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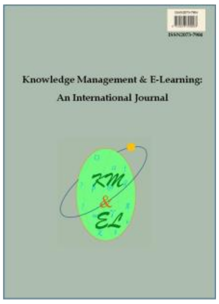

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Utility of electronic decision-support tools for patients with head and neck cancer: A scoping review

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Abstract: The objective of this scoping review is to evaluate the range and nature of electronic decision-support tools that have been researched and/or trialled for patients with head and neck cancer (HNC), and to explore the implication on patient safety through improving risk communication. A scoping review was conducted by: (1) identifying the research question; (2) identifying relevant studies; (3) study selection; (4) collecting data and data items; (5) and reporting on results. Six databases, reference lists and grey literature from Google and Google Scholar were searched, including articles in English from January 2010 to January 2021. Articles discussing electronic decision aids (DAs) for oncology patients were searched then sorted by specificity for HNC. This returned 4217 articles for oncology but only 167 for HNC. Twelve articles met the inclusion criteria and were incorporated in the analysis. Five DAs have been created with varying design characteristics but four consistent themes: appreciation for DAs, usefulness of visuals, impact on reducing decisional conflict and anxiety while increasing knowledge, satisfaction, and shared decision-making, and the variability of patient information needs. Findings demonstrate the paucity of developed and/or trialled electronic DAs for patients with HNC and confirms their value and need for further research and development in this area.

Keywords: Patient decision aid; Head and neck cancer; Risk communication; Behaviour; Health information

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1. Introduction

Head and neck cancer (HNC) is the sixth leading type of cancer by incidence worldwide and contributes to 5.7% of global cancer-related mortality (Patterson et al., 2020). HNC is diagnosed in approximately 4,300 Canadians per year, and includes cancers of the mouth (such as lip and tongue), the pharynx, and the larynx (Patterson et al., 2020). Radiation therapy is one of the main treatments for this disease but can also include surgery, chemotherapy, targeted therapy, immunotherapy or often a combination of treatments (National Cancer Institute, 2013). HNC is attributed with high morbidity and even with successful treatment, physical and psychosocial complaints can persist (Perry et al., 2003).

Despite advances in diagnostic tools and treatment modalities, HNC is associated with substantial symptoms. Treatment can lead to considerable long-term functional impairments due to the frequent compromise of critical structures for primary daily functions such as speech, eating, and breathing (Fang & Heckman, 2016). Treatment can also result in changes to appearance, malnutrition, and decreased quality of life (QOL) (National Cancer Institute, 2013; Müller-Richter et al., 2017). Specific concerns, such as xerostomia, pain, dysphagia, and speech disruption often dominate the post-treatment QOL experience (Ringash, 2011).

Furthermore, treatment impacts social activities and interactions as patients report reduced sexuality (Evans & Powell, 2014; Baxi et al., 2013) and increased depression (Rieke et al., 2017). In a cross-sectional study of 280 surgical patients surveyed regarding body image, 75% reported feeling concerned or embarrassed by bodily changes related to the cancer and/or its treatment. Despite overall levels of satisfaction with their healthcare team, 25% of patients reported dissatisfaction with the information received about the degree of scarring/disfigurement following surgery; 32% about the potential effects of radiation therapy on physical appearance, and 44% about potential effects of chemotherapy on physical appearance. Overall, more than one-third of patients reported that greater informational resources to manage concerns would have been helpful (Fingeret et al., 2012).

The past decade has observed a new clinical profile of those with HNC as the etiology has shifted from alcohol and tobacco use to the Human Papilloma Virus (HPV) which now incites 70% of oropharyngeal cancers in the United States (CDC, 2019; Pytynia et al., 2014; Marur et al., 2010). These patients respond better to treatment, have a decreased risk of recurrence, and better survival rates than individuals with non-HPV HNCs (Pytynia et al., 2014; Marur et al., 2010). Younger age at diagnosis leads to prolonged survivorship but also contributes to shorter productive work years, increased distress after treatment, and a diminished cancer-specific QOL (Wells et al., 2016).

Patients in Western Canada with HPV-associated HNC are demonstrated to have high information needs (Saroa et al., 2018), though the extent of these needs can vary considerably (Humphris & Ozakinci, 2006). Numerous studies have demonstrated associations between appropriate cancer-related information provision and improved health-related QOL and QOL (Saroa et al., 2018). Patients frequently suffer undue anxiety because they are not provided "relevant and timely health information" (Kushniruk et al., 2020) and/or find the treatment incomprehensible. The uncertainty is partially a function of the limited supply of information in a form the patient understands (Humphris & Ozakinci, 2006).

It has been suggested that some patients with HNC struggle to take part in decision-making regarding treatment options because of the complexity of information that needs to be accurately conveyed (Drew et al., 2001; Fang & Heckman, 2016). This can be particularly challenging for patients with limited health literacy (Fang & Heckman, 2016). Furthermore, a globalized world consisting of cultural differences increases the need to enhance transparent communication of risk (Garcia-Retamero & Galesic, 2013a). Research on risk literacy and medical decision-making validates that across different cultures, people often have severe obstacles in grasping a host of prerequisite concepts for understanding health-related risk information such as numbers, graphs, and basic medical facts (Garcia-Retamero & Galesic, 2013a). Errors occur because inappropriate information formats complicate and mislead adaptive decision makers (Garcia-Retamero & Galesic, 2013a).

Providing balanced and comprehensive information is imperative from an ethical and safety perspective (Johansson & Brodersen, 2015). "Information giving is an integral part of obtaining informed consent and decision-making with regard to the patients' treatment preferences" (Ziegler et al., 2004). Drew et al. (2001) claim "it is widely recognized that if patients have been involved in discussions about treatment options and understand and support the decision about what is prescribed, medical outcomes are likely to be improved."

In a qualitative study of patients with HNC who underwent surgery and their family members, the majority of participants did not ask questions nor perceived having a choice regarding treatment modalities (Newell et al., 2004). Individuals wanting an active role in decision-making felt they could not obtain the necessary information to assist them which could involve discussions, for example, of survival trade-off for maintaining greater function (Newell et al., 2004). To participate in their care, patients must comprehend their disease and treatment options. Patients who directed decisions, even if more than they hoped for, fared better on all decision-related outcomes. These results emphasize the need for oncologists to endorse and facilitate patient participation in treatment decision-making (Brown et al., 2012).

