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Consumer information on tonsillectomy for children

An environmental scan

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Level 5, 255 Elizabeth Street, Sydney NSW 2001

Phone: (02) 9126 3600

Fax: (02) 9126 3613

Email: mail@safetyandquality.gov.au

Website: www.safetyandquality.gov.au

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Introduction

The Australian Commission on Safety and Quality in Health Care (the Commission) was established in 2006 to lead and coordinate national improvements in safety and quality in health care. Since that time the Commission has helped identify, raise awareness of and take action on key safety and quality issues within the healthcare system.

An important part of the Commission's work has been to explore the links between safety and quality and person-centred care, and support the consumer role in safety and quality. This focus is a core part of the Commission's strategic approach to safety and quality.

Partnering with consumers is integral to a number of the Commission's national frameworks including the Australian Safety and Quality Framework for Healthcare, the Australian Charter of Healthcare Rights and the National Safety and Quality Health Service Standards.

In order for healthcare providers to partner with consumers in their own care they must work with patients, families, friends and other support people to understand and address the needs and preferences of the patient. Healthcare providers must treat patients holistically and comprehensively with dignity and respect, collaborating, and sharing decisions and responsibility for care.

For these kinds of partnerships to work well, information needs to be provided to consumers in a way that is easy to understand and use and that is clear and describes the options, risks and benefits of different treatment pathways. However, there is currently a vast amount of information available to consumers on health and health care that is extremely variable in quality.

The Commission is working to identify whether high-quality health information exists for some key safety and quality issues. This process involves identifying the information that is available, assessing the quality of the information, and determining whether any additional information or resources might be required to support consumer understanding of their healthcare options.*

This paper

The first *Australian Atlas of Healthcare Variation (Atlas)* identified substantial variation in the use of tonsillectomy in children in Australia. It was proposed that one of the contributing factors to this variation may have been consumers' understanding of the treatment options for children presenting with indications for tonsillectomy, and that this understanding may have been influenced by the type and quality of consumer information resources available.

The Commission has undertaken an environmental scan to identify consumer information resources on tonsillectomy in children. This report describes this work including data on variation in tonsillectomy that was highlighted in the first Atlas, the methods used for identifying and assessing the quality of health information resources, and key findings of the review.

* This review of consumer information was completed in July 2017. Details of the resources were accurate at that time but may have changed in the intervening period.

Tonsillectomy in Australia

Tonsillectomy is a surgical procedure to remove the tonsils (palatine tonsils), which are soft tissue masses on each side at the back of the throat.¹

Tonsils are prone to inflammation and enlargement that can lead to tonsillitis. In some children, significant enlargement of the tonsils may cause breathing problems or sleep apnoea.¹ Recurrent acute throat infections and sleep-disordered breathing are the most common indications for tonsillectomy.^{2,3}

International evidence-based guidelines recommend that watchful waiting is more appropriate than tonsillectomy for children with mild sore throats.⁴

The indications for tonsillectomy in children and young people include:

- Frequent recurrent bouts of acute tonsillitis
- Peritonsillar abscess
- Suspected tumour or abnormality
- Frequent ear infections associated with tonsillitis and/or adenoid infection
- Upper airway obstruction in children with obstructive sleep apnoea
- Failing to thrive because of difficulty in swallowing.⁵

Atlas data on tonsillectomy

The first Atlas reported on variation in hospital admissions for tonsillectomy for children aged 17 years and under. The Atlas found that in 2012-13:

- There were 38,575 tonsillectomy admissions to hospital, representing 724 admissions per 100,000 people aged 17 years and under
- The average number of admissions varied across states and territories, from 388 per 100,000 people aged 17 years and under in the Northern Territory, to 898 in South Australia
- After excluding the highest and lowest results, the tonsillectomy hospital admission rate across the 290 remaining local areas was 3.0 times higher in the highest local area compared to the lowest.¹

There were a range of reasons proposed that may contribute to variation including:

- Private health insurance status and the accessibility of private hospitals, where most tonsillectomies occur
- Variation in the availability of ear nose and throat surgeons across states and territories, and in remote areas
- Elective surgery waiting times for tonsillectomy in public hospitals, which can be around 14 weeks
- Consumers' understanding of the options, and risks and benefits, when making decisions about tonsillectomy.¹

The first Atlas made suggestions on where to focus efforts to identify and address unwarranted variation in tonsillectomy. One of the recommendations was that the Commission 'review current patient information about tonsillectomy in Australia, in conjunction with relevant clinical colleges and consumer groups, to determine the need for better patient and carer information, and shared decision making tools, and also the need to update existing materials.'¹ This environmental scan reports on this review.

Review of consumer information on tonsillectomy

Health information on tonsillectomy for children is largely aimed at parents, substitute decision-makers and carers of children with tonsillitis or sleep-disordered breathing. But it is also important that some information is available and accessible for older children and teenagers who might wish, and have capacity, to be involved in decision-making about their health care.

Providing understandable and accessible health information can improve people's knowledge, understanding and recall about their health and care.⁶⁻⁸ High-quality health information also enables shared decision making, supports informed choice about treatment options and can empower consumers to be active partners in their own care.⁸⁻¹⁰

The following sections describe how the Commission identified, reviewed and assessed health information on tonsillectomy for children.

Methodology

Several complementary strategies were used to identify consumer information about tonsillectomy for children for this review. Australian sources were the primary focus; however this was supplemented by targeted exploration of resources from key leading international organisations.

An internet search using Google and Chrome was conducted between April and May 2017. Separate searches were performed with results limited to the first 15 websites identified (excluding advertisements and map results), for each of the following terms:

- Patient information tonsillectomy au
- Consumer information tonsillectomy au
- Patient information tonsils out au
- Consumer information tonsils out au
- Question tonsillectomy au
- Question tonsils out au
- Decision tonsillectomy au
- Decision tonsils out au
- Options tonsillectomy au
- Options tonsils out au

Leading condition-specific organisations and professional bodies in Australia, relevant to otolaryngology, sleep and children's health were also identified and searches undertaken for consumer information from their homepages. These organisations were:

- The Australian Society of Otolaryngology Head and Neck Surgery (ASOHNS)
- The Royal Australasian College of Surgeons (RACS)
- Australian College of Nursing (ACN)
- Australasian College of Ear, Nose and Throat Physicians (ACENTP)
- Otorhinolaryngology Head & Neck Nurses Groups Inc. (OHNNG)
- Raising Children Network
- The Royal Children's Hospital Melbourne
- Women and Children's Health Network (Government of SA and Women and Children's Hospital)
- Sydney Children's Hospitals Network

