

Assessing Internet-Based Information used to aid patient decision-making for pelvic exenteration for locally advanced and recurrent rectal cancer

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Abstract

Background: To establish what online decision aids are currently available for patients contemplating pelvic exenteration (PE) for locally advanced and recurrent rectal cancer (LARC and LRRC).

Methodology: A grey literature review was carried out using the Google Search™ engine undertaken using a predefined search strategy (PROSPERO database CRD42019122933). Written health information was assessed using the DISCERN criteria and International Patient Decision Aids Standards (IPDAS) with readability content assessed using the Flesch-Kincaid score.

Results: Google search yielded 27,782,200 results for the predefined search criteria. 131 sources were screened resulting in the analysis of 6 sources. No sources were identified as a decision aid according to the IPDAS criteria. All sources were deemed acceptable quality of written health information, scoring a global score of 3. for the DISCERN written assessment. The median Flesch-Kincaid ease was 50.85 (32.5-80.8) equating to a reading age of 15-18 years.

Conclusions: This study has found that there is a paucity of online information for patients contemplating PE. Sources that are available are aimed at a high health literate patient. Given the considerable morbidity associated with this surgery there is a desperate need for high quality relevant information in this area. We would suggest the development of a PDA to improve decision making and ultimately improve patient experience.

Background

In the UK, 14,000 new cases of rectal cancer are diagnosed every year with an estimated 704,000 new cases worldwide in 2018 (1), of which 5–10% are locally advanced (LARC) at presentation (2, 3). The incidence of locally recurrent rectal cancer (LRRC) after treatment is 4–8% (4–6). Without treatment the prognosis for both LARC and LRRC is poor, with median survival estimated at less than 1 year and only 5% of patients surviving 5 years (7, 8). Pelvic exenteration (PE) represents the only potentially curative option in this patient group. who would otherwise only be suitable for palliative intervention. Complete oncological resection (R0) confers the greatest survival benefit (9, 10) with survival rates of 40–50% at 5 years (11–15).

Whilst PE is the only potentially curative treatment option, it is associated with a significant risk of mortality of up to 25% (median 2.2%) and morbidity of up to 100% (median 57%) (8). Whilst the surgical and oncological outcomes have been well reported, there is a paucity of research on survivorship and the psychological impact of exenterative surgery (8) despite the growing number of PE survivors dealing with the effects of radical surgery (16–18).

Shared Decision Making (SDM) between patients and clinicians represents the epitome of patient-centred care. Analysing and understanding evidence-based medicine whilst ensuring that the patient's intentions, values and preferences are considered during the decision-making process are fundamental to SDM. A good decision is one that is informed, consistent with personal values, acted upon and with which patients are satisfied (19). For patients to be able to perform part of the integral decision they need clear, evidence based patient information (EBPI) that is easy to understand, informative and discusses the treatment options that include supportive care (20). The Royal College of Surgeons of England (RCSEng) encourage surgeons to allow sufficient time for patients to read further material on their condition and available treatment, including accessing online information (21). It has been demonstrated that around two-thirds of patients use the internet to seek health information (22, 23). Previous work has shown the majority of patients choose Google™ as an initial starting point when looking for online health information (24). The internet provides patients with a platform to search for disease-related information, supportive communication, practical tips on living with cancer, to find out more about their disease and other general health issues, and to search

for information regarding diagnosis and treatments (25–27). The internet is an extensive and complex source of information however, all pages do not go through a peer review process and can therefore vary in quality and consistency.

Whilst the principles of SDM are well documented, guidance about the integration into routine clinical practice is limited. One method is to use patient decision aids (PDA). Fundamentally, PDAs provide choice, describe treatment options and assist patients in exploring their preferences to enable decisions. They therefore support a process of deliberation and aid understanding of decisions that should be influenced by what matters most to patients as individuals to develop informed preferences (28).

Given the complexity of the decision to undergo a PE, a PDA appears to be a suitable method to introduce SDM for this cohort of patients. The aim of this study was to review the presence and quality of current PDAs including internet resources available to LARC/LRRC patients contemplating PE.

Methodology

This review was carried out in accordance with Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines. This literature search was registered on the PROSPERO database CRD42019122933 (29).

The Decision Aid Library Inventory (DALI) database (30) was searched for any available decision aids for pelvic exenteration. A search of the grey literature was also performed using Google Search™ engine. Separate searches were undertaken between the 8th January 2019 and 16th January 2019 using the following terms: 1) information about pelvic exenteration; 2) patient decision aid for pelvic exenteration; 3) treatment for advanced rectal cancer; 4) treatment for recurrent rectal cancer 5) information leaflet pelvic exenteration; 6) consent for pelvic exenteration; 7) decision making in pelvic exenteration.