Decision aids (DAs) "are interventions that support patients by making their decisions explicit, providing information about options and associated benefits/harms, and helping clarify congruence between decisions and personal values" (Stacey et al., 2017). They complement, rather than replace, counselling from a healthcare practitioner as an interactional strategy to facilitate patient involvement in discussions and decisions about healthcare and thereby contribute to patient concordance (Drew et al., 2001). DAs can be useful when the best strategy for an individual depends on their preference for the benefit/harm trade-off inherent in a particular choice and help reduce decisional conflict (Col & Springmann, 2016).

A Cochrane Collaborative Review of 105 randomized controlled trials (RCTs) from 2008-2015 on the effects of DAs for people facing treatment or screening decisions found the use of DAs increased participants' knowledge, accuracy of risk perceptions, and congruency between informed values and care choices compared to usual care. Those exposed to a DA were either equally or more satisfied with their decision, the process, and/or the preparation for decision-making. Interestingly, DAs also reduced the number of people who choose major elective invasive surgery in favour of more conservative options and extended the length of consultations by a median of 2.6 minutes (7.5% increase). Those who used DAs did not appear to differ in terms of health outcomes, including QOL, or condition-specific health outcomes; however, formal subgroup analysis of clinical outcomes was not assessed to due to too few studies in each subgroup. No adverse events were reported. Overall, the use of DAs, compared to usual care, improved knowledge and accurate risk perceptions when used either within or in preparation for the consultation (Stacey et al., 2017).

Multimedia interventions may offer a promising approach to addressing risk communication and information needs (Fang & Heckman, 2016) as visual aids help to modify incorrect expectations about treatment risk (Garcia-Retamero & Galesic, 2013b). Findings derived from cancer populations suggest that electronic programs may not only be an effective and cost-efficient approach for delivering information and improving safety, but may also represent an acceptable and feasible format for communicating information about multiple topics that can be tailored to meet the unique needs of patients and family members (Fang & Heckman, 2016).

2. Methods

The scoping study method will be conducted as it is “guided by a requirement to identify all relevant literature regardless of study design” (Arksey & O’Malley, 2005). This method allows for a broader inclusion of literature on a topic where potentially few published, relevant studies exist (Walsh et al., 2020). This scoping review will follow the six-stage framework of Arksey and O’Malley (2005) (see Table 1) while engaging in each stage with an iterative and reflexive approach. These stages consist of: (1) identifying the research question; (2) identifying relevant studies; (3) study selection; (4) collecting data and data items; (5) and reporting on results. The optional, sixth step of data validation through consultation was not conducted.

Table 1
Scoping methodological framework

Stage	Description
1	Identify the research question
2	Identify relevant studies
3	Study selection
4	Charting the data
5	Collating, summarizing and reporting the results
6	Consultation exercise (optional)

2.1. Research questions

The three questions for this scoping review are: (1) What decision-support tools have been researched and/or trialed for patients with HNC? (2) What are the successes and criticisms of these collaborative, electronic decision-support tools? (3) What recommendations does this literature provide for future studies?

2.2. Search strategy

In following the framework of Arksey and O'Malley (2005), electronic journal databases, reference lists, and grey literature were searched with all study designs considered. Key terms were identified in advance to frame all searches (see Table 2); however, terms remained open for modification if refinement was required.

Table 2
Selected search terms

Key term	Boolean
Decision-making	OR decision AND support OR decision-aid OR decision AND aid
Tools	
Patients	
Cancer	OR oncology OR neoplasm
Head and neck	OR oropharyngeal

The objective was to evaluate the range and nature of articles about electronic DAs designed for use by patients with HNC through a deductive search. The first level of searches was for articles about electronic, DAs for patients with any type of cancer, before manually sorting for relevance to HNC. This strategy allowed for comparison between the robustness of literature for all cancer sites compared to HNC.

A systematic search strategy was developed then optimized by a librarian at the University of Victoria. Research databases searched included CENTRAL®, CINAHL®, Embase®, Ovid MEDLINE®, PubMed®, and IEEE Xplore® and were limited to publications in English within the past 10 years (January 2010-2021). The original search terms in Table 2 were expanded with Boolean truncation (ex. asterisk wildcard symbol to capture variations of the search terms) and operators "AND" was used to combine mandatory key terms and "OR" used to group similar terms. Medical Subject Headings (MeSH) were searched, and expanders applied with applicable databases. Various combinations of terms were run until no new results were found. References from relevant articles were searched for additional publications. Grey-literature was hand-searched through Google and Google Scholar.

2.3. Study identification, selection, and review

All results were compiled in Zotero® (2020) software and duplicates merged. Results specific to HNC were manually sorted then selection criteria applied as defined in Table 3, with one exclusion term, "pediatric" added post hoc. Final article selection was performed in a three-phase process. Firstly, a rapid title screen identified literature that may be relevant then passed to the second phase for a detailed title and abstract screen. Lastly, full articles were read leaving 12 for final review. All literature was available for download through the University of Victoria's inter-library or publicly available through search engines. A Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram illustrates the final article selection (Fig. 1).

Table 3
Study selection inclusion and exclusion criteria

Inclusion	Exclusion
- Decision-support tools were electronic - Specific to cancer - Intended for patient use	- Intended for physician/oncologist use - Not electronic - Non-English language - Only available in hard copy - Surgical focus - Pediatric population

