

There are 28 quality criteria (scored on a 1, *strongly disagree* to 4, *strongly agree* scale) to assess decision support tools' content across the dimensions of information,

probabilities, values, guidance, development, evidence, disclosure, plain language, evaluation, and test. Of these 28 criteria, 6 were deemed relevant to the study aims, across the dimensions of information, probabilities and guidance. For example, the five quality criteria in the test dimension were excluded as they relate specifically to decision support tools for decisions about undergoing a medical test (such as: "the patient decision aid includes information about the chances of having a true-positive test result").

AIM 2C (DEVELOPMENT PROCESS)

Based on any scientific studies that reported the development process of the tool, we used the 3 development criteria from IPDAS to assess the quality of the decision support tools' development process. The development process criteria predominantly assessed whether patients were involved (eg, "development process included a needs assessment with clients or patients").

AIM 2D (READABILITY)

We assessed readability using the Flesch Reading Ease test,[17] as used previously in an environmental scan of decision support tools.[11] Text was pasted into a Microsoft Word document including drug names and subheadings, but excluding reference lists, and the Microsoft Word editor tool was applied.

AIM 3 (EVALUATION AND EVIDENCE OF CHANGE)

Based on any scientific studies by developers that evaluated the tool, we used two items from the IPDAS evaluation criteria. We (T.W. and A.S.) determined if there was evidence the decision support tool "improves the match between the preferences of the informed patient and that the option is chosen" and "helps the patient improve their knowledge about the options' features." These items were scored on a 1, *strongly disagree* to 4, *strongly agree* scale.[13]

ANALYSIS

AIM 1 (IDENTIFY AND DESCRIBE)

We summarized descriptive data extracted from the free, online decision support tools.

AIM 2A−C

We converted binary yes/no ratings of the IPDASi v4.0 qualifying criteria to 1 (yes)/0 (no) and summarized the number of decision support tools that met each criteria. We summarized the number of decision support tools that met the remaining criteria (ie, scored 3 or above).

AIM 2D (ASSESS READABILITY)

We calculated a readability score for each decision support tool.[17] Readability scores were categorized as follows; 0 to 30, very difficult; 30 to 50, difficult; 50 to 60, fairly difficult; 60 to 70, standard; 70 to 80, fairly easy; 80 to 90, easy; 90 to 100, very easy. We presented readability

scores in these categories, rather than according to grade level, to be internationally interpretable.

AIM 3 (EVALUATION AND EVIDENCE OF CHANGE)

We assessed available scientific studies using the two IPDASi v4.0 criteria intended to assess evaluation. We summarized the number of decision support tools that had been shown to help parents improve their knowledge or the match between preferences and the option chosen.

RESULTS

AIM 1A (IDENTIFY)

We identified 2403 records combined across all sources. This included 803 decision support tools from repositories and key informants and 1600 URLs from the Google search. From these records, we screened 83 decision support tools with a total of 21 decision support tools meeting the inclusion criteria (Figure). The majority (n = 34) were excluded as they did not meet the definition of a chronic condition (exclusion criteria (i); Figure, for other exclusion reasons). Seven decision support tools were identified from decision aid repositories, eight from Google searches and six from contacting known experts in the field.

AIM 1B (DESCRIBE): FREE, ONLINE DECISION SUPPORT TOOL CHARACTERISTICS

Of the 21 free, online decision support tools included, 14 (67%) pertained to physical conditions (67%), six (29%) were about neurobehavioral conditions, and one (5%) was relevant to parents of children with various chronic health conditions who may be deciding on tracheostomy (n = 1, 5%). The context for the target decisions included pharmaceutical management (n = 10, 48%), non-pharmaceutical management (n = 9, 43%), clinical trials (n = 2, 10%), diagnostic testing (n = 1, 5%), and one tool could be used to make a variety of different decisions (n = 1, 5%). Two decision support tools addressed more than one context. Most of the decision support tools were from the USA (n = 13, 62%) while the remainder were from Canada (n = 4, 19%), Australia (n = 2, 10%), UK (n = 1, 5%), and the Netherlands (n = 1, 5%). Table 2 contains details about the characteristics of the included studies (Supplemental Table 1 for URLs to access decision support tools). All decision support tools were targeted at parents of children/teenagers (ages 4−17).