- Sleep Health Foundation
- Australasian Sleep Association (ASA)

Specific searches were also conducted for patient information on tonsillectomy for children from the homepages of a range of key international organisations. These organisations were:

- Wikipedia (International)
- The King's Fund (England)
- Patient Voices (United Kingdom)
- Agency for Healthcare Research and Quality (United States)
- National Health Service (England)
- Ottawa Hospital Research Institute Patient Decision Aids (Canada)
- National Institute for Health and Care Excellence (England)
- Royal College of Surgeons (England)
- ENT UK (United Kingdom)
- American Academy of Otolaryngology–Head and Neck Surgery (United States)

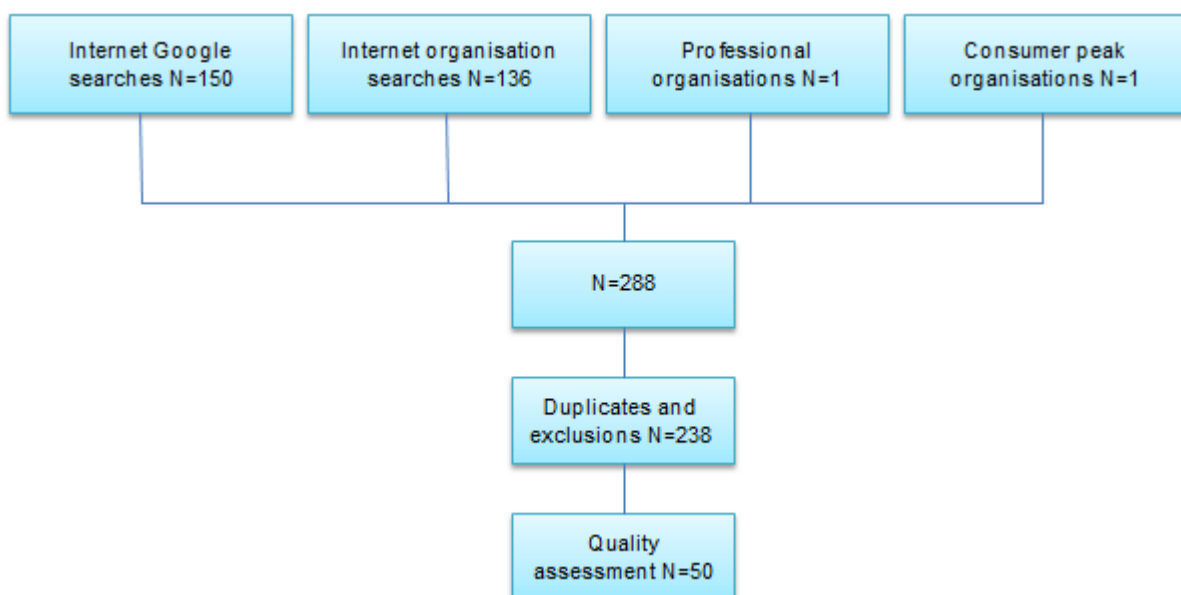
In addition, the Commission asked key professional organisations to identify and submit any consumer information resources on tonsillectomy which they knew were being used. The national and state and territory peak consumer organisations were also contacted and invited to provide any materials relevant to the review.

The resources identified through each of the search strategies were initially assessed for relevance, and those which did not align with the definition of consumer health information used for this review were discarded. Duplicated results were also excluded from further assessment.

This process identified a total of 50 discrete consumer information resources on tonsillectomy for further quality assessment which are included in [Appendix 1](#).

[Figure 1](#) illustrates the number of identified resources from each search strategy, together with exclusions and the final items retained for further quality assessment.

Figure 1: Search result refinement process



For each of the resources retained for further assessment, the following information was recorded where available:

- How the resource was identified
- Title of resources
- Type of resource (consumer information about a single option, consumer information about multiple options, option grid, patient decision aid)
- Format (web-based, printable, audiovisual)
- Length
- Author
- URL
- Source type and country (e.g. government, hospital, specialist, professional organisation etc.)
- Year published.

Preliminary assessments of quality using DISCERN

The DISCERN instrument was chosen as a framework to assess and compare the quality of the large number of consumer resources on tonsillectomy identified through the review.

The DISCERN instrument was the first standardised index for assessing the quality of consumer health information.¹¹ It was developed as a validated tool to help users of consumer health information judge the quality of written information about treatment choices.¹²⁻¹⁴ It is designed to assist in rating the quality of a publication in terms of its content and has a dual focus on the reliability and quality of information on treatment choices.^{14, 15}

The DISCERN instrument has a 5-point rating scale and asks a series of 15 questions to help determine the quality of the resource. The ratings for each of the DISCERN questions are aggregated into an overall rating of the resource.

Appendix 2 includes a list of DISCERN questions, and the following sections describe how the 50 consumer resources on tonsillectomy in children performed against the assessment.

Question 1: Are the aims clear?

Few of the resources explicitly stated the aim of providing the information, what was included or who the audience was. Such introductory content is important to orient readers and allow them to make a judgement about whether the resource is relevant for them and their circumstances.¹⁵ In its absence consumers are left to infer the aims of the resource from its title and headings with a greater or lesser degree of accuracy. Even amongst the 11 resources judged to be of higher quality, only six rated highly (rating of 4 or 5) on this particular item (Resources no. 9, 34, 35, 36, 38, 50).

Question 2: Does it achieve its aims?

Given few resources explicitly stated the aim it was difficult to identify if the resources achieved their goal. However, when allowing for the inference of aims from the title and headings of the publications, the majority of resources were rated moderately or highly for this item. Of the 11 resources judged to be of higher quality, seven were rated highly (rating of 4 or 5) for this criterion (Resources no. 9, 34, 35, 36, 38, 49, 50).

Question 3: Is it relevant?

Judging the relevance of the resources included a consideration of whether the publication addressed questions that consumers might ask, and whether the recommendations and suggestions about treatment choices were appropriate or realistic.¹⁵ For consumers considering tonsillectomy, a publication's relevance will be influenced by individual circumstances and factors related to the content and presentation of the resource.

A large majority of the reviewed resources were rated moderately or highly (rating of 4 or 5) for this item, indicating that this is a strength of consumer information on tonsillectomy currently available. Of the 11 resources judged to be of higher quality, ten rated highly on this particular item (Resources no. 9, 21, 32, 33, 34, 35, 36, 38, 49, 50).