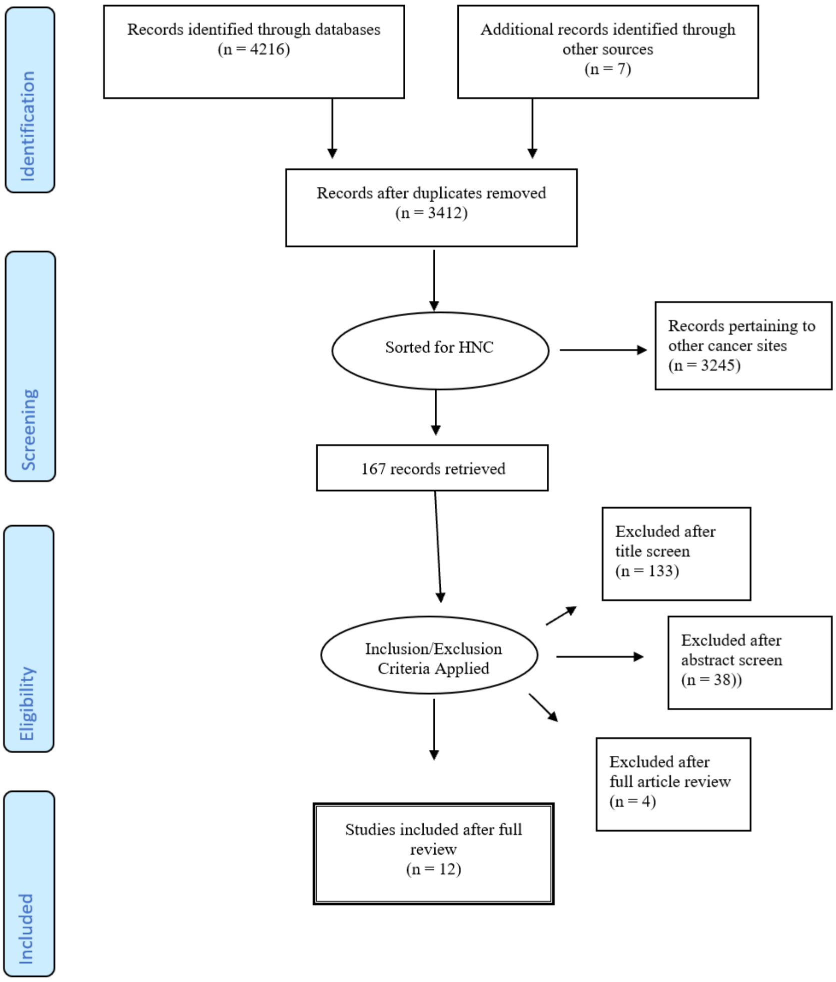

Fig. 1. PRISMA academic database diagram for the process of article selection

2.4. Analysis

The 12 articles selected for full review (full citation in Appendix I) were sifted and charted according to key design features. A "descriptive-analytical" method of narrative charting was completed with a "data extraction form" (Pawson, 2002). This form included title, author, publication, design, method, setting, subjects/participants, results, limitation, themes, recommendations, and additional notes and was collated in Microsoft Excel (see Appendix III). The features of the DA, target population, and recommendations were summarized for each article. Articles were collated and thematically analyzed for themes. Unlike a systematic review, however, evidence was not synthesized nor were aggregate findings presented (Arksey & O'Malley, 2005).

3. Results

3.1. Study selection

The search resulted in 4223 reports. After 811 duplicates were merged, 3412 articles were hand sorted for relevance to HNC. One hundred sixty-seven articles specific to HNC were screened for inclusion with four reports excluded upon full review. The remaining 12 articles presented studies that discussed or trialed an electronic decision-support tool for patients with HNC (see Fig. 1).

The final result of the search yielded 11 academic sources and 1 grey literature source, published between 2012-2019. One was from the UK (8%), another from the Netherlands (8%), and the remaining articles from Canada (84%). Though 12 reports were analyzed, they discussed five different tools, as two DAs produced multiple publications. Each tool was specific to a particular tumor location and/or staging, shown in Table 4.

Table 4
Specific tumor site and/or staging for each decision aid

Primary Author	Tumor site
Petersen et al., 2019	Advanced larynx cancer
Lam et al., 2017	Early-stage oropharyngeal squamous cell carcinoma
D'Souza et al. 2013a	Stage III and IV HNC
Sawka et al. 2011a	Post-thyroidectomy, early-stage papillary thyroid cancer
The Health Foundation, n.d.	Early cancer of the tonsil, early cancer of the vocal cords and cancer of the voice box

3.2. Developed decision aids

Reviewing the DAs chronologically, the first was developed by Anna M Sawka et al. (2011b) in 2011, designed for patients with early-stage papillary thyroid cancer (PTC) who have undergone a thyroidectomy and are considering adjuvant radioactive iodine ablation (RAI). Constructed by a multidisciplinary team, guided by PTC survivors and physician experts, this DA underwent phases of usability testing employing a "think aloud" methodology, the System Usability Scale and semi-structured interviews. The DA was refined then piloted in 50 patients which illustrated improved medical knowledge and confirmed the technical usability of the web-based format. Next, it was trialed in a single-centre, parallel design, RCT with 74 participants out of Toronto General Hospital (a Canadian tertiary/quaternary care centre). Participants were randomized 1:1 to the DA group (intervention) or usual care (control). Medical knowledge was greater and decisional conflict reduced between groups ($p < 0.001$), suggesting this patient decision aid (P-DA) may facilitate knowledge translation on cancer treatments subject to uncertainty of medical evidence (Sawka et al., 2012). A secondary analysis uncovered a high degree of variability in the number of clicks for supplemental information, a higher score in mean medical knowledge and a lower score in decisional conflict in the P-DA group (Sawka et al., 2015b). Lastly, the team followed-up with 20 participants, 15-23 months after P-DA use and ascertained survivors' short and longer-term perception of increased knowledge and confidence in decision-making, with no adverse effects (Sawka et al., 2015a).

The next tool was discovered through a Google search but associated scholarly publications were not found. Information on this tool is highly limited; however, in holding true to the objective of this scoping review, it was included. This DA for patients was developed by the Cardiff HNC tumor team and arose out of a larger project, Making Good Decisions in Collaboration (MAGIC) programme, to improve shared decision-making (The Health Foundation, 2013). Clinical experts developed "option grids"- brief list-based tools, designed for clinical encounters which listed information on key features, benefits and risks of treatments, and questions for patients organized in a table for rapid access and comparison (The Health Foundation, n.d.). Options grids were tailored for each of early cancer of the tonsil, early cancer of the vocal cords, and cancer of the larynx. They were used in primary and secondary care sites across Cardiff and Newcastle in the UK but is unclear whether these are in a computerized or paper format.

The Multimode Comprehensive Tailored Information Package (MCTIP) was developed and tested by the HNC team at the McGill University Health Centre in Montreal, Canada (D'Souza et al., 2013a). It has five parts and is available in English and French. It's effect on anxiety, depression, knowledge, and satisfaction was tested through a non-RCT of 103 patients with stage III or IV HNC. The test group exposed to the MCTIP experienced lower levels of anxiety ($p = 0.001$) and depression ($p = 0.089$) and higher levels of cancer knowledge and satisfaction ($p < 0.001$) than the control group. This trend was also found to be statistically significant in the partners of patients who received the MCTIP (D'Souza et al., 2017).

