

Quality of internet information to aid patient decision making in locally advanced and recurrent rectal cancer

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Keywords: Internet based information, Google, Patient Decision Aid, Pelvic Exenteration, Rectal Cancer, DISCERN, IPDAS.

Ethics approval

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

Funding

The authors deny any source of funding for the development of this work.

Conflicts of interest/Competing interests

The authors deny any conflict of interest or competing interests.

Abstract word count:

Word count: words (excluding title page, abstract, references, tables, and figures)

Abstract

Introduction: To review whether online decision aids are available for patients contemplating pelvic exenteration (PE) for locally advanced and recurrent rectal cancer (LARC and LRRC).

Methods and Materials: 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 reading ease test and Flesch-Kincaid grade level 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 provided an acceptable quality of written health information, scoring a global score of 3 for the DISCERN written assessment. The median Flesch-Kincaid reading ease was 50.85 (32.5-80.8) equating to a reading age of 15-18 years and the median Flesch-Kincaid grade level score was 7.65 (range 3-9.7), which equates to a reading age of 13-14.

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 PE surgery there is a need for high quality relevant information in this area. A PDA should be developed to improve decision making and ultimately improve patient experience.

Introduction

Rectal cancer is a common condition affecting 12,000 patients in the UK annually ¹. Rectal cancer that locally extends beyond the mesorectal plane is termed locally advanced rectal cancer (LARC). Disease that recurs locally within the pelvis after previous treatment is termed locally recurrent rectal cancer (LRRC). Whilst both LARC and LRRC are relatively rare conditions, the high incidence of rectal cancer in general means that a large number of patients are diagnosed with these conditions. Through the use of multi-modal oncological therapy and more radical surgery the management of LARC and locally recurrent rectal cancer LRRC has improved in recent years. ²⁻⁵. In LARC, the trimodality approach of neoadjuvant 5-fluorouracil (5FU) based chemoradiotherapy (CRT), surgery and adjuvant chemotherapy is considered the standard of care⁶. The addition of a second chemotherapy agent oxaliplatin (OXP) has been shown to improve pathological complete response (pCR) and complete surgical

resection (R0)⁷. Whilst some patients may achieve a pCR to neoadjuvant CRT, and arguably not require surgery for cure, the majority of patients do not and therefore if cure is the treatment goal pelvic exenteration may be necessary to achieve an R0 resection.

Through refined neoadjuvant therapy regimens and routine total mesorectal excision (TME) surgery local recurrence (LR) rates dramatically reduced when compared to historical rates from the pre-TME era. However, between 2.5 and 16% of patients that have been irradiated and surgically treated will get locally recurrent disease (LRRC)⁸⁻¹³. LRRC usually presents early, with 50% appearing during the first year¹⁴ and 75% within 2 years of diagnosis¹⁵. The management of LRRC is challenging and historically has been with palliative intent. However, in patients without widespread distant metastatic disease cure may be possible through radical surgery with or without further neoadjuvant oncological therapy, that may include re-irradiation in patients who have previously received pelvic radiotherapy^{16,17}.

Whilst recent and ongoing research has improved neo adjuvant oncological therapy, the mainstay of LARC/LRRC treatment remains complete surgical excision. Pelvic exenteration (PE) refers to an extended en bloc multi-visceral resection of pelvic structures. Contemporary international data from the PelvEx collaborative reported overall 3 year survival rates of 37.8%¹⁸ and 28.2%¹⁹ in LARC and LRRC respectively. There is however a significant burden associated with surgery, with morbidity rates of 37-100% (median 57%) and a reported perioperative mortality rate of 0-25% (median 2.2%)²⁰. Whilst it is widely accepted that PE is likely to impact upon quality of life there is a paucity of high-quality and robust data on the impact of pelvic exenteration on quality of life, functional outcomes and survivorship²⁰, with the majority of current data extrapolated from patients undergoing pelvic exenteration for gynaecological malignancy²¹⁻²³.

