AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTH CARE

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Consumer information on heavy menstrual bleeding

An environmental scan

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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 rates of hysterectomy and endometrial ablation across Australia. It was proposed that one of the contributing factors to this variation may have been consumers' understanding of the treatment options for heavy menstrual bleeding, and that this understanding may have been influenced by the type and quality of consumer information resources available.

In 2017 the Commission published the *Heavy Menstrual Bleeding Clinical Care Standard* to support the delivery of appropriate evidence-based clinical care, and promote shared decision making between patients, carers and clinicians.

The Commission has also undertaken an environmental scan to identify consumer information resources on heavy menstrual bleeding. This report describes this work including data on variation in hysterectomy and endometrial ablation 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 June 2018. Details of the resources were accurate at that time but may have changed in the intervening period.

Hysterectomy and endometrial ablation in Australia

Heavy menstrual bleeding is a common problem affecting 25% of women of reproductive age. ¹ It has been defined as 'excessive menstrual blood loss that interferes with the woman's physical, emotional, social and material quality of life. It can occur alone or in combination with other symptoms'. ²

Periods are a very personal experience and women who have always had heavy periods will often consider this is normal. Symptoms such as flooding through clothing, being unable to leave the house on the heaviest days and having to change pads and tampons frequently (including at night) are indicative of heavy menstrual bleeding.³

Despite being a common presentation, the causes of heavy menstrual bleeding are diverse and some women have more than one cause. Terms such as 'dysfunctional uterine bleeding' and 'menorrhagia' are no longer recommended. Instead, abnormal uterine bleeding is described by its presentation (flow, frequency and timing), and categorised into structural and non-structural causes.^{4, 5} Heavy menstrual bleeding is the most common presentation of abnormal uterine bleeding in pre-menopausal women.

There are a range of treatments available for heavy menstrual bleeding including nonsurgical and surgical options. Hysterectomy and endometrial ablation are surgical procedures used to treat heavy menstrual bleeding and are usually not recommended for first-line management unless less invasive options are inappropriate or unsatisfactory.

Hysterectomy

Hysterectomy is an operation in which the uterus (womb) is removed. In some cases, the ovaries and/or fallopian tubes are also removed. Common indications for hysterectomy include heavy menstrual bleeding, fibroids and uterine prolapse. Less common indications include chronic pelvic pain, severe endometriosis, endometrial hyperplasia and endometrial cancer. A hysterectomy can be undertaken through abdominal, vaginal or laparoscopic surgery.⁷

Endometrial ablation

Endometrial ablation is a surgical procedure to permanently remove the lining of the uterus, commonly via electrical or thermal (heat) ablation. It is used to treat abnormally heavy menstrual bleeding (menorrhagia), which is commonly caused by hormonal disorders (frequently termed dysfunctional uterine bleeding). Endometrial ablation is less suitable if the bleeding is caused by larger uterine fibroids. Endometrial ablation may be performed where non-surgical treatments, for example, hormonal medications, non-steroidal anti-inflammatory medications or hormone-releasing intrauterine devices have not been effective.⁷

Atlas data on hysterectomy and endometrial ablation

The first Atlas reported on variation in hospital admissions for hysterectomy and endometrial ablation for women 40 years and over. The Atlas reported that in 2012-13:

- There were 34,181 hysterectomy and endometrial ablation admissions to hospital, representing 297 admissions per 100,000 women
- The number of hysterectomy and endometrial ablation admissions to hospital across 315 local areas (SA3s) ranged from 131 to 687 per 100,000 women. The number of

- admissions was 5.2 times higher in the area with the highest rate compared to the area with the lowest rate
- The average number of admissions varied across states and territories, from 225 per 100,000 women in the Northern Territory, to 349 in Western Australia
- After excluding the highest and lowest results, the hysterectomy and endometrial ablation hospital admission rate across the 296 remaining local areas was 3.3 times higher in one local area compared to another
- Admission rates for endometrial ablation or hysterectomy were markedly higher in inner and outer regional areas than in major cities or in remote areas
- There was no clear link between rates and socioeconomic status.

Some reasons proposed for this variation include:

- The criteria used by doctors when deciding what treatment to recommend
- Use of the hormone-releasing intrauterine device by general practitioners and specialists
- Decision-making criteria of clinicians and patients in assessing the need for hysterectomy and endometrial ablation
- Availability of specialists, who may regard travel to very remote areas as a significant barrier.⁷

The first Atlas made suggestions about where to focus efforts to identify and address unwarranted variation in rates of hysterectomy and endometrial ablation. One of the recommendations was that the Commission 'develops a patient decision support tool to increase women's knowledge of treatment options for menorrhagia and their benefits and risks'. This environmental scan reports on the review of existing decision support tools to identify if additional guidance for women needs to be developed.