Next, an interactive multimedia web platform DA was developed for early stage oropharyngeal squamous cell carcinoma (OPSCC), the most common type of HNC (National Cancer Institute, 2020), created to supplement the traditional clinical encounter with visual descriptions of available treatment choices of transoral robotic surgery and radiotherapy. It was piloted in a single institution in southwest Ontario, Canada (Lam et al., 2017). Assuming equal oncological outcomes, 40 healthy individuals indicated their treatment preference, the trade-off point was established, and participant perceptions elicited. Treatment toxicities, duration, novelty, and perceptions all influenced treatment selection. All participants valued the DA and perceived utility in its use and indicated that they would appreciate having a similar tool available. The DA was felt to positively supplement, but not replace, the clinician-patient encounter.

The most recent tool, from the Netherlands, is a web-based PDA for patients with advanced larynx cancer who faced a decision between radiotherapy, chemoradiotherapy, or a total laryngectomy with adjuvant radiotherapy (Lam et al., 2017). The PDA was tested in three phases with nine to 14 patients and eight to 11 physicians participating in each phase. The first phase evaluated the standard counselling process and decisional needs through patient and physician interviews then a web-designer fabricated the first version of the PDA, following the International PDA Standards. The second phase alpha tested the comprehensibility and usability through interviews, think out-loud sessions and a satisfaction questionnaire regarding its effectiveness, comprehensibility, ability, and value. The third phase beta-tested the second and final PDA version by duplicating the second phase procedure. Most patients were positive about the development of a PDA and would use it if available. Patients and physicians considered the PDA to be a major improvement to the standard counselling process and the configuration found to be satisfactory.

3.3. Design features

Each article piloted or tested an electronic DA that provided various degrees of descriptions on design features (see Appendix II). The tools can be classified into one of two categories: designed to be used as adjunct material during a physician consult or independently, outside of clinical encounters. The two tools intended to be used with a physician were designed to enhance the consult, rather than provide a comprehensive review of treatment options. The DA developed by Lam et al. (2017) was devised to enhance the encounter with visual descriptions of treatment options including timelines, photos and detailed risks and side effects. The option grids developed by The Health Foundation (n.d.) allowed for rapid access and comparison of key features, benefits, risk and questions of treatment modalities in the presence of a physician.

The DAs designed to be used independently as adjunct material had augmented comprehensibility. The PDA developed by Petersen et al. (2019) can be found at https://beslissamen.nl/pda_launch.html?pda=tools/pda_larynx_en/story.html. Following diagnosis, it assists in preparing for impending oncologist consults. It is comprised of six sections and a glossary of medical terms to assist with comprehension. “My introduction” collects a profile including name, date of birth, and tumor staging used to customize content prior to providing website navigation instructions. “My treatment options” educates on treatments including videos from a patient and physician discussing each treatment. The “compare” tab also includes a video, followed by tabulated facts for accessible comparison, including survival rates pictured by symbols. “Important points” quizzing users followed by educational prompts to reinforce foundational concepts. “My preferences” elicits the users’ preferences on treatment risks and benefits to inform their oncologist of priority maters. “My results” compiles a report on the user’s knowledge and preference to be printed and shared with their oncologists to guide conversation in selecting a treatment plan congruent with the users’ preferences. The last page contains links to further information. Some additional features of this web-based tool are it’s simple, non-distracting design, printer-friendly layout, completion time of 60 minutes and language options of Dutch and English (utilizing English subtitles on several videos).

The Multimode Comprehensive Tailored Information Package (MCTIP) by D’Souza et al. (2013a) is a multimedia tools with audiovisual aids, comprised of five parts and translated in English and French: (1) a patient booklet with general information about HNC, diagnostic and treatment procedures and the care team; (2) an interactive computer booth where information can be printed and taken home; (3) computer animations that describe cancer, it’s spread, staging and specific surgical procedures; (4) a take-home DVD that provides a guided tour of the steps involved in HNC care including preparation for treatment, nutrition, and speech and swallowing therapy; (5) and computer database accessible to patients and their care team that tracks patient information (D’Souza et al., 2013a). The MCTIP is not web-based and requires the patient to be in the health centre to access the interactive computer booth; however, the booklet and DVD are provided for home. No estimation of time commitment is provided.

The patient-directed computerized decision aid (P-DA) by Sawka et al. (2012) is web-based but password protected so accessed is granted through the research team. The 16 web pages were in English at a grade seven reading level. The pages explain disease prognosis (disease-related mortality and recurrence risks), rationale for or against the treatment, potential benefits of the treatment (including the potential to facilitate disease surveillance and some conflicting evidence on the impact of recurrence risk), potential short-term adverse effects associated with the treatment (such as fatigue, nausea/vomiting, neck pain, salivary gland swelling/pain, taste changes, and xerostomia), potential long-term risks of the treatment (such as dry mouth, nasolacrimal duct obstruction, impact on menses, and the risk of second primary malignancies), uncertainty of relevant medical evidence on treatment benefit, disease follow-up implications, and reproductive considerations. The P-DA links to additional information, including numerical data, references, available support groups, and web-links to PTC clinical practice guidelines (Sawka et al., 2011a). The pages are amenable to printing and designed to complete within 60 minutes. The features most commonly cited as favourited by patients are the page/title menu, opportunity to click for additional information, references to medical literature, and diagrams (Sawka et al., 2011b). However, some of these same features were also cited as being liked the least: inconsistency of page format, too many references to the medical literature, and having to click for more information.

3.4. Themes

Upon analysis, four themes were consistent across the reviewed literature. The first is that both patients and physicians valued DAs as “the tool was felt to positively supplement, but not… replace, the clinical-patient encounter” (Lam et al., 2017). A physician who provided feedback on the PDA by Petersen et al. (2019) “agreed it was a good tool that would aid the regular counselling process and thereby improve the quality of patient care” (Petersen et al., 2019). This theme was further supported in the qualitative results from Sawka et al. (2015a) which found physician counselling to still be important in affecting the ultimate treatment decision while providing human contact that was necessary to meet the supportive, psychosocial needs of the patient. The Health Foundation reported that the participating in the Making Good Decisions in Collaboration (MAGIC) program “enabled a team-based understand of shared decision making” (The Health Foundation, n.d.).

The second strong theme is that PDAa should be visually supported by images. In phase I of the intervention by Petersen et al. (2019), interviews with physicians found “the relatively low average educational level of the typical patient” to be a barrier to good patient counseling. As a result, they recommended that “the optimal PDA should be visually supported by images and be easy to navigate through” (Petersen et al., 2019). When their PDA was alpha tested, patients “suggested summarizing text or looking for other way to present the information” as they worried “that low-educated patients might have difficulty interpreting the abundance of text in the PDA.” Patients also expressed preference for “a leaner layout with less bright and flashy colors” (Petersen et al., 2019). Sawka et al. (2011b) received a patient’s suggestion of incorporating more diagrams: ‘…if there is any places where you could put diagrams, that is a good teaching tool for those who are more visual learners’ (Sawka et al., 2011b).