The search results were limited to the first two pages, based on the assumption that internet users rarely go beyond the first page of search results (24). The articles were screened according to the eligibility criteria and all duplicates removed.

The eligibility criteria included sources that discussed surgical management of PE in LARC and LRRC that were aimed towards patients and written in English. Academic sources targeted for healthcare professionals, advertisements sponsored by Google and articles not written in the English language were excluded. Websites were viewed, screened for relevance and studies that did not meet the inclusion criteria were excluded. Sources assessed as potentially relevant were analysed further.

Sources were screened for appropriateness and checked for eligibility according to the defined inclusion criteria by two researchers (AW) and (AC). Any conflict between the two researchers were resolved by a third party, (DH). Data were extracted using a predefined extraction spreadsheet on Excel® version 16.16.16. Data were extracted on the following domains: 1) Website Descriptor: descriptors URL, upload source, country of origin, format of website, and purpose of website; 2) Health condition: classification of disease (LRRC, LARC); 3) Decision-making: Description of surgical options, description of oncological treatments, comparison of surgery versus no surgery, benefits and risks of surgery, and a description of the preoperative and recovery periods, length of recovery, prognosis, quality of life (QoL), pain and complications.

To determine whether the identified patient information sources qualified as a PDA they were assessed according to the criteria published by International Patient Decision Aid (IPDAS) Collaboration (31). This tool assesses the quality

of PDAs in terms of their development process and shared decision-making design components (32). The IPDAS assessment of PDAs is reported in three categories: Qualifying (6 items), Certifying (10 items) and Quality (28 items). Only Qualifying and Certifying domains are mandatory to define a decision aid therefore sources were judged solely on these domains. The Qualifying criteria are required in order for an intervention to be considered a decision aid whilst the Certifying criteria ensure the decision aid has no harmful bias. Items 7–10 in the Certifying criteria were not applicable to this study due to its relevance for screening tests and therefore were excluded from analysis.

The quality of the written health information was assessed using the validated DISCERN tool (33). DISCERN has been designed to help users of consumer health information determine the quality of written information about treatment choices (34, 35). The tool is formed from 16 questions; the first 8 questions assess the reliability of the publication and the latter 8, assess the quality of information on treatment choice. Each question rated the information on a 5-point scale ranging from No to Yes. The rating scale has been designed to help decide whether the quality criterion in question is present or has been 'fulfilled' by the publication. The global score indicates the assessor's overall conclusion of the quality of the source in providing written health information and can only be scored a 1, 3, or 5.

Readability was assessed using the Flesch-Kincaid reading ease score using an online tool (36, 37). Readability is scored 0-100 and corresponds inversely with school years. The challenge in using the Flesch-Kincaid Reading Ease is that test results are not immediately meaningful and a conversion table is needed to make sense of the score (37). These difficulties were rectified by implementing the Flesch-Kincaid Grade Level which calculates a score that is proportional to school years i.e. grade 1, UK school year 2 age 6–7, grade 2, UK school year 3 age 7–8. The results of the two tests correlate approximately inversely: a text with a comparatively high score on the Reading Ease test should have a lower score on the Grade-Level test.

Results

The DALI database identified six PDA's for colorectal cancer, all of which were ineligible for pelvic exenteration (30). A Google search for PDA's yielded 27,782,200 potential sources, of which 131 sources fulfilled the eligibility criteria. Ninety-nine sources were screened, of which 19 were excluded as advertisements. Eighty sources were subsequently assessed for eligibility. Seventy-four sources were excluded for the following reasons: 22 sources did not mention PE within the information; 24 sources were not aimed at LRRC/LARC; 25 sources were not written for patients and three sources had inaccessible websites at the time of analysis. Six sources were therefore eligible for inclusion (Fig. 1).

The six eligible sources were designated webpages, varying between HTML and PDF format. The sources were: 1) Canadian Cancer Charity; 2) Oxford University Hospitals NHS Foundation Trust; 3) Texas Oncology; 4) MD Anderson Cancer Centre; 5) Comprehensive Cancer Centre; 6) London Northwest Healthcare Trust (38–43). All sources were produced from centres in the Western world including; three from the USA, two from the UK and one from Canada. Two of the sources were PDF format and four were HTML format. Patient targeted information was uploaded by four hospital/specialty associations, one specialist cancer centre and one cancer charity (Table 1).