Question 4: Is it clear what sources of information were used to compile the publication (other than the author or producer)?

Few of the resources included references to the sources of information used as evidence, or included a way to check the sources used such as a bibliography, reference list or the contact details of experts or organisations quoted.¹⁵ This was true for the resources produced by individual health service organisations, and the majority of those produced by professional bodies, condition-specific organisations and government agencies.

Of the 11 resources judged to be of higher quality only five rated highly (rating of 5) on this item (Resources no. 9, 21, 32, 34, 50). The frequent absence of references and other ways for consumers to check evidence sources is a limitation of the consumer information on tonsillectomy currently available.

Question 5: Is it clear when the information used or reported in the publication was produced?

Assessing resources against this criterion included looking for dates of the main evidence sources, as well as the date of publication and any revisions to the resource itself.¹⁵ Due to the low levels of referencing and evidence source identification across the majority of the resources, dates for the information used to compile the publications were also lacking.

The majority of resources did, however, identify when they were published, even if this was based on website copyright information. All of the 11 resources judged to be of higher quality rated highly (rating of 5) for this item (Resources no. 9, 17, 21, 32, 33, 34, 35, 36, 38, 49, 50).

Question 6: Is it balanced and unbiased?

This assessment question required consideration of whether the resource was objectively written, there was evidence that a range of sources were used to compile it, and any external assessment of the publication had occurred.¹⁵ While very few resources presented information about tonsillectomy in an emotive or alarmist way, the substantial majority were not rated highly for this item as the source of their statements was unclear or unreferenced.

While some consumers would be likely to infer that information published by government agencies, condition-specific organisations and professional bodies would be more objective and unbiased, the absence of clear markers such as evidence sources may create unnecessary confusion.

Of the 11 resources judged to be of higher quality, five were rated highly (rating of 5) for this particular item (Resources no. 9, 34, 21, 32, 50).

Question 7: Does it provide details of additional sources of support or information?

Providing consumers with suggestions for further reading, or details of other organisations able to give advice and information about treatment choices is an important element of high-quality information.¹⁵ Including these details in publications assists consumers to find any additional information they need to make decisions about treatment and care. For consumers considering tonsillectomy this could include referral to leading children's health organisations and links to professional bodies such as the Australian Society of Otolaryngology Head and Neck Surgery..

Of the 50 resources reviewed, 11 included this kind of information to guide consumers, indicating an opportunity for further improvement. Of the 11 resources judged to be of higher quality seven rated highly (rating of 5) for this item (Resources no. 9, 17, 21, 32, 33, 35, 36).

Question 8: Does it refer to areas of uncertainty?

Discussing gaps in knowledge or differences in expert opinion about treatment choices is a key way in which consumer information can acknowledge where there is uncertainty.¹⁵ Providing consumers with information about areas of uncertainty which may exist supports informed choice about treatment options. For consumers with tonsillitis or sleep-disordered breathing this may include information about when the optimal time is to have surgery, what surgical technique is most appropriate, whether procedures (tonsillectomy and adenoidectomy) can occur concurrently, and differences in outcomes after surgery.

Of the 50 resources reviewed, 16 referred to areas of uncertainty in a comprehensive way (rating of 4 or 5), showing room for increased attention to be paid to this element of high-quality consumer information. Of the 11 resources judged to be of higher quality, nine were rated highly (rating of 4 or 5) for this item (Resources no. 9, 17, 32, 33, 34, 35, 36, 38, 49, 50)

Question 9: Does it describe how each treatment works?

Providing detail about how a treatment acts on the body is a key piece of information consumers need to understand their treatment options, and make informed decisions.¹⁵ For consumers considering tonsillectomy this includes information about what happens to the throat during surgery, including detail about how the procedure is carried out and what the patient can expect during that episode of their care.

A substantial proportion of reviewed resources performed well on this item, with 25 of the 50 publications rated highly. All of the 11 resources judged to be of higher quality also achieved a high rating for this item (rating of 4 or 5), indicating that this is an area of strength across the range of consumer information about tonsillectomy (Resources no. 9, 17, 21, 32, 33, 34, 35, 36, 38, 49, 50).

Question 10: Does it describe the benefits of each treatment?

Information about the benefits of treatment can include reducing or eliminating symptoms, preventing recurrence of the condition and getting rid of the condition, both short-term and long-term.¹⁵ For consumers with tonsillitis or sleep-disordered breathing this comprises information about how throat infections and breathing will be affected by tonsillectomy, as

well as whether tonsils can reform after removal, and if there may be a need for further surgery.^{4, 5, 16}

The majority of resources reviewed did not make the benefits of tonsillectomy clear, with 33 of the 50 publications performing poorly on this item, indicating significant room for improvement. However, of the 11 resources judged to be of higher quality, seven achieved ratings of 4 or 5 for this item (Resources no. 9, 17, 32, 34, 35, 36, 50).

Question 11: Does it describe the risks of each treatment?

Most treatments involve some potential risks or disadvantages. Consumer resources that provide realistic information about these risks can help people make decisions about treatment in a more considered way. Risks can include side effects, complications and adverse reactions to treatment, both short-term and long-term.¹⁵ For consumers with tonsillitis or sleep-disordered breathing, understanding the risks of tonsillectomy is important for decisions about whether and when to have surgery.

There was substantial variation in the extent to which the resources reviewed identified risks associated with tonsillectomy, as well as in the level of detail they provided about frequency, severity and reversibility of the identified risks. This variability indicates another opportunity for quality improvement across the range of consumer resources on tonsillectomy. This variability did not, however, extend to those resources judged to be of higher quality, with all of the 11 publications being rated highly (rating of 5) for this item (Resources no. 9, 17, 21, 32, 33, 34, 35, 36, 38, 49, 50).

Question 12: Does it describe what would happen if no treatment is used?

A high-quality consumer resource will include information about what would happen if the condition is left untreated. Understanding the outcome of having no treatment helps clarify what consumers can expect, and helps identify if not having any treatment is linked to an outcome that is important for them.¹⁵

For consumers considering tonsillectomy, information about what would happen if they do not have tonsillectomy or choose to delay surgery can help them make informed choices about what health care they receive and when. Some of the conditions leading to tonsillectomy may resolve as children develop.² For tonsillar infection in particular, the alternatives to tonsillectomy for mild and infrequent infections are well understood and include supportive strategies and watchful waiting.¹⁻⁵ However, 37 of the 50 resources reviewed did not include a description of what would occur if tonsillitis or sleep-disordered breathing were left untreated. Only four of the 11 resources identified to be of higher quality were rated highly (rating of 4 or 5) for this item (Resources no. 9, 32, 34, 50).