Heavy Menstrual Bleeding Clinical Care Standard

The Commission developed the *Heavy Menstrual Bleeding Clinical Care Standard* to support:

- Consumers to have a better understanding of what care should be offered and to be better able to make informed treatment decisions in partnership with their clinician
- Clinicians to be better able to make decisions about appropriate care
- Health services to be better able to examine the performance of their organisation and make improvements in the care they provide.

The *Heavy Menstrual Bleeding Clinical Care Standard* identifies a range of treatment options for heavy menstrual bleeding including pharmaceuticals, intra-uterine hormonal devices, uterine-preserving alternatives to hysterectomy such as endometrial ablation, and hysterectomy³ (see <u>Figure 1</u>).

Figure 1: Heavy Menstrual Bleeding Clinical Care Standard Quality Statements³



1 Assessment and diagnosis. The initial assessment of a woman presenting with heavy menstrual bleeding includes a detailed medical history, assessment of impact on quality of life, a physical examination, and exclusion of pregnancy, iron deficiency and anaemia. Further investigations are based on the initial assessment.



2 Informed choice and shared decision making. A woman with heavy menstrual bleeding is provided with consumer-focused information about her treatment options and their potential benefits and risks. She is asked about her preferences in order to support shared decision making for her clinical situation.



3 Initial treatment is pharmaceutical. A woman with heavy menstrual bleeding is offered pharmaceutical treatment, taking into account evidence-based guidelines, her individual needs and any associated symptoms. Initial treatment is provided to a woman who is undergoing further investigations to exclude malignancy and significant pathology.



Quality ultrasound. A woman having an ultrasound to investigate the cause of her heavy menstrual bleeding has a pelvic (preferably transvaginal) ultrasound, which assesses endometrial thickness and uterine morphology in days 5–10 of her menstrual cycle.



5 Intra-uterine hormonal devices. When pharmaceutical treatment is being considered, the woman is offered the levonorgestrel intra-uterine system if clinically appropriate, as it is the most effective medical option for managing heavy menstrual bleeding.



Specialist referral. A woman with heavy menstrual bleeding is referred for early specialist review when there is a suspicion of malignancy or other significant pathology based on clinical assessment or ultrasound. Referral is also arranged for a woman who has not responded after six months of medical treatment.



Uterine-preserving alternatives to hysterectomy. A woman who has heavy menstrual bleeding of benign causes and who is considering surgical management is offered a uterine-preserving procedure, if clinically appropriate. The woman receives information about procedures that may be suitable (such as endometrial ablation or removal of local pathology) and is referred appropriately.



B Hysterectomy. Hysterectomy for management of heavy menstrual bleeding is discussed when other treatment options are ineffective or are unsuitable, or at the woman's request. A woman considering a hysterectomy is given balanced information about the risks and benefits of the procedure before making a decision.

A Heavy Menstrual Bleeding Clinical Care Standard Consumer Fact Sheet has also been published explaining the different options to manage heavy menstrual bleeding and the care women should be offered if they have the condition. Women can use this information to help them make informed decisions in partnership with their clinician.⁸

Review of consumer information on heavy menstrual bleeding

Providing understandable and accessible health information can improve people's knowledge, understanding and recall about their health and care. 9-11 High-quality health information enables shared decision making, supports informed choice about treatment options and can contribute to health literacy so that consumers can be active partners in their own care. 11-13

For women with heavy menstrual bleeding, the availability of high-quality information about treatment options including their risks, benefits and likely outcomes is integral to support informed decision making about management.

The following sections describe how the Commission identified, reviewed and assessed consumer information on heavy menstrual bleeding.

Methodology

Several complementary strategies were used to identify consumer information about heavy menstrual bleeding for this review. The review focused on consumer information about heavy menstrual bleeding from Australian sources, supplemented by targeted exploration of resources from key leading international organisations.

An internet search using the search engine Google and internet browser Chrome was conducted between April and May 2018. Separate searches were performed with results limited to the first 10 websites identified (excluding advertisements, map results and Commission publications), for each of the terms:

- Patient information heavy menstrual bleeding au
- Patient information menorrhagia au
- Consumer information heavy menstrual bleeding au
- Consumer information menorrhagia au
- Question heavy menstrual bleeding au
- Question menorrhagia au
- Decision heavy menstrual bleeding au
- Decision menorrhagia au
- Options heavy menstrual bleeding au
- · Options menorrhagia au