Close to half (n = 9, 43%) of the decision support tools included a knowledge/understanding assessment (Table 3). Most (n = 15, 71%) engaged users by including value-based questions. There were patient stories in 29% (n = 6) of the included decision support tools. The level to which people other than the primary parent were incorporated in the decision-making process varied. None incorporated coparents, 29% (n = 6) incorporated the child, although to a limited extent (eg, encouraging the parent decision maker to talk to their child but there was limited use of child-friendly language or guidance) and most (71%,
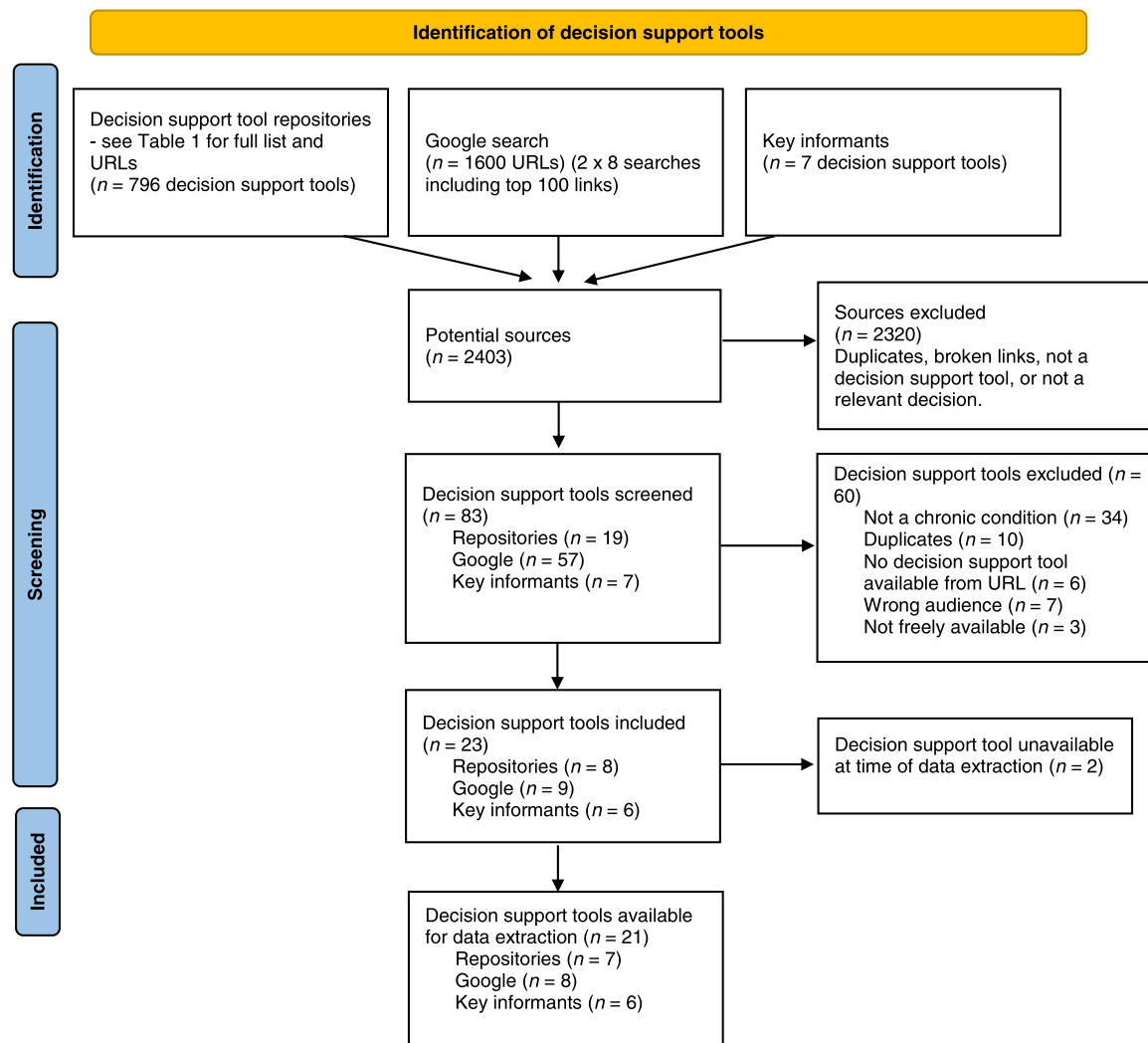
Figure. *PRISMA 2020 flow diagram for new systematic reviews which included searches of databases and registers only.* From: *Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi:10.1136/bmj.n71.*

n = 15) included activities to incorporate a clinician, such as worksheets, a list of questions or space to write additional questions.