Third, use of a DA lessened decisional conflict and anxiety and improved knowledge, satisfaction and shared decision-making. Patients who tested the comprehensibility, usability, and feasibility of the PDA from Petersen et al. (2019) concluded that use of the PDA would clarify possible outcomes and assist patients in deciding which treatments to accept. D'Souza et al. (2013b) found mean anxiety ratings to be significantly reduced (p = 0.001) in the test group who used the multimedia tool compared to the control group who did not. The team also found the test group to have higher levels of satisfaction and cancer knowledge compared to the control group at all time points (D'Souza et al., 2013b). These results were mirrored by Sawka et al. (2012) where decisional conflict was reduced in all respective subscales of the tools compared to the control group. Sawka et al. (2015a) also found that patients who used the P-DA felt significantly more informed about treatment choices than the control group.

Though the above themes demonstrate the use of electronic DAs to be valuable and effective, several of studies observed patient preferences for a varying degree of information. For example, "one patient…did not want to know any details regarding treatment, although the patient agreed the details could be useful for other patients" (Petersen et al., 2019). Sawka et al. (2015b) "observed a high degree of variability among thyroid cancer patients, in the quantity of additional detailed information sought within a computerized P-DA on RAI decision-making," which led to the conclusion that variability "exists among thyroid cancer patients, in terms of individual information seeking preferences, and resultant quantity of detailed information retrieved from a computerized P-DA. Although hypothesis generating, our results also raise some questions about the incremental value of mandating presentation of detailed numerical data within P-DAs, as some patients may prefer not to view such data, and it is not clear that those who review it, acquire more fundamental medical knowledge (as compared to a simpler explanation)." D'Souza et al. (2013b) found that delivering information in multimedia format seemed to improve health literacy and the customizable format reduced the possibility of over burdening patients with information.

3.5. Future recommendations

The final research question of this scoping review investigates the recommendations for future research. The first three of six articles by Anna Sawka et al. (2011a, 2011b, 2011c) recommend further testing of their computerized PDA which the team proceeded to complete in the latter half of their research. Their series of studies do pose several final recommendations on where to focus future research: (1) on whether DAs for other cancer treatment choices subject to similar uncertainty in the medical evidence can improve the decision-making process, long-term health and psycho-social outcomes (Sawka et al., 2012); (2) further understanding how individual information preferences may impact medical knowledge acquisition and decision-making; (3) exploring whether format personalization and the level of detail of content (particularly relating to numerical data) of PDAs to users' preferences may optimize knowledge translation outcomes; (4) understanding the evolving role of personalization of decision support tools in advancing patient autonomy regarding provision of information (Sawka et al., 2015b); (5) investigating the longer-term effects of PDA (Sawka et al., 2015a).

A full, publicized report on the option grids created by Cardiff (The Health Foundation, n.d.) was not found, therefore propositions are not available.

D'Souza et al. (2013b) suggest confirming their findings of lower anxiety and depression with tailored information through a RCT in different samples. They further recommend considering the cost-benefit analysis and highlight the importance of exploring the extent or severity of patients' informational needs and potential barriers to their healthcare teams in delivering this information to patients. The recommendations from their second article (D'Souza et al., 2013b) compliments the former by emphasizing the necessity of exploring patients' information needs before planning information services.

The recommendations from Lam et al. (2017) were specific to their DA by announcing their plans to test their DA in patients previously treated for HNC. Once pertinent modifications are completed, they plan to use with newly diagnosed OPSCC patients to facilitate shared decision-making. Broad recommendations for researchers were not provided.

Petersen et al. (2019) suggest future research be directed to testing the feasibility and satisfaction among newly diagnosed patients as well as physicians or paramedics. They began this work through a multicentre trial (ClinicalTrials.gov Identifier: NCT03292341) that started in the Netherlands comparing regular care to patients receiving the PDA. Results were expected in 2020, however, as of December 2020 no results have been posted.

4. Discussion

The use of DAs is of growing interest in clinical oncology. With survivors living longer due to improved screening practices, earlier diagnosis, and advancements in treatment, QOL is being increasingly considered as a prognostic factor (Saroa et al., 2018; Wells et al., 2016). QOL can be enhanced by supporting patients to make decisions that are congruent with their values and goals (Legare et al., 2018).

The article selection for this review followed an unconventional selection process of including articles for all tumor sites before narrowing by HNC. Filtering in this manner demonstrated the meager state of research and development in this population (n = 11) compared to other areas of oncology (n = 3245), despite its physiological location vulnerable to physical and psycho-social morbidity. This scoping review demonstrates the paucity of developed and/or trialled decision-support tools for patients with HNC, representing only 0.3% of relevant literature.

A thorough review of the features comprising each DA was not possible as most articles reported general features, deprived of detail. One DA is still available online, so features were reviewed in real time. Consistent features described amongst the majority of the DAs were visual images, rationale for and against (benefits and risk) treatment modalities and avoidance of survival prognostic statements. While the International Patient Decision Aid Standards (IPDAS) Collaboration has published on quality standards for patient decision aids (Joseph-Williams et al., 2014), including developing a quality criteria checklist (Elwyn et al., 2006), no conclusion has been reached on when to define a decision-aid "good quality, appropriate, and of a necessary standard for use" (Joseph-Williams et al., 2014).

The four predominant themes from this scoping review are congruent with the literature in their respective fields. The value of a DA as a supplement to clinical encounters is supported by Saroa et al. (2018) who found healthcare providers to be the primary source of information for patients with HPV-related HNC followed next by the Internet. Other research on information sources in oncology cite pamphlets and written material as the most common second source of information, following healthcare professionals (Saroa et al., 2018). This demonstrates that use of electronic information to be useful for patients with HNC.

Garcia-Retamero and Galesic (2013b) describe guidelines for transparent risk communication which includes the use of visual aids to enhance comprehension (Garcia-Retamero & Galesic, 2013b). They found visual aids were most useful for the participants who had low-numeracy literacy skills and concluded that “visual aids help to modify incorrect expectations about treatment risk reduction” (Garcia-Retamero & Galesic, 2013b). This finding was mirrored by the consistent theme arising from participants who supported and advocated for visual aids as a key feature in the electronic, patient decision-support tools.