Table 1
Eligible sources included in the analysis

Source	Title of website	Format	Country	Name of Uploader	Upload source type
http://www.cancer.ca	Pelvic exenteration Information for patients and their families/carers	HTML	Canada	Canadian cancer charity	Cancer charity
https://www.ouh.nhs.uk	Pelvic exenteration Information	PDF	UK	Oxford University Hospitals NHS Foundation	Hospital/specialty association
https://www.texasoncology.com	Recurrent rectal cancer	HTML	US	Texas Oncology	Hospital/specialty association
https://www.mdanderson.org	Locally recurrent rectal cancer	HTML	US	MD Anderson Cancer Centre	Hospital/specialty association
http://cancer.unm.edu	Recurrent rectal cancer	HTML	US	Comprehensive cancer centre	Cancer centre
http://www.stmarkshospital.nhs.uk	complex cancer surgery for men	PDF	UK	London Northwest Healthcare Trust	Hospital/specialty association

All sources provided information about LRRC or LARC, with half of the information sources focusing on LRRC alone. Description of surgical options and oncological treatments were reported in the majority of sources (n = 5). Five sources did not discuss the comparison of surgery vs no surgery nor the overall prognosis. Quality of life, benefits and risks of surgery, description of the preoperative and recovery periods, length of recovery, nor pain were discussed in 4 of the 6 sources. Half of the sources mentioned surgical complications within their information (Table 2).

Table 2
Decision making domains discussed within the identified sources.

SOURCE	CaCC	OUHNH	TO	MDACC	CCC	LNHT
Classification of disease (LRRRC LARC)	LARC LRRRC	LARC LRRRC	LRRRC	LRRRC	LRRRC	LARC LRRRC
Description of surgical options	Yes	No	Yes	Yes	Yes	Yes
Description of oncological treatments	No	Yes	Yes	Yes	Yes	Yes
Comparison surgery vs no surgery	No	No	No	No	No	Yes
Benefits and risks of surgery	Yes	No	No	No	No	Yes
Description of the preoperative and recovery periods	No	Yes	No	No	No	Yes
Length of recovery	No	Yes	No	No	No	Yes
Prognosis	No	No	No	No	No	No
Quality of life	Yes	No	No	No	No	Yes
Pain	No	Yes	No	No	No	Yes
Complications	Yes	Yes	No	No	No	Yes
(Abbreviations: CaCC - Canadian Cancer Charity, OUHNH- Oxford University Hospitals NHS Foundation, TO - Texas Oncology, MDACC - MD Anderson Cancer Centre, CCC - Comprehensive Cancer Centre, LNHT - London Northwest Healthcare Trust)						

International Patient Decision Aid Standards

The information was inadequate when assessed according to the IPADS criteria, with no source identified as a decision aid. London Northwest Healthcare Trust met the highest number of IPADS criteria; fulfilling 5 out of 12 requirements. The median score was 3.5 for all identified sources (Table 3). All sources described the health condition for which an index decision is required. No source described the positive or negative features of each option, showed positive and negative features of options with equal detail, provided information about the funding source used for development nor provided information about the level of uncertainty around outcome probabilities. Five of the sources did not provide information of a future review to update the current information. Half of the sources explicitly stated the decision under consideration and described the treatment options available for the index decision. Four of the 6 sources did not describe the features of available treatment options available to help patients imagine the physical, social and/or psychological effects. Four of the 6 sources provided citations to the evidence provided.

Table 3
IPDASi criteria for each source identified.

IPDASi	CaCCC	OUHNH	TO	MDACC	CCC	LNHT
Qualifying						
Describes health condition or problem for which index decision is required	Yes	Yes	Yes	Yes	Yes	Yes
Explicitly states decision under consideration (index decision)	No	No	Yes	no	Yes	Yes
Describes the options available for the index decision	No	No	Yes	Yes	Yes	No
Describes the positive features of each option	No	No	No	No	No	No
Describes the negative features of each option	No	No	No	No	No	No
Describes the features of options to help patients imagine: the physical, social and/or psychological effects	No	Yes	No	No	No	Yes
Certification						
Shows positive and negative features of options with equal detail	No	No	No	No	No	No
Provides information about the funding source used for development	No	No	No	No	No	No
Provides citations to the evidence selected	Yes	No	Yes	Yes	Yes	No
Provides a production or publication date	No	Yes	No	No	No	Yes
Provides information about update policy	No	No	No	No	No	Yes
Provides information about the level of uncertainty around outcome probabilities	No	No	No	No	No	No
Total Score: criteria discussed (/12)	2	3	4	3	4	5
Percentage of criteria discussed	17%	35%	25%	25%	35%	42%

Abbreviations: CaCC - Canadian Cancer Charity, OUHNH- Oxford University Hospitals NHS Foundation, TO - Texas Oncology, MDACC - MD Anderson Cancer Centre, CCC - Comprehensive Cancer Centre, LNHT - London Northwest Healthcare Trust.

