Royal College of Obstetricians & Gynaecologists

National Heavy Menstrual Bleeding Audit

Final report

July 2014

A national audit to assess patient outcomes and experiences of care for women with heavy menstrual bleeding in England and Wales

Commissioned by:

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

Ipsos MORI

HQIP
Healthcare Quality Improvement Partnership

Royal College of Obstetricians & Gynaecologists

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First published 2014

Published by the Royal College of Obstetricians and Gynaecologists, 27 Sussex Place, Regent's Park, London NW1 4RG

www.rcog.org.uk

Registered charity no. 213280

Copy-edited and typeset by Andrew Welsh (www.andrew-welsh.com)

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Acknowledgements

The National Heavy Menstrual Bleeding (HMB) Audit was funded by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). The audit was led by the Royal College of Obstetricians and Gynaecologists.

The audit's project team would like to thank all NHS providers and staff members who provided information for the organisational audit and participated in the prospective audit. We would also like to thank all women who took the time to complete and return the initial and follow-up questionnaires. The National HMB Audit was only possible because of the dedication and commitment of NHS staff members and patients who contributed. We are very grateful for their support.

The project team would like to thank:

- members of the Clinical Reference Group (Chair, Angela Hyde) for overseeing the delivery of the audit and providing clinical guidance
- members of the Project Board (Chair, Robert Shaw) for providing project governance
- the Clinical Advisors to the project for their valuable input to the project implementation
- the Clinical Effectiveness Unit at the Royal College of Surgeons of England, particularly Lynn Copley, for support on data management and information governance.

A list of members of the Clinical Reference Group, the Project Board and the Clinical Advisors is provided in Appendix 1.

Sadly, Professor Donna Lamping, a member of the project team, died in June 2011. We would like to acknowledge Professor Lamping's rigorous contribution to the project and her input to the team.

The National HMB Audit's project team consisted of:

Royal College of Obstetricians and Gynaecologists

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- Jonathan Nicholls, Director of Health Research
- Danny Slater, Research Executive

Abbreviations

EA	endometrial ablation
GP	general practitioner
HES	Hospital Episode Statistics
HMB	heavy menstrual bleeding
HRQoL	health-related quality of life
HSCIC	Health and Social Care Information Centre
IQR	interquartile range
IMD	Index of Multiple Deprivation
LHB	local health board (Wales)
LNG-IUS	levonorgestrel-releasing intrauterine system
LSOA	Lower Super Output Area
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
ONS	Office for National Statistics
OR	odds ratio
PCT	primary care trust
PEDW	Patient Episode Database for Wales
RCOG	Royal College of Obstetricians and Gynaecologists
sd	standard deviation
SHA	strategic health authority
UAE	uterine artery embolisation

Glossary of terms

Adapted UFS-QoL

A disease-specific HRQoL instrument for women with HMB. It was adapted from the UFS-QoL and validated for women with HMB in the pilot study for this audit.

Clinical Reference Group

The National HMB Audit's Clinical Reference Group comprised representatives of the key stakeholders in HMB care. Members advised the project team on particular aspects of the project and provided input from the wider clinical and patient community.

Clinician

A healthcare professional providing patient care, such as a doctor or nurse.

Endometrial ablation (EA)

A medical procedure that is used to remove (ablate) or destroy the endometrial lining of a woman's uterus.

EQ-5D

A standardised instrument for use as a measure of health outcome. EQ-5D is applicable to a wide range of health conditions and treatments. It provides a simple descriptive profile and a single index value for health status.

Health-related quality of life (HRQoL)

A person's quality of life as it is affected by their health condition. There is no universal definition of HRQoL, but it is usually taken to mean a multidimensional construct including physical, psychological and social functioning, often including the ability to perform usual roles within each of these domains. General health perceptions and opportunity for health, pain, energy, independence, environment and spirituality are also sometimes included.

Heavy menstrual bleeding (HMB)

Excessive menstrual blood loss that interferes with a woman's physical, social, emotional and/or material quality of life. It can occur alone or in combination with other symptoms.

Hospital Episode Statistics (HES)

Hospital Episode Statistics is the national statistical data warehouse for England of the care provided by NHS hospitals and for NHS hospital patients treated elsewhere. HES is the data source for a wide range of healthcare analysis for the NHS and government and for many other organisations and individuals.