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

- Royal Australasian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG)
- The Australian Women's Health Nurse Association Inc (AWHNA)
- National Association of Specialist Obstetricians and Gynaecologists (NASOG)
- The Royal Australasian College of Surgeons (RACS)
- Australian College of Nursing (ACN)
- Sexual Health and Family Planning ACT
- Family Planning NSW
- Family Planning NT
- True Relationships & Reproductive Health (QLD)

- Shine SA
- Family Planning Tasmania
- Family Planning Victoria
- Sexual Health Quarters (WA)
- Jean Hailes for Women's Health
- Australian Women's Health Network
- Women's Health and Research Institute Australia

Searches for consumer information on heavy menstrual bleeding were also performed through Australian organisations that link to multilingual and Indigenous resources. These organisations were:

- Health Translations
- Australian Indigenous Health InfoNet

Specific searches were also conducted for consumer information on heavy menstrual bleeding from the homepages of a range of key international organisations. These organisations were:

- Wikipedia (International)
- The King's Fund (England)
- Patient Voices (England)
- 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)
- Royal College of Obstetricians and Gynaecologists (England)

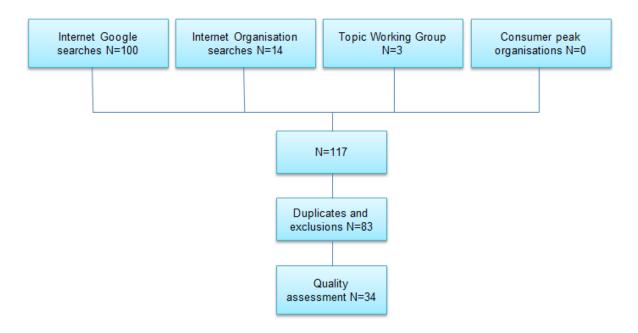
The Commission also asked nominees to the Heavy Menstrual Bleeding Topic Working Group to identify and submit any consumer information resources on heavy menstrual bleeding which they knew were being used by health professionals or professional colleges. The national and state and territory peak consumer 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 34 discrete consumer information resources on heavy menstrual bleeding for further quality assessment which are included in <u>Appendix 1</u>.

<u>Figure 2</u> illustrates the number of resources identified from each search strategy, together with exclusions and the final items retained for further quality assessment.

Figure 2: Search result refinement process



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

- How it was identified
- Title of information
- Type of resource (consumer information about a single option, consumer information about multiple options, option grid, patient decision aid)
- Format (web-based, printable, audio-visual)
- Length
- Author
- URL
- Source type and country (e.g. government, hospital, day procedure service, 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 heavy menstrual bleeding identified through the review.

The DISCERN instrument was the first standardised index for assessing the quality of consumer health information.¹⁴ It was developed as a validated tool to help users of consumer health information judge the quality of written information about treatment choices.¹⁵⁻¹⁷ 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.^{17, 18}

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.

<u>Appendix 2</u> includes a list of DISCERN questions, and the following sections describe how the 34 consumer resources on heavy menstrual bleeding performed against the assessment.

Question 1: Are the aims clear?

Few of the resources explicitly stated what the information was about, what it would cover or who might find it useful. Such introductory content is important to orientate readers and allow them to make a judgement about whether the resource is relevant for them and their circumstances. ¹⁸ 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. Among the seven resources judged to be of higher quality, four rated highly (rating of 4 or 5) for this item (Resources no. 15, 23, 26, 27).

Question 2: Does it achieve its aims?

Given few resources explicitly stated their aims it was difficult to identify whether 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 to highly (rating of 3, 4 or 5) for this item. Of the seven resources judged to be of higher quality, all were rated highly (rating of 4 or 5) for this item (Resources no. 1, 2, 9, 15, 23, 26, 27).

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. For women with heavy menstrual bleeding, 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 for this item (rating of 3, 4 or 5), indicating that this is a strength of the consumer information on heavy menstrual bleeding currently available. Of the six resources judged to be of higher quality, all were rated highly (rating of 4 or 5) for this item (Resources no. 1, 2, 9, 15, 23, 26, 27).

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. This was true for the resources produced by individual health service organisations and the majority of those authored by professional bodies, condition-specific organisations and government agencies. The absence of references and other ways for consumers to check evidence sources is a limitation of the consumer information on heavy menstrual bleeding currently available.

Of the seven resources judged to be of higher quality four were rated highly (rating of 4 or 5) for this item (Resources no. 9, 15, 23, 27).

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.¹⁸ Due to

the low levels of referencing and evidence source identification across all of the resources, dates for the information used to compile the publications were also lacking. For a minority there was no information provided, inferred or otherwise, by which a consumer could judge when a resource had been published.

Of the seven resources judged to be of higher quality five were rated highly (rating of 4 or 5) for this item (Resources no. 2, 9, 15, 26, 27).