DISCERN

The quality of the written information provided by all information sources was acceptable, with all sources scoring a global score of 3 on the DISCERN tool (Table 4). Despite the acceptable quality of the written information, there was significant variation in reliability (score range 18–34) and quality of information (score range 11–22) provided. The majority of sources did not have clear aims or report when the publication was produced. Four of the 6 sources met the criteria for relevance and provided details of additional information. Half of the sources did not meet the criteria for: source of information used to compile the publication; reference the areas of uncertainty the benefits and risks of each treatment described; or explain how treatment choices would affect quality of life. Five of 6 sources were scored 4–5 for their balanced and unbiased representation of information. All sources were scored 1–3 for description of

how each treatment works. Two sources did not meet the criteria for clarity on whether there may be more than one possible treatment choice available.

Table 4
DISCERN assessment of each source identified (answers : 1 no, 3 partially, 5 yes)

	CaCC	OUHNH	TO	MDACC	CCC	LNHT
1. Are the aims clear?	3	1	1	1	1	5
2. Does it achieve its aims?	3	1	1	1	1	5
3. Is it relevant?	5	5	5	3	5	5
4. Is it clear what sources of information were used to compile the publication?	5	1	3	1	3	1
5. Is it clear when the information used or reported in the publication was produced?	1	1	1	3	1	5
6. Is it balanced and unbiased?	4	4	5	3	5	5
7. Does it provide details of additional sources of support and information?	5	5	1	5	1	5
8. Does it refer to areas of uncertainty?	1	1	3	1	3	3
9. Does it describe how each treatment works?	2	3	3	1	3	3
10. Does it describe the benefits of each treatment?	1	1	3	1	3	3
11. Does it describe the risks of each treatment?	3	3	1	1	1	3
12. Does it describe what would happen if no treatment is used?	1	1	1	1	1	4
13. Does it describe how the treatment choices affect overall quality of life?	3	3	1	1	1	3
14. Is it clear that there may be more than one possible treatment choice?	1	1	4	5	4	5
15. Does it provide support for shared decision-making?	1	1	1	1	1	1
16. Based on the answers to all of the above questions, rate the overall quality of the publication as a source of information about treatment choices.	3	3	3	3	3	3
Abbreviations: CaCC - Canadian Cancer Charity, OUHNH- Oxford University Hospitals NHS Foundation, TO - Texas Oncology, MDACC - MD Anderson Cancer Centre, CCC - Comprehensive Cancer Centre, LNHT - London Northwest Healthcare Trust.						

Readability

The average reading age of the UK population is 11 years (44) yet patient information is recommended to be written at a level of a 14 year old (45). The median Flesch-Kincaid reading ease was 50.85 (32.5–80.8). This equates to 10–12th grade reading, age 15–18 years i.e. fairly difficult to read. The median Flesch-Kincaid grade level score was 7.65 (3–9.7), age 13–14 reading age (Table 5).

Table 5
Flesch-Kincaid reading ease and grade for each source identified.

	CaCC	OUHNH	TO	MDACC	CCC	LNHT
Flesch-Kincaid Reading ease	53.5	80.8	48.2	40.9	32.5	79.7
Flesch-Kincaid Reading ease grade equivalent	10–12	6	College	College	College	7
Flesch-Kincaid Reading Grade level	7.5	3.5	7.8	9.3	9.7	3
Abbreviations: CaCC - Canadian Cancer Charity, OUHNH- Oxford University Hospitals NHS Foundation, TO - Texas Oncology, MDACC - MD Anderson Cancer Centre, CCC - Comprehensive Cancer Centre, LNHT - London Northwest Healthcare Trust.						

Discussion

This is the first review of the literature to focus exclusively on the information available to patients with LRRC or LARC who require PE. There are no PDA's and limited online resources available to assist patients in this particular decision-making process. Most of the available information is of poor quality and does not aid patient decision-making, as reflected in low DISCERN and IPDAS scores.