Decision-making in PE is complex. Patients have to make trade-offs between the possibility of cure, curative and treatment-related morbidity, mortality and health related quality of life (HrQOL). Exenterative surgery impacts upon a range of domains including body image, social impact, sexual function, treatment expectations, symptoms, communication, psychological impact, relationships and work and finance²⁴. Patients who undergo other major complex operations describe that the impact of surgery on their HQOL guides their treatment decisions. Some decide against potentially curative treatment because of the magnitude of the negative impact that the treatment has on HQOL²⁵. It is therefore essential that the clinical complexity underlying pelvic exenteration is

appropriately communicated to patients and reflected in the decision-making process. Ensuring patients have clear, evidence-based information, that is easy to understand and discusses all treatment options is key part of the decision-making process²⁶. The majority of the currently available literature for rectal cancer is limited to primary rectal cancer, with limited patient-level literature specifically for pelvic exenteration. When there is a paucity of dedicated clinical literature available, patients often seek alternative sources of information, with the majority using the internet to seek health information^{27,28}. Online internet resources may provide extensive and complex information however, due to the lack of a peer-review process, there is significant variation in the quality and consistency of the published literature.

The aims of this study were to assess the quality, content and readability of online health-related information available to patients with locally advanced and recurrent rectal cancer contemplating pelvic exenteration.

Methods and Materials

This systematic review was carried out in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guideline and was registered on the PROSPERO database CRD42019122933²⁹.

Eligibility Criteria

All sources that discuss pelvic exenteration (PE) in LARC and LRRC for a patient audience written in English were eligible for inclusion. Academic sources targeted for healthcare professionals, sponsored advertisements and articles not written in the English language were excluded.

Search Strategy

An online search was performed using Google Search™ engine alone. The majority of patients choose Google™ as an initial starting point when looking for online health information³⁰. 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. Between searches the prior internet history, cache and cookies were appropriately deleted. 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 results³⁰. The articles were screened according to the eligibility criteria and duplicates

removed. 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 by two researchers (AW) and (AC). Any conflict between researchers were resolved by a third party, (DH).

Data Extraction

Data were extracted using a predefined extraction spreadsheet on Excel® version 16.16.16. Data were extracted across 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 and oncological treatments, comparison of surgery versus no surgery, benefits and risks of surgery, and a description of the preoperative and recovery periods, overall length of recovery, prognosis, quality of life (QoL), pain and complications. These domains were extracted based on previous qualitative work undertaken with patients and experts.

Data Quality

Data quality was assessed using three validated scoring systems; DISCERN, IPDAS and the of the Flesch-Kincaid Reading Ease test.

DISCERN Scores

The quality of identified internet resources was assessed using the validated DISCERN tool³¹. DISCERN judges the quality of written health information regarding treatment choices^{32,33}. The tool is formed from 16 questions; eight (Q1-8) that assess the reliability of the publication, seven (Q9-15) that assess the quality of information on treatment choice and one (Q16) that provides the overall rating of the quality of information. Each question rates the information on a 5-point scale and is divided into poor (1-2), moderate (3) and excellent (4-5) quality scores. The rating scale helps to 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.

IPDAS Scores

All identified patient information sources were scored using the International Patient Decision Aid (IPDAS) Collaboration criteria³⁴ to assess their ability to guide patient decision-making. The IPDAS assessment is reported

in three categories: Qualifying, Certifying and Quality.³⁵ The IPDASi assessment is reported in three categories: Qualifying (6 items), Certifying (10 items) and Quality (28 items) using yes or no measures. Only Qualifying and Certifying domains are mandatory to define a decision aid therefore sources were judged solely on these domains. Items 7-10 in the certifying criteria were not applicable due to its relevance for screening tests and therefore were excluded from analysis. The maximum score was 12.