Question 6: Is it balanced and unbiased?

This assessment criterion required a consideration of whether the resource was written from a personal or objective point of view, if there was evidence that a range of sources were used to compile it, and if any external assessment of the publication had occurred. While very few resources presented information about heavy menstrual bleeding in an emotive or alarmist way, the substantial majority were not rated highly for this item as the source of their statements were 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 seven resources judged to be of higher quality, five were rated highly (rating of 4 or 5) for this item (Resources no. 9, 15, 23, 26, 27).

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. Including these details in publications assists consumers to find any additional information they need to make decisions about treatment and care. For consumers with heavy menstrual bleeding this could include referral to leading women's health organisations such as Jean Hailes for Women's Health and links to professional bodies such as the Royal Australasian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG).

Of the 34 resources reviewed, 11 included this kind of information to guide consumers, indicating an opportunity for further improvement. This was also reflected in the seven resources judged to be of higher quality, with only two rating highly (rating of 4 and 5) for this item (Resources no. 9, 15).

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. For women with heavy menstrual bleeding this is of particular importance as there are a large number of treatment options and navigating them can be challenging.

Only four of the 34 resources reviewed referred to areas of uncertainty in a comprehensive way, showing room for increased attention to be paid to this element of high-quality consumer information. Of the seven resources judged to be of higher quality, three were rated highly (rating of 4 or 5) for this item (Resources no. 9, 23, 27).

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. For women with heavy menstrual bleeding this includes information about how medicines work to reduce bleeding, how the intra-uterine hormonal is inserted and how it functions as well how surgical procedures such as endometrial ablation and hysterectomy are performed, and their effects on the body. 3, 19

A substantial proportion of reviewed resources performed well on this item, with 14 of the 34 publications rated highly (rating of 4 or 5). All of the seven 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 heavy menstrual bleeding (Resources no. 1, 2, 9, 15, 23, 26, 27).

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.¹⁸ For women with heavy menstrual this comprises information about how bleeding will be affected by treatment, how long the treatment will last, whether it is reversible and if there may be a need for future treatment. ^{3, 19}

There is a strong evidence base describing the benefits of different treatment options for heavy menstrual bleeding ^{3, 19} and the majority of the resources reviewed described these benefits to some extent (rating of 3, 4 or 5). Of the seven resources judged to be of higher quality, six achieved ratings of 4 or 5 for this item (Resources no. 1, 9, 15, 23, 26, 27)

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. For women with heavy menstrual bleeding, understanding the risks of different options is important for decisions about why and when to choose particular treatments.

There was substantial variation in the extent to which the resources reviewed identified risks associated with different treatment options for heavy menstrual bleeding, as well as in the level of detail they provided about their frequency, severity and reversibility. This variability indicates another opportunity for quality improvement across the range of consumer resources on heavy menstrual bleeding. However, of the seven resources assessed as higher quality, six rated highly for this item (rating of 4 or 5) (Resources no. 1, 9, 15, 23, 26, 27).

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.¹⁸

For women with heavy menstrual bleeding, information about what would happen if they elect not to have treatment can help them make informed choices about what health care

they receive and when. The potential consequences of heavy menstrual bleeding in terms of anaemia, impact on quality of life and financial cost are well understood ^{3, 6} however the majority of resources reviewed did not include a description of what would occur if it was left untreated. Only four of the seven resources identified to be of higher quality were rated highly for this item (rating of 4 or 5) (Resources no. 9, 23, 26, 27).

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.¹⁸

For women with heavy menstrual bleeding these include short-term factors such as the expected length of a procedure or the need for general anaesthetic or time in hospital. Some long-term considerations might include the impact on a woman's physical function, mental health, emotional well-being, safety, and overall quality of life.^{6, 19} Very 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 three of the seven achieving a high rating of 4 for this item (Resources no. 9, 26, 27).

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. For women with heavy menstrual bleeding, there are a range of treatment options available, which include non-surgical and surgical management.

The large majority of the resources reviewed here were consumer information about multiple treatment options. As expected, this type of consumer information, together with the patient decision aid, performed well against this item with 25 of the 34 resources achieving a rating of 4 or 5. Of the seven resources identified to be of higher quality, all received the highest rating of 5 and specified that there were multiple treatment options available (Resources no. 1, 2, 9, 15, 23, 26, 27).

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.¹⁸

For women with heavy menstrual bleeding, this could include issues such as treatment choices, risks and benefits, costs and outcomes. Only four of the 34 consumer resources reviewed provided good support for shared decision making. Of the seven resources identified to be of higher quality, three were rated highly (rating of 4 or 5) for this item (Resources no. 15, 26, 27). Providing support for consumers to share decisions about treatment choices is a gap in consumer information about heavy menstrual currently available in Australia.