From a patient's perspective, the decision whether to undergo PE surgery is complex. Patients require support to understand the proposed care, treatment and non-operative options available. Supplied information must include the risks, benefits and consequences of treatment options in order for them to make an informed decision and participate in SDM. The principal concept of SDM is a joint decision made between a clinician and an informed patient without the use of the internet, however, patients continue to access online health information for education. None of the sources in this study described how life would change after surgery in detail. The consequences of exenterative surgery, length of recovery, QOL and post-operative pain were only discussed in 2 available resources and complications in 3 resources. SDM cannot be achieved with such limited evidence based-literature available. With 2 resources not comparing all available treatment options and not discussing risks and benefits associated with each option, a balanced decision based on the information away from the consultation is impossible. Without a PDA or reliable evidence-based literature, patients have no other alternative than to use the internet which currently has poor content.

Less than half of the 12 IPDAS criteria were discussed in the available internet sources. London Northwest Healthcare Trust currently has the most informative piece of literature, however, only met 42% of the IPDASi criteria. This resource lacks sufficient balanced detail to qualify as a decision aid and insufficient information to exclude any harmful bias. The overall quality of all sources was adequate according to the DISCERN tool. The lack of high-quality patient information is not limited to LARC/LRRC. Poor quality online health information about other conditions including perianal Crohn's fistulae (46), ulcerative colitis (47), breast surgery (48) and full thickness rectal prolapse surgery (49) have been reported. This is alarming when so many patients turn to online resources and trust these sources of information.

The readability assessment of online health information for PE surgery is not patient-friendly with a median Flesch-Kincaid reading ease of 50.85. Information should be aimed towards the lowest health literate patient in order to support patients to understand their treatment options and what is known of the benefits, harms, consequences and burdens of those options. The text intended for readership by the general public should aim for a schooling age 13–

14 years (36) and some of the literature analysed in this study required the reader to have attended University to understand the text. Further efforts are required to invest in health literate decision support materials and ensure that healthcare professionals tailor conversations to take account potential low health literacy.

Limitations of the study include non-inclusion of printed PDAs that individual health care providers have produced but which aren't available on the internet. Further limitations were that searches were limited to the first two pages and a more extensive search may have resulted in more literature. TO and CCC literature were analysed separately for this study as they were identified as different websites with different descriptors, URL, upload source and purpose. However, the content and layout of both were very similar which may introduce some bias to the results.

The importance of PDAs in clinical practice has been acknowledged by NICE, who have developed 39 decision aids which cover conditions that may be surgically treated, including breast cancer, hip and knee osteoarthritis and gynaecological procedures (50). Whilst there are a few surgically based NICE PDAs available, the majority have been developed for conditions usually managed medically for example atrial fibrillation, coronary heart disease, stroke, heartburn, dementia etc. Despite the increasing acceptance and use of PDA's, as things stand, currently nothing exists for patients specifically diagnosed with LARC or LRRC. It is evident from the literature there is a clear need for accurate and informative PDA highlighting the risks, benefits and range of treatments available to these patients.

Conclusion

Current online health information relating to PE surgery for LARC or LRRC is of limited use in aiding patient decision-making, as reflected in low DISCERN and IPDAS scores. The current information available is scant and of variable but predominantly poor quality. Given the peri-operative morbidity and mortality risks of PE surgery and lifelong QOL implications, there is a need to develop and disseminate high quality information to facilitate SDM. Further studies need to determine whether local literature is being used at different centres and given the complexity of the decision making, ideally a universally acceptable PDA should be developed.

List Of Abbreviations

CaCC - Canadian Cancer Charity

CCC - Comprehensive Cancer Centre

DALI – Decision Aid Library Inventory

EBPI – Evidence based patient information

IPDAS – International Patient Decision Aid Collaboration

LARC – Locally Advanced Rectal Cancer

LNHT - London Northwest Healthcare Trust

LRRC - Locally Recurrent Rectal Cancer

MDACC - MD Anderson Cancer Centre

OUHNF- Oxford University Hospitals NHS Foundation

PDA – Patient Decision Aid

PE – Pelvic exenteration

PRISMA - Preferred Reporting Items for Systematic Reviews and Meta-analyses

RCSEng – Royal College of Surgeons of England

SDM – Shared Decision Making

TO - Texas Oncology

Declarations

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Ethics approval and Consent to Participate

Ethical approval was obtained for this study by NHS Grampian, North of Scotland Research Ethics Service. IRAS 257890.