AIM 2A (ASSESS FOR POTENTIAL TO REDUCE HARM)

Table 4 (and Supplemental Table 2 for raw scores) details the scores based on the IPDASi v4.0 Collaboration checklist. All 6 qualifying criteria were met by 14 (67%) decision support tools. The qualifying criteria met by most decision support tools (n = 18, 86%) were those that describe the health condition/problem, the available options and the positive features (benefits or advantages) of each option.

None of the decision support tools addressed all six certification criteria. Sixteen (76%) showed the negative and positive features of options in equal detail, one showed both positive and negative features but not equally (ID #16) and another showed only positive features (ID #12). Only one of the decision support tools met the certification criteria for providing information on the update policy (ID #13).

AIM 2B (ASSESS CONTENT)

One third (n = 7, 33%) of decision support tools provided more than one way of viewing the probabilities (eg, words, numbers, or diagrams). It was possible to compare the positive and negative features of the options in 18 (86%) decision support tools. There were 16 (76%) decision support tools that engaged users by asking them to think about which positive and negative features mattered most to them and 14 (67%) engaged users by providing a step-by-step way to decide, 13 (62%) of which did both.

AIM 2C (ASSESS DEVELOPMENT PROCESS)

Corresponding peer-reviewed articles that described the development process were found for 13 (62%) decision support tools (the citations for which are in Supplemental Table 1). Of these 13, most scored highly in the development process criteria, including conducting a needs assessment with clients or patients (n = 13/13, 100%), review by parents not involved in producing the tool (n = 11/13, 85%) and testing with parents who were facing the decision about their child (n = 12/13, 92%).

Table 2. Decision Support Tools That Met Inclusion/Exclusion Criteria. Decision support tools are presented according to target decision, followed by health condition alphabetically.

ID	Title	Developer and Country	Year of Update	Source	Format	Health Condition
		Target decision: pharmaceutical management				
1	Can I take a break from my ADHD medication?	Division of Pharmacy Practice, University of Reading, UK	ND	Google	PDF	ADHD
2	ADHD: should my child take medicine for ADHD?	Healthwise, USA	2021	DALI	Online, paper	ADHD
3	Environmental allergies: should my child get allergy shots?	Nemours Children's clinic, USA	2012	Google	PDF	Allergy: environmental
4	Peanut allergy treatment shared-decision-making tool	The American College of Allergy, Asthma and Immunology, USA	ND	Expert	Online	Allergy: peanut
5	Autism: should my child take medicine for challenging behavior	Autism Speaks, USA	2011	DALI	PDF	Autism
6	Help your child or teenager control their severe asthma	The American College of Allergy, Asthma and Immunology, USA	ND	Expert	Online	Asthma
7	Complex behavior problems in children and youth: treatment options*	Option Grid Collaborative, USA	2016	Option Grid	PDF	Behavior problems
8	Depression: should my child take medicine to treat depression?	Healthwise, USA	2021	DALI	Online, paper	Depression
9	Starting my child on prophylaxis: when and what dose	Universite Laval & McMaster University, Canada	2014	Google	PDF	Hemophilia
10	Importance of decision making and my child's IBD treatment*	Crohn's & Colitis Foundation, USA	2019	Google	PDF	Inflammatory bowel disease
		Target decision: nonpharmaceutical management				
11	SDM JIA treatment cards	Cincinnati Children's Hospital Medical Center, USA	2013	Expert	PDF	Arthritis: juvenile idiopathic
12	Choice Aid for complementary care	Louis Bolk institute, Netherlands	ND	Google	Online	Cancer
13	Should my child have a second cochlear implant?	Institute of Population Health at University of Ottawa, Canada	2009	Google	PDF	Deafness
14	Scoliosis: should I (or my child) have surgery?	Healthwise, USA	2021	DALI	Online, paper	Scoliosis
15	When a child may use a ventilator for a long time	Columbia University Irving Medical Center, USA	2020	DALI	Online, paper, PDF	Respiratory failure
16	Neuromuscular scoliosis: understanding the options	Nemours Children's clinic, USA	2013	DALI	PDF	Scoliosis: neuromuscular
17	Child tracheostomy decision guide	Winnipeg Regional Health Authority, Canada	ND	Google	PDF	Range of acute and chronic conditions which may require a tracheostomy
		Target decision: clinical trials				
18	DELTA: decision-making in childhood cancer	Kids Cancer Centre, Sydney Children's Hospital, Australia	2021	Expert	Online	Cancer
19	Making the right choice about clinical trials	RTI International, USA	ND	Expert	Online	Muscular dystrophy: Duchenne and Becker