According to a 2017 Cochrane Review on DAs for people facing health treatment or screening decisions, compared to usual care, “people exposed to decision aids feel more knowledgeable, better informed and clearer about their values, and they probably have a more active role in decision-making and more accurate risk perceptions” (Stacey et al., 2017). They further explain that use of DAs does not result in adverse effects on health outcomes or satisfaction. The 12 articles included in this review support that DAs can reduce decisional conflict and anxiety while increasing knowledge, satisfaction, and shared decision-making; however, these articles also observed patient’s preferences for varying degrees of information, consistent with the literature (Fang & Heckman, 2016; Humphris & Ozakinci, 2006).

Future recommendations are centered around understanding patient’s needs and their healthcare journey (Borycki et al., 2020), further testing the impact of DAs, and the need for long-term follow up. These recommendations mirror finding from the 2018 Cochrane review on interventions for increasing the use of shared decision-making (Legare et al., 2018) which describes the difficulty in drawing conclusions on the effectiveness of interventions on the use of shared decision-making between patients and healthcare profession as the certainty of the evidence is low or very low. Col and Springmann (2016) further point out that “DAs thus represent a heterogenous group of decision support tools, complicating any global statement about their effectiveness using any single metric.”

4.1. Limitations

A limitation of this scoping review was that the study selection was performed by a single researcher only. The scarcity of literature on the use of electronic decision-support tools for patients with HNC hinders the ability to draw conclusions. The most notable of limitations is that each DA was designed for a specific tumor site and/or staging, so findings cannot be generalized to all HNCs. Furthermore, various study designs were employed, reducing the comparability. The articles have relatively small sample sizes, ranging from 25 to 103 participants, and were tested in small regional areas consisting of only one or two institutions and, therefore, will have inherent biases such as language, cultural, and religious beliefs that may impact their respective findings. Long-term outcome data on the effect of using DAs is scant, as only one tool followed up on patients’ perceptions 16-23 months after using the DA.

5. Conclusion

This scoping review demonstrates the paucity of literature on electronic decision-support tools for patients with HNC, especially in comparison to other tumor sites. Four themes were woven through these articles and are consistent with the research in their respective fields. This scoping review demonstrates that DAs in this population have been viewed as a positive addition to standard clinical encounters and supports future work in this area. Furthermore, it demonstrates the value of involving survivors HNC in the development and implementation of DAs for patients with HNC to address health literacy and shared decision-making with the ultimate goal of reducing decisional conflict and improving QOL. The long-term impact of DAs, including impact on outcomes, patient understanding and reduction of error warrants further investigation.

Author Statement

The authors declare that there is no conflict of interest.

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Appendix I

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Appendix II

Design features of each DA

Primary Author	Type of Tool	Features	Time (mins)	Used w/ physician ?	Web based?
Sawka et al. 2011a, 2011b, 2011c, 2012, 2015a, 2015b	Computerized patient decision aid (P-DA) with 16 web pages, on website but password protected, access available through the research team.	Grade 7 reading level; explains disease prognosis, rationale for or against RAI, potential benefits of the treatment, potential short-term adverse effects, potential long-term risks of the treatment, uncertainty of relevant medical evidence on treatment benefit, disease follow-up implications, and reproductive considerations.	Max 60	No	Y but password protected
The Health Foundation, n.d.	Option grids	Option grids: key features, benefits, risks, and questions for pts are organized in a table for rapid access and comparison	Unknown	Yes?	Unknown
D'Souza et al. 2013a, 2013b, 2017	Multimedia tool: Multimode Comprehensive Tailored Information Package (MCTIP)	Available in English and French; 5 parts: booklet, interactive computer booth, animation of treatment procedures, take-home DVD, computer database common to all health professionals.	Unknown	No	No
Lam et al., 2017	Interactive, web-based DA	Meant to supplement clinical encounter with visual descriptions of treatments. Times lines and photos, details risks and side effect	Unknown	Yes	Yes
Petersen et al., 2019	Electronic patient decision aid (PDA)	Structure is explained with an intro. Includes My introduction, My treatment options, Compare, My preferences, My results, Glossary. Includes voice-overs on text, photos and animations	60	No (in preparation)	Yes

Appendix III

Data extraction form (a, b)