Hysterectomy

The surgical removal of the uterus.

Interquartile range (IQR)

The difference between the value of a variable below which lie 25% of the population, and that below which lie 75%; a measure of the spread of the distribution.

Intrauterine system (IUS)

Hormonal contraceptive inserted into the uterus.

Myomectomy

The surgical removal of fibroids from the uterus.

Parity

The number of times a woman has given birth to a baby.

Uterine Fibroid Symptom and Quality of Life (UFS-QoL) questionnaire

A uterine-fibroid-specific questionnaire developed to evaluate the symptoms of uterine fibroids and their impact on health-related quality of life.

Foreword

I am delighted to introduce the *Final Report* of the National Heavy Menstrual Bleeding (HMB) Audit. This important 4-year audit describes the provision of services for HMB in hospitals in England and Wales and patient-reported outcomes in an outpatient setting. HMB is a common condition that affects a quarter of women of reproductive age and impacts their physical, emotional, social and material quality of life.

In this *Final Report* we have seen some improvements, since the start of the audit (2010), in the management of HMB by organisational services. Half of all hospitals now have written protocols in place and have introduced new care pathways, with a higher proportion of women receiving treatment in primary care and reduced referral of women with HMB. This is key to ensuring that primary care and secondary care are working together efficiently so that local resources are used to their best potential.

At the provider level, there was notable variation in the treatment received by women in hospital, even after differences in baseline characteristics (case mix) was taken into account. While this was largely attributed to random fluctuations, hospitals should continue to compare themselves against their peers for the treatments they offer to women with HMB.

We also found differences in the treatment, outcomes and care received in hospital by women of differing ethnicity and socio-economic status. Overall, women from a white ethnic background and those from less deprived areas were more likely to have surgical treatment and experience a greater improvement of their condition in the year after their first outpatient clinic visit than their non-white and more deprived counterparts. This report highlights the need for further work to understand the access to care for non-white women and for women from more deprived areas, and it has provided a significant advance in our understanding of the treatment and care received by women in hospital for HMB and the impact on their quality of life.

Alan Cameron
Vice President (Clinical Quality), RCOG

Executive summary

Heavy menstrual bleeding (HMB) is a common condition that affects a quarter of women of a reproductive age.[1] It impacts women's physical, social, emotional and material quality of life[2] and is estimated to be the fourth most common reason for referral to gynaecological services.[3] Each year, 30 000 women undergo surgical treatment for HMB in England and Wales.

The National Institute for Health and Care Excellence (NICE) has issued clinical guidelines (2007)[2] and quality standards (2013)[4] for the management of women with HMB. The Royal College of Obstetricians and Gynaecologists (RCOG) included guidance on the management of women with HMB in their *Standards for Gynaecology* (2008).[5] However, information on how the NHS has responded to these guidelines is lacking.

The RCOG, in partnership with the London School of Hygiene & Tropical Medicine (LSHTM) and Ipsos MORI, have conducted the National HMB Audit to describe the management of HMB in hospitals in England and Wales, and the treatment, experience and care received by women referred to NHS outpatient clinics. The 4-year audit started in 2010 and had two principal components: an organisational audit of acute NHS trusts in England and NHS local health boards (LHBs) in Wales, and a prospective audit of patient-reported outcomes for women with HMB.

In this *Final Report*, organisational changes in the management of HMB are described and patient-reported outcomes are also examined in more detail by ethnicity and socio-economic status using linked Hospital Episode Statistics (HES) data and Patient Episode Database for Wales (PEDW) data. The generalisability and validity of patients as a source of information are also reviewed.

Repeat organisational survey

The organisational survey completed by hospitals in the first year of the audit was repeated in the fourth year of the audit. Over the 4 years, the organisation of clinical services for women with HMB has remained relatively stable. However, information and communication has been improved, with an increase in written protocols and more hospitals providing women with an information leaflet.

Over half of the hospitals indicated changes in the management of HMB in primary care, with the introduction of new care pathways and a higher proportion of women than before receiving treatment in primary care.