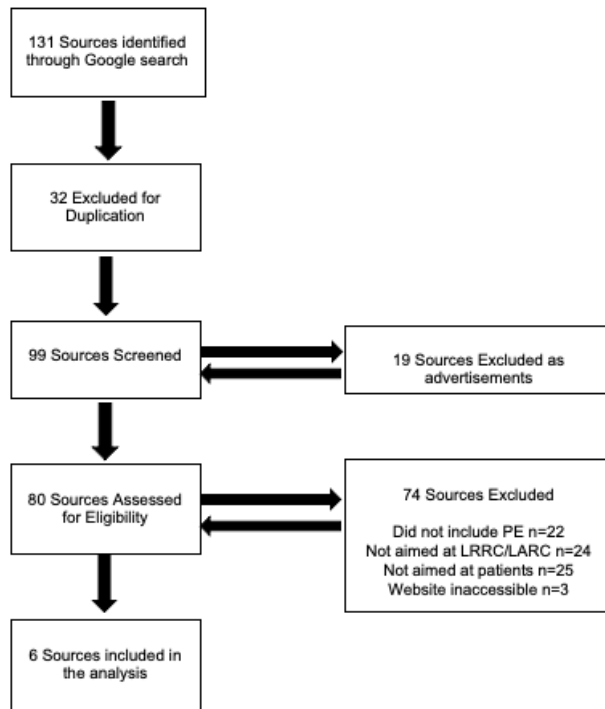
Flesh-Kincaid Reading Scores

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 results of the Flesch-Kincaid Reading Ease test are not immediately meaningful, therefore a conversion table is needed to make sense of the score³⁷. The Flesch-Kincaid Grade Level score was therefore used, that calculates a score that is proportional to school years i.e. grade 1 equates to age 6-7, grade 2 equates to age 7-8 etc. The results of the two tests correlate inversely: a text with a comparatively high score on the Reading Ease test should have a lower score on the Grade-Level test. Patient information is recommended to be written at a level of a 14 year old³⁸.

Results

An online search yielded 27,782,200 potential resources, of which 131 sources fulfilled the eligibility criteria, 32 resources were duplicates and 19 were considered to be advertisements. Eighty resources were assessed in full of which 6 resources were included in this systematic review (Figure 1).

Figure 1: PRISMA flowchart of study selection



The six eligible sources were designated webpages, of which 4 were HTML and 2 were 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 ³⁹⁻⁴⁴. 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 Pelvic exenteration Information for patients and their families/carers

<u>Source</u>	<u>Title of website</u>	<u>Format</u>	<u>Country</u>	<u>Name of Uploader</u>	<u>Upload source type</u>
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
https://www.texasoncology.com	'Recurrent rectal cancer'	HTML	US	Texas Oncology	Speciality association
https://www.mdanderson.org	'Locally recurrent rectal cancer'	HTML	US	MD Anderson Cancer Centre	Hospital
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

All sources provided information about LRRC or LARC, with 3 resources focusing specifically on LRRC (Table 2). Description of surgical options and oncological treatments were reported in the majority of sources (n=5). Five resources provided an outline of oncological treatments, however, only one resource provided comparative outcomes between surgical and non-surgical treatments. Important outcomes related to treatment including, benefits and risks of surgery, description of the preoperative and recovery periods, length of recovery, quality of life and pain had poor coverage across the identified resources. One source was specifically targeted at men with no equivalent female version appearing within the search strategy.

Table 2: Decision making domains discussed within the identified sources.

<u>Decision Making Domain</u>	<u>SOURCE</u>					
	Canadian Cancer Charity	Oxford University Hospitals NHS Foundation	Texas Oncology	MD Anderson Cancer Centre	Comprehensive Cancer Centre	London Northwest Healthcare Trust
Classification of disease	LARC LRRC	LARC LRRC	LRRC	LRRC	LRRC	LARC LRRC
Description of surgical options	√	x	√	√	√	√
Description of oncological treatments	x	√	√	√	√	√
Comparison surgery vs no surgery	x	x	x	x	x	√
Benefits and risks of surgery	√	x	x	x	x	√
Description of the preoperative and recovery periods	x	√	x	x	x	√
Length of recovery	x	√	x	x	x	√
Prognosis	x	x	x	x	x	x
Quality of life	√	x	x	x	x	√
Pain	x	√	x	x	x	√
Complications	√	√	x	x	x	√

Quality of Internet Sources

Overall, the quality of identified internet sources was of poor to moderate quality based on the combined DISCERN, IPDAS and Flesch-Kincaid scores (Table 3).