*Full references found in Appendix I

Part a

Citation*	Design	Methods	Setting	Participants	Results
Sawka et al., 2011a	Multi-phase, mixed-methods	1) Multidisciplinary development of DA guided by PTC survivors and physician experts 2) Individual usability testing followed methodology of Kushniruk et al. of "think aloud" for qualitative analysis. 3) Secondary usability testing utilizing the System Usability Scale (SUS) questionnaire for qualitative and quantitative data.	Toronto General Hospital, University Health Network (Canadian tertiary/quaternary care centre)	12 patients, 7 endocrinologists, 30 lay individuals.	Usability acceptable, significant increase in medical knowledge. Despite physicians' concern re: disclosure of treatment controversy and evidence uncertainty, the DA was acceptable to non-physicians.
Sawka et al., 2011b	Multi-phase, mixed-methods	After using the DA, participants were interviewed using semi-structured questions. Qualitative participant feedback obtained, major themes were categorized and quantified.	Research office at Toronto General Hospital	50 patients with early stage PTC, post thyroidectomy	All 97 comments on usability and all 67 comments on credibility of the DA, were positive. Opinions on understandability: 37 positive, 8 neutral, no negative. Opinions on relevance of the medical content: 52 positive, 2 neutral, 1 negative. General comments about the DA: 75 positive, 11 neutral, 8 negative.
Sawka et al., 2011c	Pilot study, single arm intervention.	DA tested between Nov 2009- Feb 2010 and a self-administered medical knowledge questionnaire and an adapted SUS questionnaire completed then analyzed.	Toronto General Hospital, University Health Network	50 patients with early stage PTC, post thyroidectomy	Use of the DA improved medical knowledge and the technical usability (web based format) of the tool is acceptable.
Sawka et al., 2012	Single-centre, parallel design RCT	Participants randomized using 1:1 to either the DA group with usual care or usual care alone. Medical knowledge about PTC and RAI treatment (primary outcome), as well as decisional conflict (secondary outcome), were measured by using validated questionnaires, and scores compared between groups.	Toronto General Hospital, University Health Network	74 patients with early stage PTC, post thyroidectomy	Medical knowledge about PTC and RAI treatment was significantly greater and decisional conflict was significantly reduced in the DA group compared with the control group ($P < .001$). The use of adjuvant RAI treatment was not significantly different between groups. DAs may facilitate knowledge translation for decisions on cancer treatment that are subject to uncertainty of medical evidence.
Sawka et al., 2015a	Single-centre, parallel design RCT, pre-planned secondary analysis	Participants randomized to a one-time viewing of a computerized P-DA (with usual care) or usual care alone. The relationship between information preference style (Miller Behavioural Style Scale, including respective monitoring [information seeking preference] and blunting [information avoidance preference] subscale scores) and the following were examined: 1) quantity of detailed information obtained from the P-DA (number of supplemental information clicks), and 2) medical knowledge. Spearman correlation values were calculated to quantify relationships.	Toronto General Hospital, University Health Network	74 patients with early stage PTC, post thyroidectomy	In the 37 P-DA users, high monitoring information preference was moderately positively correlated with higher frequency of detailed information acquisition in the P-DA ($r = 0.414$, $p = 0.011$). The monitoring subscale score weakly correlated with increased medical knowledge in the entire study population ($r = 0.268$, $p = 0.021$, N = 74), but not in the respective study arms. There were no significant associations with the blunting subscale score.
Sawka et al., 2015b	In-dept interviews	Participants were contacted 15-23 months after decision-making to evaluate longer term outcomes.	Toronto General Hospital, University Health Network	20 patients with early stage PTC, post thyroidectomy who were involved in the 2015 RCT	The P-DA improved cancer survivors' actual and long-term perceived medical knowledge and confidence in decision-making. No adverse effects found.
The Health Foundation	Editorial	They created 'option grids' – brief list-based tools, designed for clinical encounters. Information about the key features, benefits and risks of treatments, and questions for patients, are organised in a table for rapid access and comparison.	Primary and secondary care sites across Cardiff and Newcastle, UK	Early cancer of the tonsil, early cancer of the vocal cords and cancer of the voice box	Not discussed
D'Souza et al., 2013a	Non-RCT	One hospital delivered the MCTIP and the second hospital provided normal care. All participants were evaluated at baseline, 3 and 6 months later using the Hospital Anxiety and Depression Scale. Data were analyzed using descriptive statistics, T tests, chi square tests and	2 academic hospitals in Montreal, Canada	103 patients, stage III and IV HNC, recruited between diagnosis and treatment start	All time points collected for 96 participants. The Test group experienced lower levels of anxiety ($p = 0.001$) and depression ($p = 0.089$) than the control group. Subjects receiving tailored information had lower levels of anxiety than their counterparts, and a reduction of depression.

		finally mixed model analyses to test the differences in outcome variables.			
D'Souza et al., 2013b	Non-RCT	One hospital delivered the MCTIP and the second hospital provided normal care. All participants were evaluated at baseline, 3 and 6 months later using the Satisfaction with Cancer Information Profile and a Cancer Knowledge questionnaire. Data were analyzed using descriptive statistics, T tests, chi square tests and finally linear mixed model analyses to test the potential impact of the intervention.	2 academic hospitals in Montreal, Canada	103 patients, stage III and IV HNC, recruited between diagnosis and treatment start	All time points were collected for 96 participants. The Test group reported higher levels of Cancer Knowledge and Satisfaction at all time points ($p < 0.001$) compared to the Control group. Those who received the multimedia based tailored information had higher levels of satisfaction and cancer knowledge compared to those who receive information in ad hoc manner.
D'Souza et al., 2017	Non-RCT	The Test participants received the MCTIP, while the Control participants received information in an ad hoc manner. All participants were evaluated using the Hospital Anxiety and Depression Scale, Satisfaction with Cancer Information Profile and a cancer knowledge questionnaire at baseline, and 3 and 6 months later.	2 academic hospitals in Montreal, Canada	31 partners of patients with HNC	The partners in the Test group experienced significantly lower levels of anxiety ($p = 0.001$) and depression ($p = 0.003$) and were more satisfied ($p = 0.002$) with cancer information provided than partners in the Control group
Lam et al., 2017	Pilot study, single arm intervention.	A DA was developed and piloted. Assuming equal oncologic outcomes of the treatments, participants indicated their preference. The treatment trade-off point was established, and participant perceptions were elicited.	Early stage OPSCC, single institution in SW Ontario	40 healthy volunteers	More than 80% of participants initially selected transoral robotic surgery for treatment. For all participants, the treatment trade-off point changed after an average 15% cure benefit. Treatment toxicities, duration, novelty, and perceptions all influenced treatment selection. All subjects valued the DA.
Petersen et al, 2019	Mixed methods, single arm intervention.	Phase 1 evaluated the regular counseling process and decisional needs, phase 2 tested the comprehensibility and usability of the PDA, and phase 3 beta tested the feasibility of the PDA.	Outpatient oncology settings, Netherlands.	Post-treatment, advanced larynx cancer	Patients and doctors agreed on the need for development of a PDA. Major revisions were conducted after phase 1 to improve the readability and replace the majority of text with video animations. Patients and physicians considered the PDA to be a major improvement to the current counseling process.

Part b

Citation	Limitations	Themes	Recommendations	Notes
Sawka et al., 2011a	Not discussed	A DA may increase medical knowledge. Preferences for the level of detail in the provided information varied.	To make modifications to their DA based on study feedback for future research and clinical applications.	--
Sawka et al., 2011b	1) A non-randomized design, 2) use of a single study institution, 3) a single coder extracting qualitative themes, and 4) the lack of long-term follow-up of participants.	Focus on person-centered medicine: This trial will help understand the impact of the DA on short- and long-term patient outcomes, generating further information of direct relevance to the development of person-centered medicine for the patient with thyroid malignancy.	Complete the current testing of the DA in a RCT, examining the impact of the DA on outcomes including: patients' medical knowledge, decisional conflict, treatment choice and decisional regret, as compared to usual care	In a minority of cases, the information in the DA was perceived to be overwhelming, or not congruent with a preference for the physician to be the primary treatment decision-maker, or potentially not relevant to a particular medical circumstance (for example, an immuno-compromised state).
Sawka et al., 2011c	1) Most participants were comfortable with using computers and well-educated, so findings may be not be generalizable to patients unfamiliar with computer technology. 2) For most participants, the decision to accept or reject RAI had already been made prior to exposure to the DA.	The DA complements physician counselling.	Test in an RCT.	---
Sawka et al., 2012	1) Relatively small sample size, 2) uncertainty of the clinical significance of the measured differences in medical knowledge, 3) a lack of measurement of thyroid hormone levels in study participants, 4) a lack of data on the medical knowledge of treating physicians providing usual care, 5) a lack of prospectively collected objective data on the interactions between study participants and their treating physicians (such as audio or video recordings of clinical discussions or measurements of clinical time used), and 6) a lack of long-term outcome data on the effects of the P-DA.	A computerized P-DA improves informed decision-making in patients with early-stage PTC who are considering adjuvant RAI treatment. DAs are useful for patients facing decisions subject to medical evidence uncertainty.	More research is needed to determine whether DAs that focus on other choices for cancer treatment subject to similar medical evidence uncertainty can improve the decision-making process and long-term health and psychosocial outcomes.	The P-DA is intended to be used in patients where either accepting or declining adjuvant RAI treatment may be clinically reasonable.