Overall rating

All consumer resources have deficiencies and it is unlikely that any single publication will rate highly for all of the items. ¹⁸ Consumer information about heavy menstrual bleeding is no different, as the results of this review indicate.

While no single resource was rated highly across all of the criteria (rating of 4 or 5), seven resources were judged to be of higher quality. The individual ratings given for each of the 34 reviewed resources are included in <u>Appendix 2</u> and details of the seven higher quality resources are listed in <u>Table 1</u>.

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 what kind of consumer resources can support women understand their treatment options, together with the *Heavy Menstrual Bleeding Clinical Care Standard*.

Table 1: Highly rated consumer resources on heavy menstrual bleeding

Resource No.	Overall DISCERN rating	Title	Туре	Format	Author	Source Type and country	Year Published
1	4	Heavy periods	Consumer information about multiple options	Web- based	The Women's (The Royal Women's Hospital VIC Australia)	Australian specialist hospital	Unavailable
2	4	Heavy menstrual bleeding	Consumer information about multiple options	Printable	Royal Australasian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG)	Australian professional body	2018
9	4 Heavy periods menorrhagia		Consumer information about multiple options	Web- based Printable Audio- visual content	Patient	Independent health platform in the United Kingdom	2018
15	4	You don't have to live with heavy periods	Consumer information about multiple options	Web- based Printable Audio- visual content	Hologic (Novasure)	Medical device manufacturer in Australia	2018
23	4	Choosing the right treatment for you	Consumer information about multiple treatment options	Printable	Hologic (Novasure)	Medical device manufacturer in Australia	Unavailable
26	4	Abnormal Uterine Bleeding: Should I Have a Hysterectomy?	Patient decision aid	Web- based Printable	Healthwise	Not-for-profit provider of health information in the United States	2017
27	5	Shared Decision Making – heavy menstrual bleeding (menorrhagia)	Consumer information about multiple treatment options	Printable	NHS Rightcare	National health service in the United Kingdom	2017

Conclusion

For women with heavy menstrual bleeding, accessing high-quality information about management options can influence their 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. It may also help to reduce unwarranted variation in the treatment of some conditions.

There is a large amount of information available to consumers about heavy menstrual bleeding in Australia, however this information varies substantially in terms of its quality. This review suggests that the majority of consumer resources on heavy menstrual bleeding have been developed with the aim of meeting the local needs of individual health service organisations, or professions, and may not be considered high-quality.

Reviewing consumer health information resources on heavy menstrual bleeding has identified a number of opportunities to improve quality within individual resources 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 seven higher-quality resources that provide comprehensive information about treatment options for heavy menstrual bleeding including the risks and benefits of non-surgical and surgical options. Although none of these seven resources meet all criteria to the highest rating, overall they provide a reasonable basis to inform women about their options for managing heavy menstrual bleeding.

Consequently, rather that developing a new resource the Commission can best support women's need to access to high-quality information about heavy menstrual bleeding by directing them to the higher-quality resources that have been identified through this review.

Appendix 1

Consumer information resources on heavy menstrual bleeding

Resource No.	Title	Search strategy	Туре	Format	Length	Author and URL	Source type and country	Year published
1	Heavy periods	Google search 1: Patient information heavy menstrual bleeding au	В	Web	1 web page with linked content	The Women's (The Royal Women's Hospital VIC Australia) https://www.thewomen s.org.au/health-information/periods/heavy-periods	Public hospital VIC Australia	N/A
2	Heavy menstrual bleeding	Google search 1: Patient information heavy menstrual bleeding au	В	Printable	2 printable pages	RANZCOG PDF https://www.ranzcog.ed u.au/RANZCOG SITE/ media/RANZCOG- MEDIA/Women%27s% 20Health/Patient%20inf ormation/Heavy- menstrual-bleeding- bleeding- pamphlet.pdf?ext=.pdf or online https://www.ranzcog.ed u.au/Womens- Health/Patient- Information- Resources/Heavy- Menstrual-Bleeding	AU professional body	2018
3	Heavy bleeding	Google search 1: Patient information heavy menstrual bleeding au	В	Web	1 web page	Jean Hailes https://jeanhailes.org.a u/health-a- z/periods/heavy- bleeding	Australian non-profit women's health NGO	2017
4	Heavy periods	Google search 1: Patient information heavy menstrual bleeding au	A	Web	1 web page	Healthdirect https://www.healthdirec t.gov.au/heavy-periods	Australian gov. Australia	2017