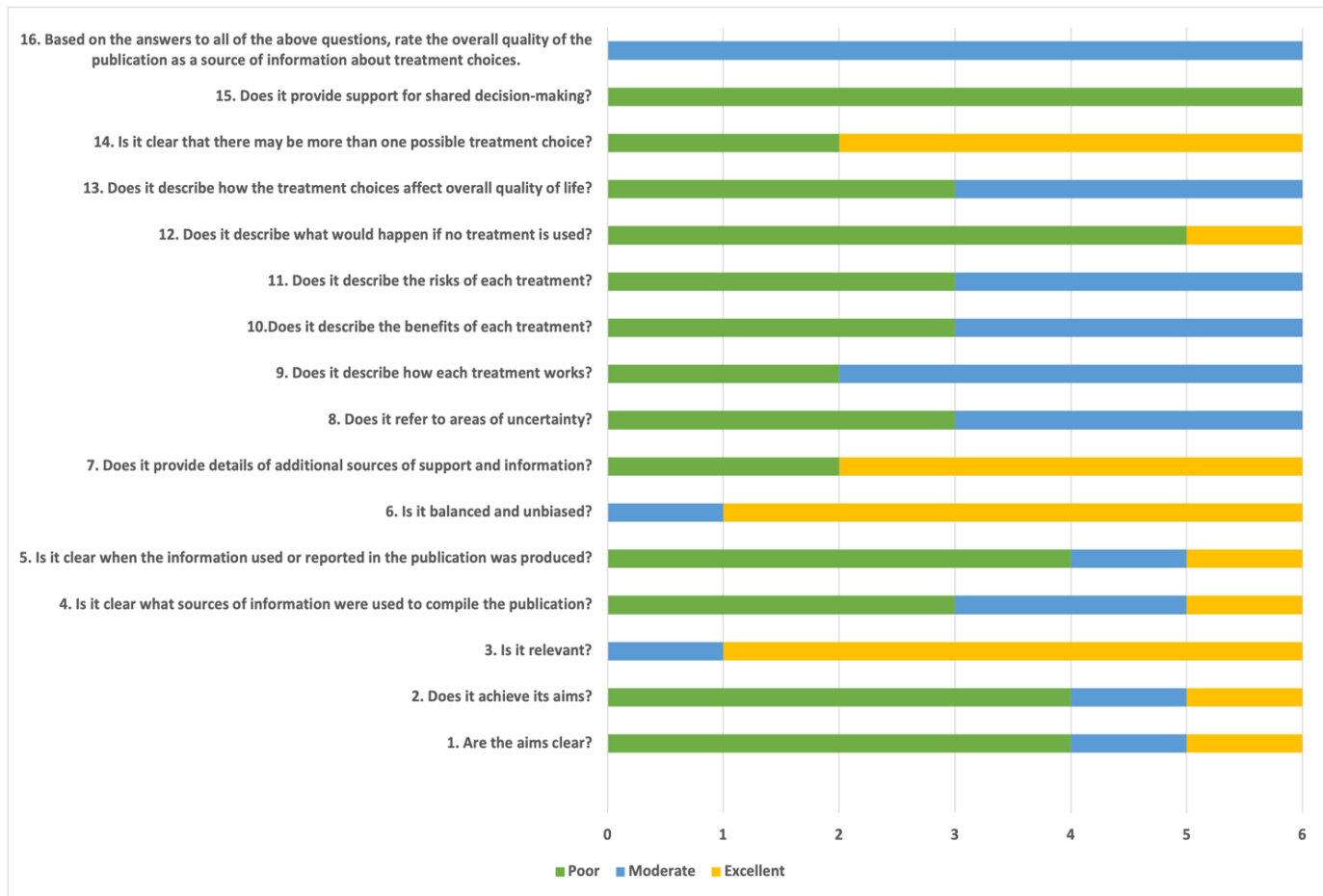
Table 3: Summary Scores on Quality of Internet Information

Identified Source	Overall DISCERN Score	IPDAS Score	IPDAS Criteria Coverage (%)	Flesch-Kincaid Reading ease	Flesch-Kincaid Reading ease grade equivalent	Flesch-Kincaid Reading Grade level
Canadian cancer charity	3	2	17	53.5	10 – 12	7.5
Oxford University Hospitals NHS Foundation	3	3	35	80.8	6	3.5
Texas Oncology	3	4	25	48.2	College	7.8
MD Anderson Cancer Centre	3	3	25	40.9	College	9.3
Comprehensive cancer centre	3	4	35	32.5	College	9.7
London Northwest Healthcare Trust	3	5	42	79.7	7	3

DISCERN

The overall quality of the written information provided by all information sources was moderate, with all sources scoring a global DISCERN tool score of 3 (Figure 2). Identified internet sources performed poorly with regards to identifying clear aims, highlighting appropriate sources used in their development and their publication date, referring to areas of uncertainty, clear description of risks and benefits associated with treatments, no description of outcomes associated with no treatment and no provision of support for shared-decision-making. Areas where the identified resources performed well included; relevance (n=5), provision of balanced and unbiased information (n=5), provision of additional sources of support and information (n=4) and highlighting more than one treatment choice (n=4).