Over 85% of clinicians surveyed 'agreed' or 'strongly agreed' that patients, rather than clinicians, were an appropriate source of information for clinical audits of care aimed at improving a patient's quality of life.

Variation by provider in treatments, outcomes and experiences

There was substantial variation between hospitals in the treatment that women with HMB reported to have received in the year after their first outpatient clinic visit, even if differences in baseline characteristics (case mix) were taken into account. The differences between hospitals were substantial, with the percentage of women reporting surgical treatment varying from 20% to 60%. However, most of the variation between hospitals in the treatments that women reported is likely to be the result of random fluctuations.

Women, especially those who had had surgical treatment, reported large improvements of their symptoms and health-related quality of life (HRQoL) in the year after their first outpatient clinic visit. Women who reported that they had had surgical treatment reported on average better outcomes than those who reported other treatments. Adjustment for baseline characteristics increased the differences even further.

About 60% of the women reported that they were 'satisfied' or 'very satisfied' with the care they had received from the hospital, 60% felt 'definitely' involved in the decision making about their treatment, and 90% rated the care that they had received as 'good', 'very good' or 'excellent'.

The percentages varied considerably between hospitals but no hospitals were identified as potential outliers.

Description of the care received by women, by ethnicity and deprivation

The audit highlighted differences by ethnicity and deprivation in the treatment and care reported by women. Women from a non-white ethnic background were more likely to report no treatment and less likely to have had surgery than women from a white background. Women from a more deprived background were less likely to report surgical treatment and more likely to report no treatment than women from a less deprived background, but these differences were relatively small.

Women from a white ethnic background and those from less deprived areas experienced a greater improvement of their condition in the year after their first outpatient clinic visit than their non-white and more deprived counterparts. Women from non-white ethnic background were less positive than white women with respect to the information they had received and their involvement in the decision making about their treatment.

Validity and generalisability of the results

For the prospective audit, the overall case ascertainment rate was 25.3%,[3] which is likely to be an underestimate of the true rate. The baseline characteristics of women across providers with low, mid and high case ascertainment rates were similar, except for ethnicity and deprivation.

The response rate for questionnaires completed 1 year after the first visit to a gynaecology outpatient clinic was 55.6%.[6] Women of older age or white ethnicity were more likely to return the follow-up questionnaire, whereas women with more severe pain or in poorer health at the first outpatient clinic visit were less likely to do so.

Compared with the surgical treatment recorded in HES and PEDW, most women in the prospective audit accurately reported whether they had had a surgical procedure but they were less accurate about the type of procedure. Similarly, most women who had surgical treatment recorded in the case note reviews also reported a surgical procedure in the prospective audit.

Implications for service delivery

The vast majority of women with HMB rated the care received from hospitals in the year after their first outpatient clinic visit as 'good', 'very good' or 'excellent'. The majority of women experienced substantial improvement of their symptoms.

However, the National HMB Audit demonstrates that care can be further improved. The audit's findings are important because they allow an assessment of the extent to which the NICE guidelines[2] and quality standards[4] and the RCOG *Standards for Gynaecology*[5] are being followed in clinical practice.

Comparing the results of the audit with the recommendations in these documents, we conclude the following.

- The existing referral pathways between primary and secondary care should be reviewed, given that nearly one-third of women reported that they had not received any treatment for their HMB in primary care. This review should carefully explore the reason why some women do not receive treatment in primary care as, in a number of cases, immediate referral is an appropriate option, for example for women with extensive fibroids.

- Care provided to women of non-white ethnicity and those from more socio-economically deprived areas should be reviewed, as these women are less likely to have surgical treatment and they report smaller improvements of their conditions than white women and those from a less deprived background. A greater awareness of cultural differences and enhancing access to dedicated menstrual bleeding clinics may further improve how the individual needs of women are being met.
- For women with severe symptoms and a poor quality of life, surgical treatment (if appropriate) could be considered sooner as this audit found that it produced the greatest improvement.
- Information for patients should be further improved. About 10% of the hospitals reported that they do not provide written patient information about HMB and the treatment options that are available.
- Written protocols for the management of women with HMB should be more widely available as only about 50% of the hospitals reported having such a protocol in place.
- The organisation of gynaecology outpatient clinics may need to be reviewed given that only one-third of hospitals reported that they had a dedicated menstrual bleeding clinic (with about 90% of these being one-stop clinics).
- Hospitals should continue to compare themselves against their peers with regard to the treatments they offer to women with HMB, given the considerable variation that we observed across hospitals in treatments offered in secondary care. The results of each of the participating hospitals presented in Appendix 5 can be used for this purpose.