Resource No.	Title	Search strategy	Туре	Format	Length	Author and URL	Source type and country	Year published
5	Menorrhagia (heavy periods)	Google search 1: Patient information heavy menstrual bleeding au	В	Web	1 web page	Dr Brett Marshall http://www.drbrettmars hall.com.au/conditions/ menorrhagia-heavy- periods	Specialist practise VIC Australia	2012 Website ©
6	Treatment for heavy periods	Google search 1: Patient information heavy menstrual bleeding au	A	Printable	4 printable pages	Hologic (NovaSure) http://www.wearwhitea gain.com.au/resources/ NovaSure-Patient- Brochure AU hi.pdf	Medical device manufacturer Australia	N/A
7	Menstruation - abnormal bleeding	Google search 1: Patient information heavy menstrual bleeding au	В	Printable	3 printable pages	Better Health Channel PDF https://www.betterhealt h.vic.gov.au/health/hea lthyliving/menstruation- abnormal- bleeding?viewAsPdf=tr ue or online https://www.betterhealt h.vic.gov.au/health/hea lthyliving/menstruation- abnormal-bleeding	VIC gov. Australia	2017
8	Heavy periods - menorrhagia	Google search 2: Patient information menorrhagia au	В	Printable	7 printable pages	Health NSW (WSLHD) & Women's and Newborn Health Westmead Hospital file://central.health/dfsu serenv/Users/User_06/ SBRONW/Downloads/ WSP%20492%20heav y%20periods%20- %20menorrhagia%20V 2.pdf	NSW gov. Australia	2016
9	Heavy periods - menorrhagia	Google search 2: Patient information menorrhagia au	В	Web, printable, audio- visual content	9 printable pages	Patient https://patient.info/healt h/periods-and-period- problems/heavy- periods-menorrhagia	UK Independent health platform	2018

Resource No.	Title	Search strategy	Туре	Format	Length	Author and URL	Source type and country	Year published
10	Menorrhagia	Google search 2: Patient information menorrhagia au	В	Web	1 web page	Dr Stas Vashevnik http://www.vashevnik.c om.au/patient- info/gynaecology/meno rrhagia/	Specialist practise WA Australia	N/A
11	Brand name: Mirena	Google search 3: Consumer information heavy menstrual bleeding au	A	Web	1 web page	Healthdirect https://www.healthdirec t.gov.au/medicines/bra nd/amt,519460110000 36109/mirena	Australian gov. Australia	N/A
12	MIRENA® Consumer Medicine Information	Google search 4: Consumer information menorrhagia au	A	Printable	6 printable pages	Bayer http://www.bayerresour ces.com.au/resources/ uploads/cmi/file9398.p df	Medicine manufacturer Australia	2017
13	Period Problems	Google search 4: Consumer information menorrhagia au	В	Printable	4 printable pages	Pharmaceutical Society of Australia http://www.hardingspha rmacy.com.au/wp-content/uploads/2016/0 8/PeriodProblems-web.pdf	AU professional body	2011
14	MIRENA® Consumer Medicine Information	Google search 4: Consumer information menorrhagia au	А	Web	1 web page	Bayer http://www.mydr.com.a u/medicines/cmis/miren a-intrauterine-device	Medicine manufacturer Australia	2017
15	You don't have to live with heavy periods	Google search 5: Question heavy menstrual bleeding au	В	Web, printable, audio- visual content	9 linked web pages; audiovisual contient; PDF treatment comparison chart	Hologic (Novasure) http://www.wearwhitea gain.com.au/	Medical device manufacturer Australia	2018 Website ©
16	A Guide to Heavy Periods (Menorrhagia)	Google search 6: Question menorrhagia au	В	Web	1 web page	Dr Bevan Brown http://drbevanbrown.co m.au/a-guide-to-heavy- periods-menorrhagia/	Specialist practise NSW Australia	2018 Website ©