Question 13: Does it describe how the treatment choices affect overall quality of life?

Treatment choices may involve major changes in lifestyle or circumstances or have effects on family and friends that consumers need to know and consider before making a decision. A high-quality resource will include information about the broader aspects of treatment choices on everyday life.¹⁵

For consumers with tonsillitis or sleep-disordered breathing these include short-term factors such as the need for time off school and limited physical activity after surgery as well as long-term considerations such as increased sleep quality, fewer throat infections and overall

quality of life.^{2-5, 16} Few of the resources reviewed included a clear reference to overall quality of life in the information they provided. This weakness was also observed in those resources judged to be of higher quality with only two of the 11 achieving a high rating of 5 for this item (Resource no. 34, 50).

Question 14: Is it clear that there may be more than one possible treatment choice?

A high-quality resource will indicate that there is a choice about treatment, even if full details of the alternatives are not presented in the publication.¹⁵ For consumers considering tonsillectomy, there may be different options to treat each of the different conditions for which surgery is indicated.

There was a high degree of variability observed for this item in the 50 publications reviewed with 24 performing poorly, 6 receiving a moderate score and 20 rating highly. As expected, consumer information about multiple treatment options and patient decision aids were more likely to be rated highly for this criterion than consumer information about a single treatment option. Of the 11 resources assessed to be of higher quality, eight were rated highly (rating of 4 or 5) for this item (Resources no. 9, 33, 34, 35, 36, 38, 49, 50).

Question 15: Does it provide support for shared decision making?

Consumer resources can provide support for shared decision making by raising issues for consumers to discuss with clinicians about what are the best treatment choices for them. High-quality consumer resources help consumers prepare for consultations with clinicians and to talk through issues that might affect people close to them regarding their care.¹⁵

For consumers considering tonsillectomy, this could include issues such as treatment choices, risks and benefits, costs and outcomes. Of the 50 resources assessed, only seven provided good support for shared decision making. Six of the 11 resources judged to be of higher quality rated highly (rating of 4 or 5) for this item (Resources no. 34, 35, 36, 38, 49, 50). Providing support for consumers to share decisions about treatment choices is a gap in the consumer information about tonsillectomy currently available.

Overall rating

All consumer resources have deficiencies and it is unlikely that any single publication will rate highly for all of the items.¹⁵ Consumer information about tonsillectomy is no different, as the results of this review indicate.

Substantial variation was observed in the quality of resources assessed in this review with a significant proportion judged to be of low quality (rating of 1 or 2) with serious or extensive shortcomings (n = 20). A similar number of resources were judged to be of moderate quality (rating of 3) with potentially important but not serious shortcomings (n=19).

While no single resource was rated highly across all of the criteria (rating of 4 or 5), 11 resources were judged to be of higher quality. The individual ratings given for each of the 50 reviewed resources are included in [Appendix 2](#) and details of the 11 higher-quality resources are listed in [Table 1](#).

Within this group are resources of different types and formats, authored by a range of organisations both within Australia and overseas. They provide a foundation of high-quality information on which the Commission can draw when considering the need for better or updated patient and carer information, and shared decision making tools about tonsillectomy for children.

Table 1: Highly rated consumer resources on tonsillectomy

Resource number	Overall DISCERN rating	Title	Type	Format	Author	Source Type and country	Year Published
9	4	Tonsillectomy	Consumer information - multiple options	Web-based Printable Audiovisual content	Patient	Independent health platform (UK)	2016
17	4	Tonsillitis	Consumer information - multiple options	Web-based Printable	Better Health Channel	Victorian government (AU)	2016
21	4	Tonsillectomy	Consumer information - single option	Web-based	Mayo Clinic	Not-for-profit health (USA)	2015
32	4	Tonsillectomy	Consumer information - single option	Web-based	Wikipedia	International web-based openly editable encyclopaedia	2017
33	4	Treating Tonsillitis	Consumer information - multiple options	Web-based	NHS Choices	National Health Service (UK)	2015
34	5	Tonsillitis: Should my child have a tonsillectomy?	Patient decision aid	Web-based Printable	Healthwise	Not-for-profit (USA)	2015
35	4	Understanding NICE guidance – information for people who use NHS services: Tonsillectomy using ultrasonic scalpel	Consumer information - single option	Printable	National Institute for Health and Care Excellence (NICE)	National health guidance and quality organisation (UK)	2006
36	4	Understanding NICE guidance – Information for people who use NHS services: Tonsillectomy using laser	Consumer information - single option	Printable	National Institute for Health and Care Excellence (NICE)	National health guidance and quality organisation (UK)	2006
38	4	About Children's Tonsil Surgery	Consumer information - single option	Printable	ENT UK	Professional body (UK)	2015

Resource number	Overall DISCERN rating	Title	Type	Format	Author	Source Type and country	Year Published
49	4	Surgical Removal of Tonsils and Adenoids – A Guide for Patients and Parents	Consumer information - single option	Hardcopy (unavailable online)	Royal Australian College of Surgeons and The Australian Society of Otolaryngology Head and Neck Surgery	Professional bodies (AU)	2016
50	5	Deciding what to do about recurrent sore throat	Consumer information multiple options	Web-based Printable	NHS RightCare	National Health Service (UK)	2017

Conclusion

For children with tonsillitis or sleep-disordered breathing, as well as their parents, substitute decision makers and carers, accessing high-quality information about tonsillectomy can influence expectations and preferences about treatment. The Commission has a role in supporting both access to and the use of high-quality information as a means of empowering consumers to work in partnership with their healthcare provider, and share decisions about health care. Access to high-quality information may also help to reduce unwarranted variation in the treatment of some conditions.

There is a large amount of information available to consumers about tonsillectomy in Australia however this information varies substantially in terms of its quality. This review suggests that the majority of consumer resources on tonsillectomy have been developed for different purposes, with the aim of meeting the local needs of individual health service organisations and are not high quality.

One of the challenges in developing high-quality consumer health information for tonsillectomy is that there are the multiple morbidity and disease pathways that may lead to the need to consider surgery.^{2, 4, 5} This means that, depending on the underlying condition or symptom, the content of the information on tonsillectomy may differ and need to focus on different conditions. The majority of publications reviewed focused on one of the two most common indications for surgery, namely recurrent acute tonsillitis or sleep-disordered breathing. Some resources provided information relevant to both conditions.