1 Introduction

1.1 Heavy menstrual bleeding – background and aims of the audit

Heavy menstrual bleeding (HMB) is a common condition that affects around a quarter of women of reproductive age[1] and can have a profound effect on a woman's 'physical, social, emotional and material quality of life' (National Institute for Health and Care Excellence (NICE) guideline).[2] Although it can be treated by various types of medication in primary care, these treatments are not always effective. Approximately 30 000 women in England and Wales undergo surgical treatment for HMB each year.

Clinical guidelines on the treatment of HMB were first published in 1995 and have been updated periodically. The latest guidelines were published by NICE in 2007[2] and the Royal College of Obstetricians and Gynaecologists (RCOG) published its *Standards for Gynaecology* in 2008[5] to support implementation of the above guideline. NICE has recently published quality standards to support commissioning.[4] However, information on how the NHS has responded to these guidelines is lacking.

The RCOG, in partnership with the London School of Hygiene & Tropical Medicine (LSHTM) and Ipsos MORI, has conducted the National HMB Audit. The audit was established in February 2010 with the overall aims of describing the care received by women with HMB referred to NHS outpatient clinics in England and Wales and assessing patient outcomes and experience of care.

Specific audit objectives were to investigate:

- the severity of menstrual problems experienced by women referred to NHS outpatient clinics
- the care received by women with HMB in the first year after their initial outpatient consultation, taking into account the severity of their symptoms and the effect these have on their overall health and quality of life
- the effects that treatments received in the first year after their outpatient clinic visit have had on women's health and quality of life.

The 4-year audit had two principal components:

- an organisational audit of acute NHS providers in England and Wales
- a prospective audit of patient-reported outcomes for women with HMB.

For the first component, the organisational audit, information was collected from hospitals to evaluate the organisation of hospital gynaecological services, current referral patterns and local protocols with reference to the management of HMB. The results of the organisational audit were published in the *First Annual Report*.[7]

For the second component, the prospective audit, women at their first outpatient gynaecology visit were asked to complete a baseline questionnaire on the severity of the their condition, the impact its symptoms had on their quality of life and the treatments they had received in primary care prior to referral to secondary care. Recruitment took place between 1 February 2011 and 31 January 2012. Results of this phase of the prospective audit were published in the *Second Annual Report*.[3]

Consenting women who had completed a baseline questionnaire were then sent a follow-up questionnaire 1 year after their first outpatient clinic visit. The follow-up questionnaire included questions on the treatments and care received since their first outpatient clinic visit as well as the same questions on their quality of life used in the baseline questionnaire. Results from the follow-up questionnaire were published in the *Third Annual Report*.[6]

In this *Final Report*, patient-reported information gathered using both the baseline and follow-up questionnaires has been linked to Hospital Episode Statistics (HES) and Patient Episode Database

for Wales (PEDW) data to give an additional dimension for reporting patient care and outcomes. Patient-reported outcomes have been further analysed to ascertain which treatment had the biggest effect on their overall quality of life. We were able to further investigate issues around inequitable access to care by various ethnic groups in the community in different regions of the country. Patient-reported data were assessed for validity and generalisability through a case note review exercise, and these data were also used to describe women's perception of a high-quality service for HMB.

A repeat of the organisational survey was also undertaken in order to report on changes in the management of HMB in secondary care since the start of the audit. These findings, together with the results of the previous annual reports, have been used to improve our understanding of how women with HMB are managed in secondary care, and to subsequently provide recommendations on how local commissioning can contribute to delivering a high-quality evidence-based service.

In Appendix 5 we report for each participating hospital trust the results of the repeat organisational audit, and outcomes reported by patients at their first gynaecological outpatient clinic visit and 1 year thereafter.

1.2 Summary of findings from the *First Annual Report*

The *First Annual Report*[7] described results of the organisational audit and the pattern of surgical treatment for women with HMB across England and Wales.