Resource No.	Title	Search strategy	Туре	Format	Length	Author and URL	Source type and country	Year published
17	Dealing With Heavy Periods (Menorrhagia)	Google search 6: Question menorrhagia au	В	Web	1 web page	Eve Health http://evehealth.com.au /2016/08/09/dealing- with-heavy-periods- menorrhagia/	Specialist practise QLD Australia	2016
18	Heavy Periods - Menorrhagia	Google search 7: Decision heavy menstrual bleeding au	В	Web	1 web page with links	Dr Sarah Choi http://www.drsarahchoi. com.au/menorrhagia.ht ml	Specialist practise NSW Australia	2014
19	Menorrhagia	Google search 8: Decision menorrhagia au	В	Web, printable	1 web page	Dr Philip Thomas http://philipthomas.com .au/menorrhagia/	Specialist practise VIC Australia	2011
20	Treating Menstrual Disorders and Menorrhagia	Google search 10: Options menorrhagia au	В	Web	1 web page	Dr Gopalan Poovalingam http://www.doctorg.com .au/treating-menstrual- disorders-menorrhagia/	Specialist practise VIC Australia	2016 Website ©
21	Menorrhagia	Google search 10: Options menorrhagia au	В	Web	1 page	Dr Gopalan Poovalingam http://www.doctorg.com _au/menorrhagia/	Specialist practise VIC Australia	2016 Website ©
22	Menstruation	Google search 10: Options menorrhagia au	A	Web	1 web page	QLD Health https://www.qld.gov.au/ health/staying- healthy/men- women/women/menstr uation	QLD gov. Australia	2017
23	Choosing the Right Treatment for You	Google search 10: Options menorrhagia au	В	Printable	1 printable page	Hologic (Novasure) http://www.wearwhitea gain.com.au/resources/ Comparison-Table.pdf (need to copy and paste link into internet browser)	Medical device manufacturer Australia	N/A
24	Menorrhagia	Wikipedia	В	Web	1 web page	Wikipedia https://en.wikipedia.org /wiki/Menorrhagia	Web-based, openly editable encyclopedia	2018

Resource No.	Title	Search strategy	Туре	Format	Length	Author and URL	Source type and country	Year published
25	Heavy periods - Treatment	NHS	В	Web	3 linked web pages	NHS Choices https://www.nhs.uk/con ditions/heavy-periods/	UK national health service	2016
26	Abnormal Uterine Bleeding: Should I Have a Hysterectomy?	NHS	A	Web, printable	6 linked pages	Healthwise https://www.healthwise. net/cochranedecisionai d/Content/StdDocumen t.aspx?DOCHWID=aa1 17176	US not-for-profit provider of health information, decision support tools, behaviour change assistance etc.	2017
27	Shared Decision Making – heavy menstrual bleeding (menorrhagia)	NHS	В	printable	10 printable pages	NHS Rightcare http://www.valeofyorkc cg.nhs.uk/rss/data/uplo ads/shared-decision- making/sdm-heavy- menstural-bleeding- menorrhagia.pdf	UK national health service	2017
28	Heavy menstrual bleeding: the care you should expect	NICE	A	Web	1 web page	NICE https://www.nice.org.uk /guidance/ng88/Inform ationForPublic	UK national health guidance and quality organisation	2018
29	Heavy periods (Menorrhagia)	NASOG	В	Web, printable	1 web and printable page	NASOG http://www.nasog.org.a u/women/gynaecology/ general/heavy-periods/	AU professional body	2016 Website ©
30	Menstrual problems	True relationships and reproductive health	A	Web	1 web page	True relationships and reproductive health http://www.true.org.au/Health-information/Menstruation/menstrual-problems	QLD gov. not-for-profit Australia	2015 Website ©
31	Menstrual Cycle	Family Planning Victoria	В	Web	1 web page	Family Planning VIC https://www.fpv.org.au/f or-you/reproductive- and-sexual- health/menstrual-cycle	VIC gov. not-for-profit Australia	2016
32	Heavy Bleeding - Webinar	Jean Hailes for Women's Health	В	Audio- visual	12 minutes	Jean Hailes for Women's Health https://player.vimeo.co m/video/136174315?au toplay=1	Not-for-profit organisation Australia	N/A

Resource No.	Title	Search strategy	Туре	Format	Length	Author and URL	Source type and country	Year published
33	Heavy Periods	Women's Health & Research Institute of Australia	В	Web	1 web page	Women's Health & Research Institute of Australia http://www.whria.com.au/for-patients/gynaecology/heavy-periods/	Specialist practise NSW Australia	2014 Website ©
34	Yarning about periods	Jean Hailes for Women's Health	A	printable	4 printable pages	Jean Hailes https://jeanhailes.org.a u/contents/documents/ Resources/Fact_sheet s/Yarning_about_perio ds.pdf	Not-for-profit organisation Australia	N/A

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 A: consumer information single option; B: consumer information multiple options C: option grid D: patient decision aid	Are the aims clear?	Does it achieve its aims? (1-5)	Is it relevant? (1-5)	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? (1-5)	Does it provide details of additional sources of support or info?	Does it refer to areas of uncertainty? (1-5)	Does it describe how each treatment works?	Does it describe the benefits of each treatment? (1-5)	Does it describe the risks of each treatment? (1-5)	Does it describe what would happen if no treatment was used? (1-5)	Does it describe how treatment choices affect overall quality of life? (1-5)	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? (1-5)
1	В	3	4	4	1	1	3	2	3	5	5	5	3	2	5	3	4
2	В	3	4	5	1	5	3	3	2	4	3	3	3	3	5	3	4
3	В	5	5	4	4	5	5	3	3	3	2	2	3	3	5	2	3
4	А	2	2	2	3	5	4	4	2	1	1	1	2	1	1	1	2
5	В	2	2	3	1	2	2	2	2	1	1	1	2	2	5	1	2