(*Continued*)

Table 2. (Continued)

ID	Title	Developer and Country	Year of Update	Source	Format	Health Condition
	Target decision: diagnostic testing					
20	Parent decision-making guide for children with disability, autism and additional needs	Raisingchildren.net, Australia	2021	Google	Online	Autism and disability
	Target decision: general					
21	Decision-aid and E-counseling for inherited disorder evaluation	University of British Columbia, Canada	2014	Expert	Online	Genetic conditions

*Target decision addresses both medication and management, nonpharmaceutical.

ADHD indicates attention deficit hyperactivity disorder; DALI, Decision Aid Library Inventory; IBD, inflammatory bowel disease; JIA, juvenile idiopathic arthritis; SDM, shared decision making; UK, United Kingdom; ND, no date; and USA, United States of America.

AIM 2D (ASSESS READABILITY)

Decision support tools were an average of 9.7 pages long (SD, 9.6). Readability varied from easy to very difficult (Table 5). Three (14%) had a Flesch reading ease score of 70.1 or above (ie, were "fairly easy" or "easy" to read). Two (10%) were available in a language other than English (Table 5).

AIM 3 (EVALUATION AND EVIDENCE OF CHANGE)

We found published evidence of evaluation for six decision support tools (29%, ID#3, #4, #13, #15, #16, and #18—Supplemental Table 1). Evidence that the decision support tool improved the match between preferences and the option chosen was available for two tools. Four tools were found to show evidence of improving knowledge about the features of the options.

DISCUSSION

MAIN FINDINGS

We found 21 free, online decision support tools available for parents of children across a variety of chronic health conditions. These tools engage parents in the decision-making process beyond simply providing information. Most decision support tools we found were for parents making management (pharmaceutical or nonpharmaceutical) decisions for their children with a chronic, physical condition. Two thirds met the minimum IPDAS qualifying criteria, meaning they provided sufficient detail for making a specific decision. None met all IPDAS certifying criteria (considered essential to reduce potential harms to patients when using the decision support tool). There was little evidence available to suggest that these tools have a significant impact on aligning patient preferences or increasing knowledge, as reported in the literature.

COMPARISON WITH LITERATURE

We found limited evidence in the context of chronic childhood conditions that the use of decision support tools by parents leads to improvements in knowledge or improves the match between patient preferences and the option chosen. While the use of decision support tools in adult health care improves knowledge and the match between patient preferences and the option chosen,[18] this evidence may not translate to the context of pediatric health care where parents are proxy decision makers. Decisions people make for themselves differ from what they would decide for others.[19] For example, parents are more risk averse when making decisions on their children's behalf compared to decisions they would make about their own health.[20]

Previous reviews have investigated interventions (including decision support tools) that promote shared decision making between parents and health care providers.[2,21] Most of this work has been conducted in acute settings or with healthy children (eg, for parents deciding whether to vaccinate their child). These studies have found that a variety of such interventions exist, and