Reviewing consumer health information resources on tonsillectomy in children has identified a number of opportunities to improve quality including by better articulating aims, demonstrating objectivity, linking statements about treatment choices with evidence sources, considering the effect of treatment choices on overall quality of life, and improving support for shared decision making.

This review has however, identified 11 higher-quality resources that provide comprehensive information about risks, benefits, and options related to tonsillectomy in children. Although none of these 11 resources meets all criteria to the highest rating, overall they provide a reasonable basis to inform consumers about their options for tonsillectomy.

Consequently, rather than developing a new resource the Commission can best support consumers' need to access to high-quality information about tonsillectomy by directing consumers to the higher-quality resources that have been identified through this review.

Appendix 1

Consumer information resources on tonsillectomy

Resource no.	Title	Search strategy	Type	Format	Length	Author and URL	Source type and country	Year published
1	Patient Information Tonsillectomy	Google search 1: Patient information tonsillectomy au	A PI single option	Printable	2 printable pages	Dr N Agar & Dr D Phillips - Austin Hospital ENT Unit http://www.austin.org.au/Assets/Files/ENT%20-%20Adult%20Tonsil%20Info.pdf	Public hospital VIC Australia	Unknown
2	Patient Information Paediatric Tonsillectomy +/- Adenoidectomy	Google search 1: Patient information tonsillectomy au	A PI single option	Printable	2 printable pages	Dr N Agar & Dr D Phillips - Austin Hospital ENT Unit http://www.austin.org.au/Assets/Files/ENT%20-%20Paeds%20TA%20Info.pdf	Public hospital VIC Australia	Unknown
3	Tonsillectomy	Google search 1: Patient information tonsillectomy au	A PI single option	Web-based	1	Mater Hospital Brisbane http://brochures.mater.org.au/brochures/mater-hospital-brisbane/tonsillectomy	Private hospital QLD Australia	2015
4	Tonsil Removal – Tonsil and Adenoid Surgery	Google search 1: Patient information tonsillectomy au	A PI single option	Web-based	1	ENT Clinic http://www.ent-surgery.com.au/throat-surgery/tonsil-and-adenoid-surgery/	Specialist practise NSW Australia	2015 Website ©
5	Tonsillectomy, Tonsillitis Treatment	Google search 1: Patient information tonsillectomy au	A PI single option	Web-based	1	Dr Gillian Dunlop http://www.artofrhinoplasty.com.au/procedures/tonsillectomy/	Specialist practise NSW Australia	2017 Website ©
6	Recovery from Tonsillectomy and or Adenotonsillectomy	Google search 1: Patient information tonsillectomy au	A PI single option	Web-based	1	Ear Nose Throat Ballarat https://entballarat.com.au/patient-information/recovery-info	Specialist practise VIC Australia	Unknown
7	<u>Tonsillectomy & Adenoidectomy</u>	Google search 1: Patient information tonsillectomy au	A PI single option	Web-based	1	St. George Ear Nose Throat http://www.ent.com.au/index.php/information-for-patients/throat/tonsillectomy-adenoidectomy	Specialist practise NSW Australia	2017 Website ©

Resource no.	Title	Search strategy	Type	Format	Length	Author and URL	Source type and country	Year published
8	Day surgery: Tonsils and adenoids removed - discharge care	Google search 1: Patient information tonsillectomy au	A PI single option	Web-based	1	The Royal Children's Hospital Melbourne http://www.rch.org.au/kidsinfo/factsheets/Day_surgery_T_and_A_discharge_care/	Public Hospital VIC Australia	2013
9	Tonsillectomy	Google search 1: Patient information tonsillectomy au	B PI multiple options	Web-based; printable and audiovisual content	4 printable pages	Patient https://patient.info/health/tonsillectomy	UK Independent health platform	2016
10	Tonsillectomy Procedural Consent Form	Google search 1: Patient information tonsillectomy au	A PI single option	printable	3 printable pages	Queensland Health https://www.health.qld.gov.au/_data/assets/pdf_file/0014/143600/ent_31.pdf	QLD gov. Australia	2011
11	Tonsillectomy	Google search 1: Patient information tonsillectomy au	A PI single option	Web-based; printable	2 printable pages	The Children's Hospital at Westmead, Sydney Children's Hospital, Randwick and Kaleidoscope Children, Young People and Families. https://www.schn.health.nsw.gov.au/files/factsheets/tonsillectomy-en.pdf	Public Hospital NSW Australia	2016
12	Tonsillectomy post-operative patient information	Google search 1: Patient information tonsillectomy au	A PI single option	Web-based	1	ENT PARKVILLE at the Kid's http://www.entparkville.com.au/tonsillectomy-post-operative-patient-information/	Specialist practise VIC Australia	2017 website ©
13	Tonsillectomy	Google search 2: Consumer information tonsillectomy au	A PI single option	Web-based; printable	2 printable pages	Healthdirect https://www.healthdirect.gov.au/tonsillectomy	Australian gov. health platform	2016
14	Tonsillectomy (child)	Google search 2: Consumer information tonsillectomy au	A PI single option	Web-based; printable	2 printable pages	Better Health Channel https://www.betterhealth.vic.gov.au/health/surgicalbrochures/tonsillectomy-child	VIC gov Australia	2015

Resource no.	Title	Search strategy	Type	Format	Length	Author and URL	Source type and country	Year published
15	Discharge Information for Same Day Tonsillectomy - With or without Adenoidectomy	Google search 2: Consumer information tonsillectomy au	A PI single option	Printable	2 pages	Child and Adolescent Health Service Princess Margaret Hospital for Children http://www.pmh.health.wa.gov.au/brochures/consumers/cahs0164.pdf	Public hospital WA Australia	2008
16	Paediatric Tonsil and Adenoid Surgery	Google search 2: Consumer information tonsillectomy au	A PI single option	Printable	2 printable pages	ENT Albury Wodonga http://www.entalburywodonga.com.au/wp-content/uploads/2011/08/Tonsillectomy-Childrens1.pdf	Specialist practise NSW Australia	Unknown
17	Tonsillitis	Google search 3: Patient information tonsils out au	B PI multiple options	Web-based; printable	4 printable pages	Better Health Channel https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/tonsillitis	VIC gov. Australia	2016
18	Tonsillectomy and Adenoidectomy	Google search 3: Patient information tonsils out au	A PI single option	printable	2 printable pages	Women's and Children's Hospital http://www.wch.sa.gov.au/services/az/divisions/psurg/ent/documents/tonsillectomy_adenoidectomy_fs.pdf	Public hospital SA Australia	2016
19	Removal of Tonsils	Google search 3: Patient information tonsils out au	A PI single option	Web-based	15 linked pages	HCF https://www.hcf.com.au/preparing-for-hospital/removal-of-tonsils	Private health insurer Australia	2017 website ©
20	12 questions answered about tonsillitis and tonsillectomy	Google search 5: Question tonsillectomy au	A PI single option	Web-based	1	ENT Wellbeing http://www.entwellbeing.com.au/tonsillitis-and-tonsillectomy/	Allied health practise NSW Australia	2015 website ©
21	Tonsillectomy	Google search 5: Question tonsillectomy au	A PI single option	Web-based	5 linked web pages	Mayo Clinic http://www.mayoclinic.org/tests-procedures/tonsillectomy/basics/definition/prc-20019889	US not-for-profit health organisation and platform	2015
22	Children's Tonsils and Adenoid Removal	Google search 6: Question tonsils out au	A PI single option	Web-based	1	ENT Clinic http://www.ent-surgery.com.au/childrens-ent/tonsils-and-adenoid-removal/	Specialist practise NSW Australia	2015