Figure 2: Overall DISCERN scores



International Patient Decision Aid Standards

The quality of all identified sources was poor according to the IPDAS criteria, with a median score of 3.5 (range 2-5) and a percentage domain coverage of 17-42%. Figures 3a and 3b highlight the coverage of the internet sources across the IPDAS criteria for the Qualifying and Certifying domains. Across the qualifying domain the only criteria fulfilled by all 6 sources was the description of the health problem, with only 3 sources explicitly describing the index decision in question and its associated treatment options (Figure 3a). There was no coverage of the positive and negative features associated with treatments across the 6 sources and only 2 sources provided any patient level descriptors on the physical, social and psychological impact of treatments. For the certification domain the identified sources only covered 3 out of the 6 criteria; provision of citations for the selected evidence, provision of a publication date and provision of an update policy. There was no coverage of criteria describing equal discussion of positive and negative features associated with different treatment options, detail regarding funding sources and provision of data on uncertainty associated with outcomes.

Figure 3a: IPDAS Qualifying Criteria

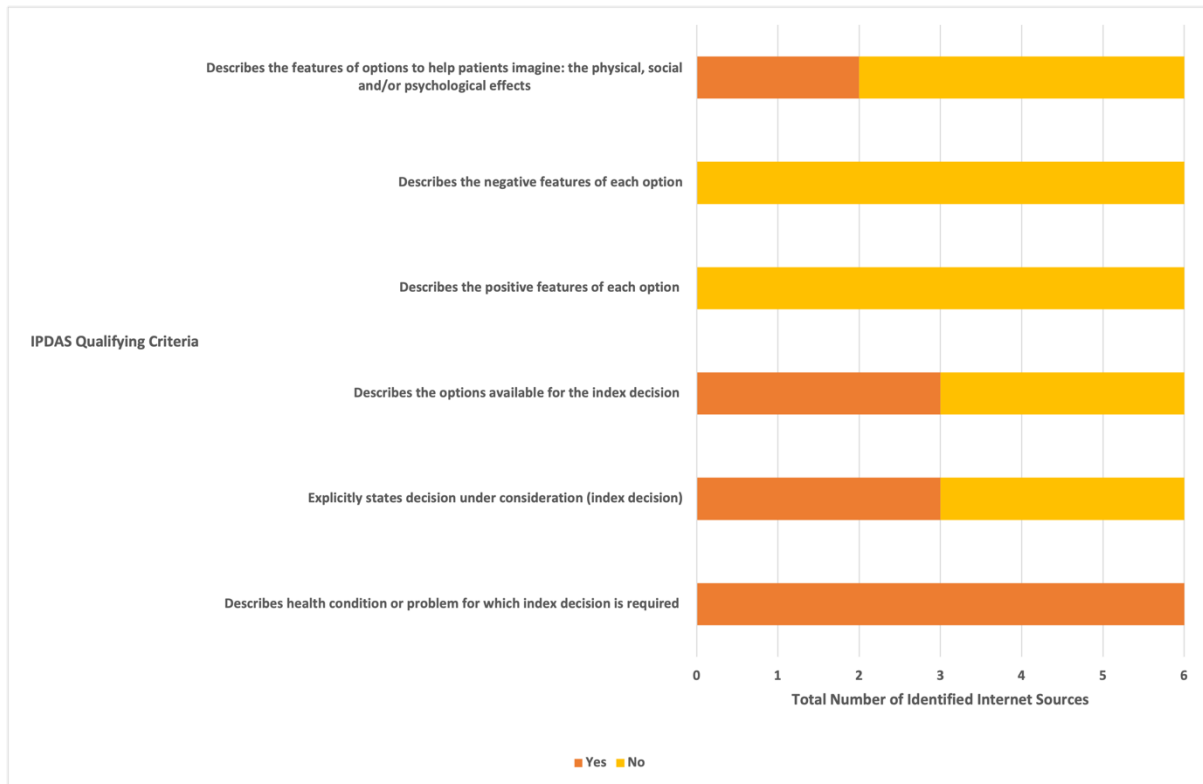
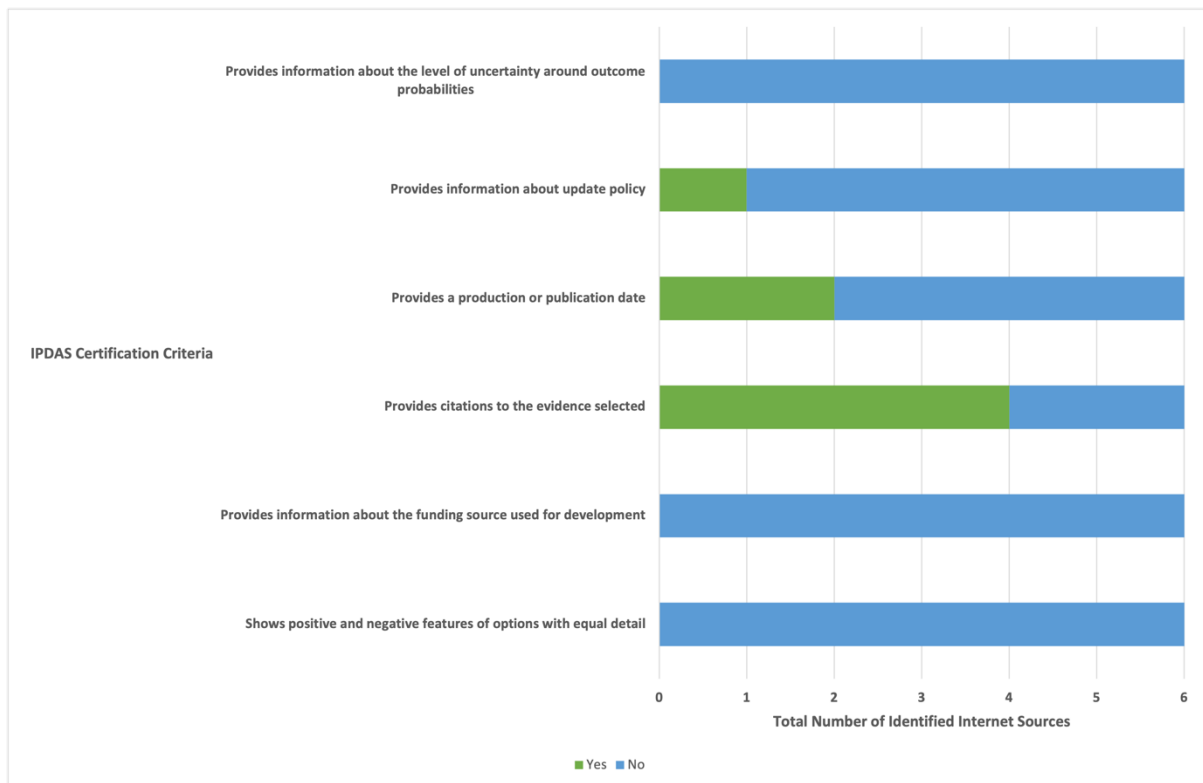


Figure 3b: IPDAS Certification Criteria



Readability

The overall readability of the identified resources was considered to be high, with a median Flesch-Kincaid reading ease score of 50.85 (32.5 – 80.8). This equates to a school grade of 10-12 and a reading age of age 15-18 years. The median Flesch-Kincaid grade level score was 7.65 (range 3-9.7), which equates to a reading age of 13-14 years.

Discussion

The current online information available for patients considering pelvic exenteration surgery for LARC or LRRC is limited and fails to adequately capture the complexity and nuances of decision-making in this complex clinical arena. Our study highlights that the limited number of resources available are of poor quality and do not adequately aid patient-decision-making, as reflected in their low DISCERN and IPDAS scores. Furthermore, these resources fail to comply with current recommendations to ensure ease of readability for patients and therefore, are considered unsuitable for all patient use.