Table 3. Decision Support Tool Characteristics

ID	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21
Incorporates child in decision	Y	N	Y	N	N	Y	N	N	N	Y	N	N	N	N	Y	N	N	Y	N	N	N
Includes tools like worksheets or lists of questions to use when discussing options with a practitioner	Y	Y	Y	Y	Y	Y	N	Y	N	Y	N	N	Y	Y	N	Y	Y	Y	Y	N	Y
Includes knowledge/understanding assessment	N	Y	Y	N	N	N	Y	N	N	N	N	Y	N	Y	N	Y	Y	N	Y	N	Y
Includes value-based questions	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	N	N	Y	Y	N	Y	N	Y	Y	N	Y
Includes patient stories	N	Y	N	N	Y	N	N	Y	N	N	N	N	N	Y	N	N	N	Y	N	N	Y
Includes risk/benefit analysis	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	N	Y	Y	Y	Y	N	Y

many contain essential shared decision-making elements such as exploring the decision makers' values, goals, and preferences as well as allowing professionals to make recommendations.[21] There is some evidence that shared decision-making interventions for parents improve knowledge and reduce decisional conflict.[2] We did not assess decisional conflict as this is not included in the evaluation criteria of IPDASi v4.0.

These previous studies have focused on shared decision making between parents and health care professionals.[2,21] Parents also make decisions in collaboration with coparents/spouses or their children, often relying on information that is freely accessible online, either prior to or following an encounter with a health care professional.[22−24] Therefore, our study focused on decision support tools that are freely accessible. We found the role of coparents was not accounted for in these tools. The child's influence was only considered in six tools and in these, to a limited extent.

STRENGTHS AND LIMITATIONS

We conducted systematic searching, screening, and data extraction by two independent researchers with good replication of results across researchers and search sources, demonstrating consistency. The validated environmental scan methodology was applied, along with the stringent IPDAS criteria, aligning with best practice in systematic searches of decision support tools. We used both Google Australia and USA and supplemented these searches with two additional sources which enhance the generalizability of our findings.

Despite these strengths, our study had several limitations. Google is a dynamic search engine that makes direct

Table 4. Number of Decision Support Tools That Met Each Criteria

Category	International Patient Decision Aid Standards (IPDAS) Criteria	n
Qualifying (required to provide sufficient detail for making a specific decision)	Describes the health condition or problem (treatment, procedure, or investigation) for which the index decision is required	18/21
	Explicitly states the decision that needs to be considered (index decision)	17/21
	Describes the options available for the index decision	18/21
	Describes the positive features (benefits or advantages) of each option	18/21
	Describes the negative features (harms, side effects, or disadvantages) of each option	17/21
	Describes what it is like to experience the consequences of the options	17/21
Certification (required to ensure patients are making decisions based on current evidence and options are provided in equal detail)	Shows the negative and positive features of options with equal detail (eg, using similar fonts, sequence, presentation of statistical information).	16/21
	Provides citations to the evidence selected	8/21
	Provides a production or publication date	12/21
	Provides information about the update policy	1/21
	Provides information about the levels of uncertainty around event or outcome probabilities	12/21
	Provides information about the funding source used for development	6/21
Content quality (includes dimensions information, probabilities, and guidance)	Describes next steps	13/21
	Describes the natural course of the health condition or problem, if no action is taken (when appropriate)	11/21
	Makes it possible to compare the positive and negative features of the available options	18/21
	Provides more than 1 way of viewing the probabilities (eg, words, numbers, and diagrams)	7/21
	Asks patients to think about which positive and negative features of the options matter most to them (implicitly or explicitly)	16/21
	Provides a step-by-step way to make a decision	14/21
Development process	Development process included a needs assessment with clients or patients	13/13*
	Development process included review by clients/patients not involved in producing the decision support intervention	11/13[a]
	Field tested with patients who were facing the decision	12/13*
Evaluation	Evidence that decision support tool improves the match between the preferences of the informed patient and the option chosen	2/6†
	Evidence that decision support tool helps patients improve their knowledge about options' features	4/6†

*Denominator is number of peer-reviewed articles found that describe development process.

†Denominator is number of peer-reviewed article found that describe evaluation by developers.