Resource no.	Title	Search strategy	Type	Format	Length	Author and URL	Source type and country	Year published
23	Tonsillectomy or Adenotonsillectomy Sydney	Google search 7: Decision tonsillectomy au	A PI single option	Web-based	1	Dr Jason Roth http://www.drjasonroth.com.au/tonsils-and-adenoids-sydney/tonsillectomy-or-adenotonsillectomy/	Specialist practise NSW Australia	2017 website ©
24	Children Tonsillectomy	Google search 7: Decision tonsillectomy au	B PI multiple options	Web-based	1	Ear, Nose & Throat Sydney http://www.ents.com.au/tonsillectomy-children.html	Specialist practise NSW Australia	Unknown
25	Tonsillectomy	Google search 7: Decision tonsillectomy au	A PI single option	Web-based	1	entgeelong http://www.entgeelong.com.au/tonsillectomy	Specialist practise VIC Australia	2015 website ©
26	Adenoids-Tonsil Surgery	Google search 8: Decision tonsils out au	A PI single option	Web-based	1	Dr William Mooney http://www.rhinoplastysydney.com.au/procedures/adenoids-tonsil-surgery.html	Specialist practise NSW Australia	2013 website ©
27	Removal of the Tonsils and Adenoids	Google search 8: Decision tonsils out au	A PI single option	printable	6 printable pages	Dr A. Simon Carney http://bridgeclinic.com.au/media/docs/tonsilremoval.pdf	Unknown	Unknown
28	Tonsillitis	Google search 8: Decision tonsils out au	A PI single option	Web-based	1	Dr A Ananda http://www.drananda.com.au/tonsillitis/	Specialist practise NSW Australia	2017 website ©
29	Tonsillectomy	Google search 9: Options tonsillectomy au	A PI single option	Web-based	1	Havas ENT Clinics http://www.earnosethroat.com.au/voice-clinic/tonsillectomy/	Specialist practise NSW Australia	2017 website ©
30	Options for pain relief (analgesic) medication after tonsillectomy in children	Google search 9: Options tonsillectomy au	A PI single option	printable	2 printable pages	Anaesthetic Group http://anaestheticgroup.com.au/wp-content/uploads/doctor-profiles/gilchrist-analgesics-after-tonsillectomy.pdf	Specialist practise NSW Australia	2016

Resource no.	Title	Search strategy	Type	Format	Length	Author and URL	Source type and country	Year published
31	Surgical Treatments For Snoring And Apnoea	Google search 9: Options tonsillectomy au	B PI multiple options	Web-based	1	The Sleep Therapy Clinic http://www.sleeptherapyclinic.com.au/Surgical-treatments-snoring-apnoea-apnea	Primary care practice QLD Australia	2011 website ©
32	Tonsillectomy	Wikipedia: tonsillectomy	A PI single option	Web-based	1	Wikipedia https://en.wikipedia.org/wiki/Tonsillectomy	Web-based, openly editable encyclopedia	2017
33	Treating Tonsillitis	NHS Choices: tonsillectomy	B PI multiple options	Web-based	4 linked web pages	NHS Choices http://www.nhs.uk/Conditions/Tonsillitis/Pages/Treatment.aspx	UK National health service	2015
34	Tonsillitis: Should my child have a tonsillectomy?	OHRI: tonsillectomy	D PDA	Web-based; printable		Healthwise https://decisionaid.ohri.ca/AZsummary.php?ID=1307	US not-for-profit provider of health information, decision support tools, behavior change assistance etc.	2015
35	Understanding NICE guidance - Information for people who use NHS services: Tonsillectomy using ultrasonic scalpel	NICE: tonsillectomy	A PI single option	printable	4 printable pages	NICE https://www.nice.org.uk/guidance/ig178/resources/tonsillectomy-using-ultrasonic-scalpel-pdf-305835229	UK national health guidance and quality organisation	2006
36	Understanding NICE guidance Information for people who use NHS services: Tonsillectomy using laser	NICE: tonsillectomy	A PI single option	printable	4 printable pages	NICE https://www.nice.org.uk/guidance/ig186/resources/tonsillectomy-using-laser-pdf-305925949	UK national health guidance and quality organisation	2006
37	Electrosurgery (diathermy and coblation) for tonsillectomy Understanding NICE guidance – information for people considering the procedure, and for the public	NICE: tonsillectomy	A PI single option	printable	12 printable pages	NICE https://www.nice.org.uk/guidance/ig150/resources/electrosurgery-diathermy-and-coblation-for-tonsillectomy-pdf-304344829	UK national health guidance and quality organisation	2005