The majority of resources highlighted by our review focus on the key clinical aspects of surgery, providing detailed information on the surgical aspects of pelvic exenteration and complimentary oncological treatments. This largely represents surgical decision-making in rectal cancer and fails to appropriately address alternative management options that an adequately informed patient may prefer.^{45 46} Patients searching for online information on pelvic exenteration are likely to be taking active decisional control regarding their health and treatment choice and are seeking detailed information regarding their diagnosis, treatment and prognosis⁴⁷. Patient priorities and information needs in rectal cancer are complex and centre around the consequences of cancer and treatment choices⁴⁸, including their physical impact and the overall impact on quality of life.

Our identified resources failed to adequately address key patient information needs with the majority (n=4) of internet resources failing to provide adequate information on risks associated with surgery, data on post-operative recovery, post-operative pain and impact on quality of life. This is further supported by the DISCERN scoring with a number of resources lacking in providing adequate detail regarding treatment risk and benefit, treatment-related outcomes and a lack of acknowledgement regarding areas of uncertainty. This is reflective of clinical practice⁴⁹, with Steel et al, reporting patients undergoing extended resection for colorectal cancer were adequately informed regarding the clinical aspects of treatment during pre-operative counselling with clinicians, however,

were inadequately informed about treatment outcomes, recovery and lifestyle adjustment following surgery⁵⁰. Postoperative health related quality of life (HRQL) can yield information relevant for clinical decision-making and help to inform patients about the long-term consequences of surgery. This highlights the need for patient reported outcomes (PRO) for both conservative and surgically treated patients to make informed decisions⁵¹.

Our work contributes to the growing body of evidence that high-quality, procedure-specific, patient-level information is required pre-operatively for patients undergoing complex pelvic surgery^{21, 50, 52, 53}. Providing patients with dedicated literature, which aids decision-making is associated with reduced uncertainty, decisional conflict and decisional regret and improved decisional quality⁵⁴. The current online resources identified do not adequately aid patient-decision-making, as reflected in the globally poor IPDAS scores and the failure of all resources to adhere to the DISCERN criteria of providing support for shared decision-making. This is likely a reflection of the design of the identified online resources, with the focus largely placed on clinical aspects of pelvic exenteration, a lack of information on broader outcomes of importance to patients and the relatively high level of literacy required to understand the information. . Co-design with patients is required to improve the quality, content and readability of online resources.

Online patient resources provided by charitable organisations and healthcare organisations must contain high quality and relevant clinical content, whilst adhering to quality standards. However, it is important to acknowledge their role as an adjunct to shared decision-making within the clinical setting. It is clear from our study that the aims of these resources are to provide patient-level information, with very limited role in aiding decision-making. Patient decision-making is a complex entity and requires appropriate, evidence-based information on treatment options and outcomes, coupled with a value-based assessment of patient preferences and priorities. There is emerging interest in improving the process and quality of decision-making in rectal cancer, balancing clinical priorities with quality of life and functional outcomes⁵¹. This can be potentially done in a number of ways, including, through the use of patient decision aids, exploration of patient preferences and use of patient reported outcomes for both surgical and non-surgically managed patients. Wu et al explored the feasibility of implementing a decision-aid for patients with mid- or low rectal cancer in clinical practice⁵⁶⁻⁵⁸. They reported the use of a patient-decision aid was associated with improved patient knowledge and reduced decisional conflict⁵⁸. Kunneman et al explored patient preferences and values in when considering pre-operative radiotherapy in rectal cancer and found increased active engagement in the decision-making process by patients when their values

and preferences were appropriately voiced and considered ⁵⁹ . Integrating these strategies into existing patient resources will potentially help improve their utility and improve the process of decision-making.

We acknowledge limitations to the study. The limitation to the English language alone must be considered in the analysis of such few resources. The use of one search engine and a limited number of internet pages may also have resulted in a small number of sources and potentially expanding our search strategy, use of other search engines and not limiting to the first 2 pages may have led to the identification of further resources.

Conclusion

Our work demonstrates the paucity of high-quality patient information to aid decision-making in pelvic exenteration for locally advanced or recurrent rectal cancer. Our work uses robust measures to benchmark current resources against, using a number of validated criteria reflecting the quality and readability of the written information, as well as its ability to aid in the decision-making process. There is a desperate need for high quality relevant information in this area. A high quality PDA should be developed that should be made freely available on the internet and disseminated at treatment centres to all patients diagnosed with LARC/LRRC being considered for surgery.

List of abbreviations (alphabetical order)

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

SDM – Shared Decision Making

TO - Texas Oncology

Acknowledgements

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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