Table 5. Readability, Page Length, and Language

ID	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21
Readability (Flesch reading score)*	44.4	71.2	51.8	57.2	55.9	63.2	27.3	67.3	34.2	25.7	25.0	36.9	61.8	78.8	64.5	50.1	65.6	54.3	84.6	60.0	55.6
Readability (Flesch-Kincaid grade level)**	14.1	6.3	9.6	8.7	9.3	8.6	12.7	7.3	16.8	15.1	12.6	12.0	8.3	5.4	8.5	10.6	7.6	11.1	4.3	8.4	10.2
Number of pages	18	6	5	4	21	4	1	6	2	12	6	5	4	6	25	9	16	40	6	1	6
Language	E	E	E	E	E	E	E	E	E	E	E	E,D	E	E	E,S	E	E	E	E	E	E

E indicates English; S, Spanish; and D, Dutch.
*Scored between 1 and 100 with 100 being the highest score. Scoring between 70 and 80 is equivalent to school grade level 8.
**Scored between 0 and 18 reflecting the US grade level of education required to understand the text. Scoring of 0 indicates basic level of learning to read books, whereas 18 is the reading level for an academic paper.

replication of results difficult as it can be dependent on time and location of the searcher. Due to the nature of conducting environmental scans, it is not possible to precisely replicate our Google search and key informant sources. Free, online decision support tools that met the inclusion criteria may have been missed in the search, although the methods used are likely to have captured the most common and popular search results.

Six of the decision support tools sourced from key informants were not discovered through our initial Google search. These tools met our inclusion criteria and were freely available online but were hard to find unless the exact title of the tool was used in the Google search. This highlights the importance for developers of decision support tools to consider the discoverability of their resources, to improve the implementation of these tools.

Our strategy to identify literature detailing evaluation by developers may have missed any evidence of evaluation conducted by parties other than the developers. The search was biased to predominantly English-speaking countries which may influence our finding that limited decision support tools exist in a language other than English.

IMPLICATIONS AND FUTURE RESEARCH

We provide a central list of free, online decision support tools that clinicians could use with or recommend to parents of children with chronic health conditions, along with an independent assessment of their quality. The decision support tools that incorporate the child in the decision and scored at least a standard readability score such as ID #6 (Help your child or teenager control their severe asthma) and ID #15 (When a child may use a ventilator for a long time) may be more appropriate than other tools to be used to facilitate discussions with parents and their children.

Mostly, we found that the decision support tools for parents of children with chronic conditions could be easily improved to meet quality criteria. For example, explicitly stating the decision to be made, including citations, and providing a publication date would improve the quality of the tool. These requirements are particularly important given that development of decision support tools has recently moved beyond academia, gaining interest from commercial companies.

Language used in the decision support tools could also be simplified to make them accessible to a more diverse range of individuals, including those with low English proficiency. A tension exists between simplifying information while retaining necessary detail.[25] Decision support tool developers may consider producing a supplemental "easy read" version of the tool or visual aids to improve the tool's reach and usability, particularly for those with low literacy and for children.[25]

Further work is indicated to assess the outcomes of decision support tools for parents making health decisions on behalf of their child with a chronic condition. Alongside such work is a need to develop parent-defined outcomes. The IPDASi v4.0 evaluation criteria focus on improving knowledge and matching preferences with the final choice. Additional outcomes could be considered

such as improved parent engagement, deliberation, the match between parent and child preferences, and the ability to weigh the benefits and harms.[26]

Finally, future work should incorporate prior evidence and theory regarding decision making involving multiple individuals. For example, theoretical models of interdependence are relevant in parent decision making that may involve coparents and/or the child.[27] This model acknowledges the influence of both the individual and partners on decisions and behavior. Decision coaching (nondirective guidance to prepare a patient to make a health decision) provided to young people and their parents reduces decisional conflict and improves agreement between the child-parent dyads.[28] The theory and principles of such family decision coaching could be incorporated into parent decision support tools.

CONCLUSIONS

We found 21 free, online decision support tools for parents of children with chronic health conditions. Most tools were for parents making decisions about medical management (both pharmaceutical and nonpharmaceutical) of their child's physical chronic condition. The decision support tools were difficult to read and of variable quality. We found limited evidence these decision support tools lead to a change in parents' knowledge or alignment of their preferences with their final decision. Future research should focus on developing decision support tools that can be understood by people with a range of health literacy levels including children.

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SUPPLEMENTARY DATA

Supplementary data related to this article can be found online at https://doi.org/10.1016/j.acap.2023.02.002.

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