Resource no.	Title	Search strategy	Type	Format	Length	Author and URL	Source type and country	Year published
38	About Children's Tonsil Surgery	ENT: Tonsillectomy & patient information section browse	A PI single option	printable	2 printable pages (brochure style)	ENT UK https://www.entuk.org/sites/default/files/files/ENT/Children%20Tonsil%20Surgery%206pp%20DL%20(09002)_7_16.pdf	UK professional body	2015
39	Pediatric Sleep Disordered Breathing/Obstructive Sleep Apnea	AAO-HNS: tonsillectomy & patient information section browse	B PI multiple options	Web-based	1	AAO-HNS http://www.entnet.org/content/pediatric-sleep-disordered-breathingobstructive-sleep-apnea	US professional body	2017 website ©
40	Tonsillectomy and Adenoids PostOp	AAO-HNS: tonsillectomy & patient information section browse	A PI single option	Web-based	1	AAO-HNS http://www.entnet.org/content/tonsillectomy-and-adenoids-postop	US professional body	2017©
41	Tonsillitis	AAO-HNS: tonsillectomy & patient information section browse	B PI multiple options	Web-based	1	AAO-HNS http://www.entnet.org/content/tonsillitis	US professional body	2017©
42	Tonsils and Adenoids	AAO-HNS: tonsillectomy & patient information section browse	B PI multiple options	Web-based	1	AAO-HNS http://www.entnet.org/content/tonsils-and-adenoids	US professional body	2017©
43	Causes of Tonsillitis	RCH: tonsillectomy & patient information section browse	B PI multiple options	Web-based	1	Raising Children Network http://raisingchildren.net.au/articles/tonsillitis.html	AU Member organisation of early childhood agencies	2015
44	Obstructive sleep apnoea	RCH: tonsillectomy & patient information section browse	B PI multiple options	Web-based	1	Raising Children Network http://raisingchildren.net.au/articles/obstructive_sleep_apnoea.html	AU Member organisation of early childhood agencies	2015
45	Childhood obstructive sleep apnoea - OSA	The Royal Children's Hospital Melbourne: tonsillectomy & patient information section browse	B PI multiple options	Web-based	1	The Royal Children's Hospital Melbourne http://www.rch.org.au/kidsinfo/factsheets/Childhood_obstructive_sleep_apnoea_OSA/	Public Hospital VIC Australia	2010

Resource no.	Title	Search strategy	Type	Format	Length	Author and URL	Source type and country	Year published
46	Tonsillitis - when your throat is often sore	Women and Children's Health Network (Child and Youth Health): tonsillectomy & patient information section browse	B PI multiple options	Web-based	1	Child and Youth Health http://www.cyh.com/HealthTopics/HealthTopicDetailsKids.aspx?p=335&np=285&id=2237	Health network - Women's and Children's Hospital and community-based health services SA Australia	2015
47	Snoring can stop you sleeping well	Women and Children's Health Network (Child and Youth Health): tonsillectomy & patient information section browse	B PI multiple options	Web-based	1	Child and Youth Health http://www.cyh.com/HealthTopics/HealthTopicDetailsKids.aspx?p=335&np=285&id=3007	Health network - Women's and Children's Hospital and community-based health services SA Australia	2015
48	Childhood Snoring and Sleep Apnea	Sleep Health Foundation: tonsillectomy & patient information section browse	B PI multiple options	Web-based; printable	2 printable pages	Sleep Health Foundation https://www.sleephealthfoundation.org.au/files/pdfs/ChildhoodSnoring-1216.pdf	AU Advocacy organisation	2011
49	Surgical Removal of Tonsils and Adenoids – A Guide for Patients and Parents	Email request: ASOHNS	A PI single option	Hard-copy	4 printed pages	RACS and ASOHNS Email attachment only – cannot be found online	AU Professional bodies	2016
50	Deciding what to do about recurrent sore throat	NHS RightCare	B PI multiple options	Web-based printable	7 printed pages	NHS RightCare http://arms.evidence.nhs.uk/resources/hub/1057571/attachment	UK national health service	2017

Appendix 2

DISCERN assessment results

A rating scale of 1-5 (no to yes) is used for each DISCERN criteria. More information about this rating scale is included after the table.

No.	Type of resource	Are the aims clear?	Does it achieve its aims?	Is it relevant?	Is it clear what sources of info were used to complete the publication?	Is it clear when the info used or reported in the publication was produced?	Is it balanced and unbiased?	Does it provide details of additional sources of support or info?	Does it refer to areas of uncertainty?	Does it describe how each treatment works?	Does it describe the benefits of each treatment?	Does it describe the risks of each treatment?	Does it describe what would happen if no treatment was used?	Does it describe how treatment choices affect overall quality of life?	Is it clear that there may be more than one possible treatment choice?	Does it provide support for shared decision making?	Based on the answers to all of the questions, rate the overall quality of the publication as a source of info about treatment choices?
	A: consumer information single option; B: consumer information multiple options C: option grid D: patient decision aid	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)
1	A	1	N/A - 3	3	1	1	2	1	2	5	1	4	1	2	2	2	3
2	A	1	N/A - 3	3	1	1	2	1	2	5	2	4	1	2	2	2	3
3	A	1	N/A - 1	1	1	3	2	1	1	1	1	1	1	1	1	1	1
4	A	1	N/A - 2	3	1	3	2	1	2	1	1	2	1	2	1	1	2
5	A	1	N/A - 3	3	1	3	2	1	3	5	2	2	1	2	1	1	3
6	A	1	N/A - 3	3	1	1	2	1	2	1	1	3	1	2	1	1	2
7	A	1	N/A - 3	4	1	3	2	1	2	5	2	5	1	2	3	3	3
8	A	3	5	3	1	5	2	3	2	1	1	2	1	2	1	1	2
9	B	5	5	5	5	5	5	5	5	5	4	5	4	3	4	3	4

No.	Type of resource	Are the aims clear?	Does it achieve its aims?	Is it relevant?	Is it clear what sources of info were used to complete the publication?	Is it clear when the info used or reported in the publication was produced?	Is it balanced and unbiased?	Does it provide details of additional sources of support or info?	Does it refer to areas of uncertainty?	Does it describe how each treatment works?	Does it describe the benefits of each treatment?	Does it describe the risks of each treatment?	Does it describe what would happen if no treatment was used?	Does it describe how treatment choices affect overall quality of life?	Is it clear that there may be more than one possible treatment choice?	Does it provide support for shared decision making?	Based on the answers to all of the questions, rate the overall quality of the publication as a source of info about treatment choices?
	A: consumer information single option; B: consumer information multiple options C: option grid D: patient decision aid	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)
10	A	1	N/A - 3	3	1	5	2	1	3	2	1	5	1	1	1	3	3
11	A	1	N/A - 3	3	1	5	2	2	2	3	2	1	1	2	1	1	3
12	A	1	N/A - 3	3	1	3	2	2	1	1	1	2	1	2	1	1	2
13	A	1	N/A - 3	4	4	3	3	2	2	3	1	3	1	2	2	2	3
14	A	2	N/A - 3	4	3	5	3	1	3	5	1	5	4	2	4	2	3
15	A	1	N/A - 3	3	1	5	2	3	2	1	1	3	1	2	1	1	2
16	A	1	N/A - 2	2	1	1	2	1	2	1	1	2	1	2	1	1	2
17	B	2	N/A - 3	3	1	5	2	5	4	5	4	5	3	2	3	2	4
18	A	1	N/A - 2	3	1	5	2	2	2	1	1	2	1	2	1	1	2
19	A	5	4	4	1	3	2	2	2	5	2	2	2	1	2	1	3
20	B	1	N/A - 2	3	1	3	2	1	1	3	1	1	2	1	2	1	2
21	A	1	N/A - 3	5	5	5	5	5	2	5	2	5	2	2	1	1	4