Consent for publication

All authors consent to this publication.

Competing interests

The authors declare that they have no financial or non-financial competing interests.

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Author's contributions

AW & AC performed relevant searches and screened sources for appropriateness and checked for eligibility. AW was a major contributor in writing this paper. AC participated in the writing of this paper. DAH, HH, DH and MDE all participated in establishing the development of this study and achieving ethical approval. DAH HH and AC contributed to the editing of this paper. DH and MDE were major contributors in the editing of this paper. All authors read and approved the final manuscript.

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Figures

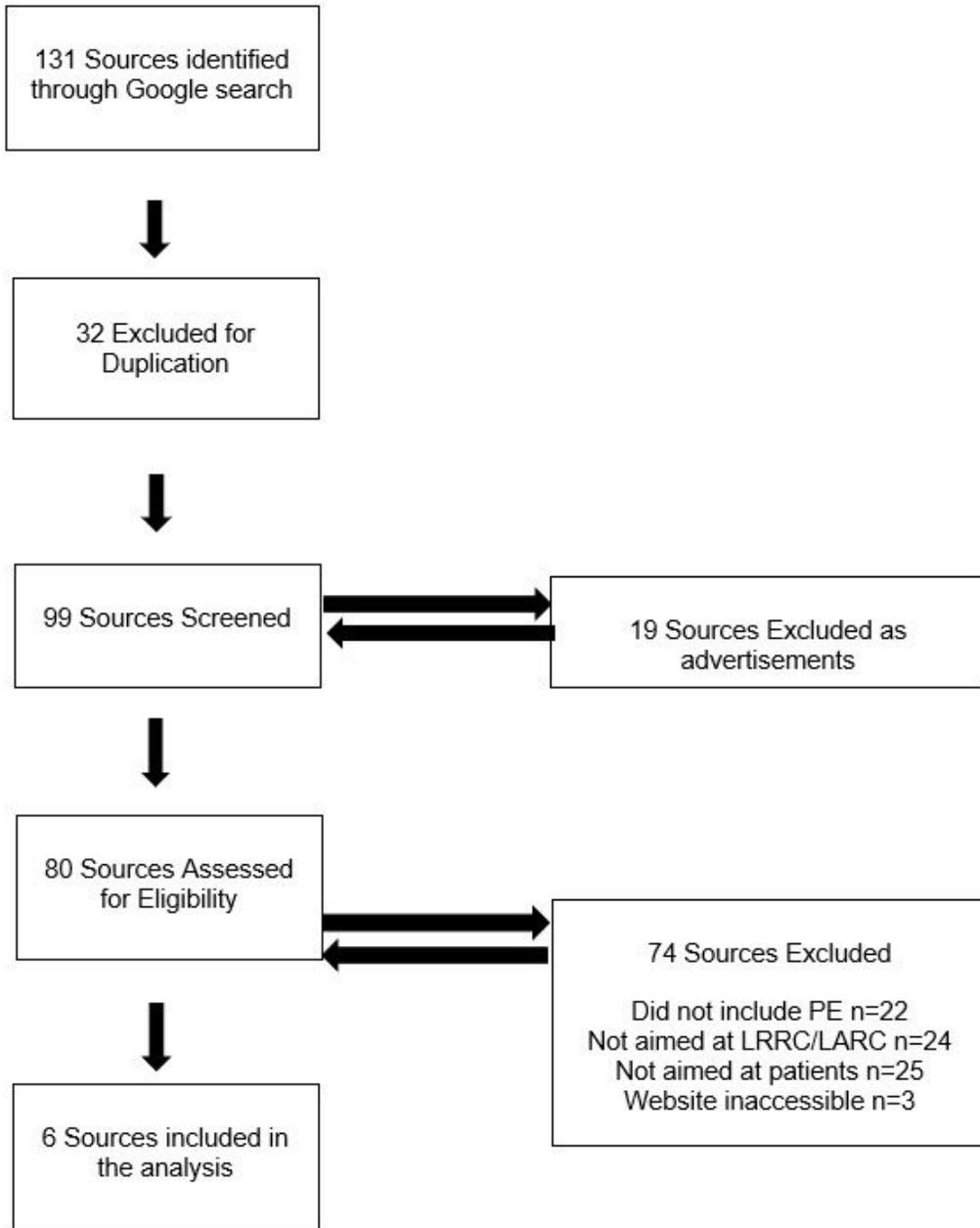


Figure 1

PRISMA flowchart of study selection