No.	Type of resource A: consumer information single option; B: consumer information multiple options C: option grid D: patient decision aid	Are the aims clear?	Does it achieve its aims? (1-5)	Is it relevant? (1-5)	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? (1-5)	Does it provide details of additional sources of support or info?	Does it refer to areas of uncertainty? (1-5)	Does it describe how each treatment works? (1-5)	Does it describe the benefits of each treatment? (1-5)	Does it describe the risks of each treatment?	Does it describe what would happen if no treatment was used? (1-5)	Does it describe how treatment choices affect overall quality of life? (1-5)	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? (1-5)
6	А	2	2	2	4	3	2	2	2	2	3	2	2	2	2	1	2
7	В	2	3	3	1	4	3	5	3	2	2	2	2	1	5	2	2
8	В	2	4	5	1	5	4	2	4	5	5	5	2	3	5	2	3
9	В	2	4	5	4	5	5	4	5	5	5	4	4	4	5	3	4
10	В	2	3	3	1	1	3	1	3	2	2	2	2	2	5	1	2
11	А	2	2	2	2	1	3	5	2	3	3	2	1	1	1	1	2
12	А	4	5	4	2	5	4	3	3	5	5	5	1	2	1	1	3
13	В	2	3	3	1	5	3	5	2	2	2	2	2	2	3	1	2
14	А	4	5	4	2	5	4	3	3	5	5	5	1	2	1	1	3
15	В	4	5	5	5	4	4	4	3	5	5	5	2	2	5	4	4

No.	Type of resource A: consumer information single option; B: consumer information multiple options C: option grid D: patient decision aid	Are the aims clear?	Does it achieve its aims? (1-5)	Is it relevant? (1-5)	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? (1-5)	Does it provide details of additional sources of support or info?	Does it refer to areas of uncertainty? (1-5)	Does it describe how each treatment works? (1-5)	Does it describe the benefits of each treatment? (1-5)	Does it describe the risks of each treatment?	Does it describe what would happen if no treatment was used? (1-5)	Does it describe how treatment choices affect overall quality of life? (1-5)	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? (1-5)
16	В	4	4	3	1	3	3	2	3	3	3	1	1	2	5	2	3
17	В	2	3	3	1	5	3	2	2	3	3	2	2	2	5	2	3
18	В	2	3	4	1	3	3	1	2	4	3	1	1	2	5	2	2
19	В	2	3	3	1	1	3	1	2	4	3	3	1	2	5	2	2
20	В	2	3	3	1	3	3	1	1	3	2	2	2	1	5	2	2
21	В	2	3	3	1	3	3	1	1	3	2	2	2	2	5	2	2
22	А	2	2	2	1	5	3	4	2	2	1	1	2	1	1	1	2
23	В	4	5	5	5	3	4	2	4	5	5	5	1	3	5	2	4
24	В	2	3	4	5	5	4	4	3	3	2	2	3	2	5	2	3
25	В	4	4	4	1	5	4	2	2	4	5	4	4	3	5	2	3

No.	Type of resource A: consumer information single option; B: consumer information multiple options C: option grid D: patient decision aid	Are the aims clear?	Does it achieve its aims? (1-5)	Is it relevant? (1-5)	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? (1-5)	Does it provide details of additional sources of support or info?	Does it refer to areas of uncertainty? (1-5)	Does it describe how each treatment works? (1-5)	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? (1-5)	Does it describe how treatment choices affect overall quality of life? (1-5)	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? (1-5)
26	В	5	5	5	2	5	4	2	3	5	5	5	5	4	5	5	4
27	В	5	5	5	5	5	5	2	4	5	5	5	5	4	5	5	5
28	В	2	2	3	2	5	4	5	3	1	1	1	1	1	4	4	2
29	В	2	3	3	2	3	4	2	2	3	2	2	1	2	5	2	3
30	В	2	2	2	1	3	3	3	3	1	1	1	1	2	1	1	2
31	В	2	2	2	2	5	4	4	2	1	1	1	3	1	4	1	2
32	В	2	3	3	1	1	4	2	3	3	3	2	2	2	5	3	3
33	В	2	3	4	1	3	3	5	3	4	4	3	2	3	5	2	3
34	В	2	3	3	1	1	3	2	2	1	1	1	3	1	1	1	2

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 depends 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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