Sawka et al., 2015a	1) This is a secondary analysis and the randomization was not stratified according to information preference. 2) The sample size was relatively small so the secondary analyses (including subgroup analyses) may have been statistically underpowered. 3) Potential selection bias (most participants reported using computers on most days and most were well-educated, further all were fluent in written and spoken English). 4) Lack of standardization of the counseling (or any related materials) received by treating physicians as part of usual care. 5) Limited external generalizability to healthcare decisions or other computerized P-DAs where users do not have the option to choose to view additional information or not.	1) A high degree of variability among thyroid cancer patients was observed in the quantity of additional detailed information sought within a computerized P-DA. 2) The mean medical knowledge score was significantly higher in the P-DA group than the control group 3) Decisional conflict score was significantly lower in the P-DA group compared to the control group.	1) More research is needed to understand how individual information preferences may impact medical knowledge acquisition and decision-making. 2) Explore whether personalization of format and the level of detail of content (particularly relating to numerical data) of PDAs to users' preferences may optimize knowledge translation. 3) Research is needed to understand the evolving role of personalization of decision support tools in advancing patient autonomy regarding provision of information.	---
Sawka et al., 2015b	1)Relatively small sample size, 2) limited population scope, 3) lack of quantitative measurements of self-efficacy or empowerment, 4) the secondary nature of the follow-up outcome analysis, and 5) statistically significant quantitative difference in the perception of feelings informed between the study arms is not known.	1) Complexity of RAI treatment decision-making, 2) the importance of physician recommendations 3) value of study participation 4) unmet information and psychosocial support needs 5) overall treatment experience, and 6) the value placed on physician counselling in the cancer treatment decision-making process was a central theme observed regardless of whether individuals were exposed to the PDA or not.	More research needed on longer-term effects of PDA use. Study findings should be confirmed though additional research.	Disclosing uncertainly of treatment evidence does not appear to result in adverse psychosocial outcomes or mistrust of the physician. In such a situation, cancer treatment decisions need to be made with explicit disclosure to patients of related uncertainties as part of a fully informed shared decision-making processes.
The Health Foundation	Limited information provided on the tool, unclear as to whether an electronic or paper format.	Effectiveness of tool not evaluated.	None provided.	Most domains could not be evaluated.
D’Souza et al., 2013a	1) Non-randomized study design, 2) possible systematic bias in the nature of the sample which may influence results, 3) compliance and referrals to psychosocial services not tracked, 4) difference in patient characteristics (notably language and educational status) between the 2 centres, 5) baseline data were collected after the initiation of the intervention, and 6) the use of a ‘normal care’ comparison group rather than a placebo control.	Informational interventions are a promising adjuvant in HNC care in preventing psychiatric morbidity. However, the intervention was noted to take significant resources in terms of time of personnel and some material costs.	1) Confirm that receiving tailored information lowers levels of anxiety and depression using a randomized approach in different samples. 2) Future research needs to consider this in a cost-benefit analysis. 3) It is important to explore the extent or the severity of their informational needs. 4) It is also very important to explore the potential barriers of their healthcare teams in delivering the needed information to their patients.	Good adherence and low drop-out rates "which is exceptional in research with HN cancer patients."
D’Souza et al., 2013b	1) Non-randomized study design, 2) baseline data were collected after the initiation of the intervention, and 3) the use of a ‘normal care’ comparison group rather than a placebo control.	1) These findings complement those in their previous paper, in which test participants had lower anxiety and depression ratings, as well as higher cancer knowledge and satisfaction scores as reported here. 2) Demonstrated an association between receiving the MCTIP and higher levels of satisfaction and cancer knowledge indicating such interventions could be beneficial adjuvant in HNC care.	Exploring patients’ information needs is necessary before planning information services to them.	---
D’Souza et al., 2017	Results of a secondary study, meaning the sample was convenient (non-randomised design) and the sample size not powered to seek hypothesised differences. Thus, there are important differences in both the outcomes and the makeup of the two groups in the sample that are likely to have been missed because the sample did not have sufficient power.	Found the same trend as when tested in patients: test participants had lower anxiety and depression ratings, as well as higher cancer knowledge and satisfaction scores as reported here.	Larger randomised studies are warranted to validate these effects.	---
Lam et al., 2017	1) Piloted in healthy volunteers, and thus our findings might not be generalizable. 2) The results are derived from a single institution in southwestern Ontario, where inherent biases, such as those related to language and cultural and religious beliefs, might be present in the population. 3) Although the side-effect profiles for the two treatments were derived from the available literature, more data about toxicities arising from treatment are available for radiation	1) All 40 participants perceived utility in DA use and indicated that they would value having a similar tool available. 2)The tool was felt to positively supplement, but not replace, the clinician–patient encounter. 3) Participants required an average of a 15% increased cure rate with the alternative therapy to abandon their initial treatment choice, which was true regardless of the	1) Test the DA in patients previously treated for HNC. 2) Once pertinent modification are made, begin to use with newly diagnosed OPSCC patients in their multidisciplinary HN oncology clinical to facilitate shared decision-making.	---

	therapy than for transoral robotic surgery.	treatment initially selected		
Petersen et al., 2019	For advanced larynx cancer only.	1) PDA should be visually supported by images. 2) Most patients were positive about the intended development of a PDA and would have used it. 3) Reasons for not remembering consisted of the amount of information given at once and the impact of the diagnosis, which made them forget about the rest. 4) Summarize text or looking for other ways to present info.	The feasibility and actual satisfaction among newly diagnosed patients as well as doctors or trained paramedics have yet to be proven.	1)Online tool www.treatmentchoice.info led to CT ClinicalTrials.gov Identifier: NCT03292341. 2) A multicentre trial has started in the Netherlands comparing regular care to patients receiving the PDA (ClinicalTrials.gov Identifier: NCT03292341); results were expected in 2020, however, no updates yet.