No.	Type of resource	Are the aims clear?	Does it achieve its aims?	Is it relevant?	Is it clear what sources of info were used to complete the publication?	Is it clear when the info used or reported in the publication was produced?	Is it balanced and unbiased?	Does it provide details of additional sources of support or info?	Does it refer to areas of uncertainty?	Does it describe how each treatment works?	Does it describe the benefits of each treatment?	Does it describe the risks of each treatment?	Does it describe what would happen if no treatment was used?	Does it describe how treatment choices affect overall quality of life?	Is it clear that there may be more than one possible treatment choice?	Does it provide support for shared decision making?	Based on the answers to all of the questions, rate the overall quality of the publication as a source of info about treatment choices?
	A: consumer information single option; B: consumer information multiple options C: option grid D: patient decision aid	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)
22	B	1	N/A - 3	4	1	3	2	1	2	4	1	2	1	1	3	2	2
23	A	1	N/A - 3	4	1	3	2	1	2	4	2	5	1	2	2	1	2
24	B	1	N/A - 3	4	1	1	1	1	2	4	2	2	3	2	5	2	2
25	A	1	N/A - 3	4	1	3	2	1	2	4	1	5	1	2	2	1	2
26	A	1	N/A - 3	3	1	3	2	1	2	4	4	1	2	2	2	1	2
27	B	1	N/A - 3	4	1	1	2	1	2	5	2	5	1	2	3	1	3
28	A	1	N/A - 3	1	1	3	2	1	1	1	1	1	1	1	2	1	1
29	A	1	N/A - 3	4	1	3	2	1	2	3	2	5	1	1	2	1	2
30	A	1	N/A - 3	2	1	4	2	1	2	1	1	1	1	1	1	1	1
31	B	1	N/A - 3	3	1	3	2	3	3	5	2	5	3	1	3	2	3
32	A	1	N/A - 3	5	5	5	5	5	5	5	5	5	4	3	3	1	4
33	B	1	N/A - 3	4	1	5	2	5	5	5	3	5	3	3	5	3	4

No.	Type of resource	Are the aims clear?	Does it achieve its aims?	Is it relevant?	Is it clear what sources of info were used to complete the publication?	Is it clear when the info used or reported in the publication was produced?	Is it balanced and unbiased?	Does it provide details of additional sources of support or info?	Does it refer to areas of uncertainty?	Does it describe how each treatment works?	Does it describe the benefits of each treatment?	Does it describe the risks of each treatment?	Does it describe what would happen if no treatment was used?	Does it describe how treatment choices affect overall quality of life?	Is it clear that there may be more than one possible treatment choice?	Does it provide support for shared decision making?	Based on the answers to all of the questions, rate the overall quality of the publication as a source of info about treatment choices?
	A: consumer information single option; B: consumer information multiple options C: option grid D: patient decision aid	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)
34	B	5	5	5	5	5	5	3	5	4	5	5	5	5	5	5	5
35	A	5	5	5	2	5	3	5	4	5	5	5	2	3	5	5	4
36	A	5	5	5	2	5	3	5	5	5	4	5	2	3	5	5	4
37	A	4	4	4	2	5	3	5	5	5	4	5	2	3	4	4	3
38	B	5	5	5	1	5	2	3	4	4	3	5	4	3	5	4	4
39	B	1	N/A - 3	4	1	3	2	2	4	2	3	5	4	3	5	3	3
40	A	1	N/A - 3	3	1	3	2	2	3	3	2	2	1	3	1	1	2
41	B	1	N/A - 3	3	1	3	2	2	2	2	2	2	2	2	5	2	2
42	B	1	N/A - 3	4	1	3	2	2	4	3	2	3	2	2	4	3	3
43	B	1	N/A - 3	4	5	5	5	3	3	2	2	1	1	1	4	1	3
44	B	1	N/A - 3	4	5	5	5	2	3	2	2	1	1	1	5	1	3
45	B	1	N/A - 3	4	2	5	2	5	4	2	3	1	1	3	4	1	3

No.	Type of resource	Are the aims clear?	Does it achieve its aims?	Is it relevant?	Is it clear what sources of info were used to complete the publication?	Is it clear when the info used or reported in the publication was produced?	Is it balanced and unbiased?	Does it provide details of additional sources of support or info?	Does it refer to areas of uncertainty?	Does it describe how each treatment works?	Does it describe the benefits of each treatment?	Does it describe the risks of each treatment?	Does it describe what would happen if no treatment was used?	Does it describe how treatment choices affect overall quality of life?	Is it clear that there may be more than one possible treatment choice?	Does it provide support for shared decision making?	Based on the answers to all of the questions, rate the overall quality of the publication as a source of info about treatment choices?
	A: consumer information single option; B: consumer information multiple options C: option grid D: patient decision aid	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)	(1-5)
46	B	2	N/A -3	4	1	5	2	3	5	3	4	2	3	3	5	3	3
47	B	2	N/A -3	3	1	5	2	3	3	2	3	2	2	2	4	2	2
48	B	1	N/A -3	4	1	5	2	5	4	3	5	1	2	2	5	2	3
49	B	3	N/A -4	5	2	5	2	3	5	5	3	5	5	3	5	4	4 (both)
50	B	5	5	5	5	5	5	2	5	5	5	5	5	5	5	4	5

Each DISCERN question is rated on a 5-point scale ranging from no to yes. The rating scale is designed to help identify whether the quality criterion in question is present or has been met by the publication. General guidelines are as follows:

- 5 should be given if the answer to the question is a definite 'yes' - the quality criterion has been completely fulfilled
- Partially (2-4) should be given if it is felt the publication being considered meets the criterion in question to some extent. How high or low the 'partial' rating is will depend on judgements about the extent of these shortcomings
- 1 should be given if the answer to the question is a definite 'no' - the quality criterion has not been fulfilled at all.

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