Questionnaires on organisational issues related to the availability of facilities, local treatment protocols and patterns of primary and secondary care were completed by all NHS providers in England and Wales with outpatient gynaecology departments. Eighty percent of hospitals reported having access to ultrasound, hysteroscopy and endometrial biopsy, 38% of hospitals had a dedicated menstrual bleeding clinic, and 30% of hospitals had a local written protocol regarding the care and management of women with HMB.

Patterns of surgical treatment for women with HMB in England were analysed using the HES database between April 2006 and December 2009. The age-standardised annual rate of surgery for HMB was 152 procedures/100 000 women. This varied by strategic health authority (SHA) region, ranging from 70 to 255 procedures/100 000 women.[3] Surgical rates also varied widely among primary care trusts (PCTs), ranging from 14 to 392/100 000 women. Similarly, using PEDW between April 2006 and March 2010,[8] surgical rates varied across the local health boards (LHBs) from 76 to 241 procedures/100 000 women. The rate of surgery had increased in recent years with more women opting for endometrial ablation (EA). However, the level of variation was similar to that observed previously.[9]

1.3 Summary of findings from the *Second Annual Report*

In the *Second Annual Report*,[3] we presented results from the prospective audit of patient-reported outcomes. Women who attended outpatient gynaecology clinics for the first time with HMB symptoms between 1 February 2011 and 31 January 2012 were asked the complete a questionnaire on the severity of menstrual problems experienced, and the care they had received prior to referral: 15 812 agreed to complete this questionnaire.

The average age of these women was 44 years and 88% were of white ethnicity. In addition to their HMB condition, almost half of the women had fibroids, endometriosis and/or uterine polyps. Three-quarters of women had had their HMB symptoms for more than 1 year and just over half of the women reported severe or very severe pain at their first outpatient clinic visit. When asked how they would feel if their symptoms persisted for the next 5 years, the majority of women (83%) said that they would feel 'unhappy' or 'terrible'.

Nearly one-third of women reported that they had received no treatment in primary care prior to referral. This proportion was higher among women of non-white ethnicity, those with HMB alone, and those who had had fewer GP visits.

Across NHS providers, there was little difference in the type of medical care that women had received in primary care, their clinical symptoms, or their quality of life scores. In summary, women who were referred to secondary care reported longer duration of symptoms and more severe pain. However, the wide variation in surgical practice seen in secondary care (as reported in the *First Annual Report*)[7] does not seem to be explained by referral practice from primary care.

1.4 Summary of findings from the *Third Annual Report*

The *Third Annual Report*[6] described the symptoms, treatments and experiences of women in secondary care, in the year following their first outpatient gynaecology visit. Women completed a 1-year follow-up questionnaire (between 1 February 2012 and 31 January 2013) which included reporting on the care received in secondary care.

Of the women who attended the initial (baseline) outpatient gynaecology clinic, 15 325 met the inclusion criteria for the follow-up study and 8517 (55.6%) completed a follow-up questionnaire. The responders had similar characteristics to the non-responders except for their average age (45 years versus 42 years) and ethnicity (90.8% white versus 85.2% white).

Over three-quarters of women received at least one treatment in secondary care in the year following their first outpatient gynaecology visit. Over one-third of women had surgical treatment as their last likely treatment and one-third of women had oral medication or had an intrauterine system (IUS) fitted. Three-quarters of women who completed the follow-up questionnaire reported fewer symptoms at follow-up than at their first outpatient clinic visit and over three-quarters had a meaningful improvement in their severity score. Almost three-quarters of women rated their overall level of care as ‘excellent’ or ‘very good’.

The treatment received by women in secondary care showed little variation at the provider level outside of expected values (control limits). In particular, women who had had a hysterectomy or EA showed little systematic difference at the provider level. The mean change in severity score and health-related quality of life (HRQoL) score also showed little variation by provider.

2 Repeat organisational audit

The first organisational audit was conducted in the first year of the audit (2010) to describe the arrangement of clinical services for women with HMB in the outpatient departments of NHS acute trusts in England and LHBs in Wales. The aim of the repeat organisational audit in 2013 was to investigate whether the organisation of services had changed.

All hospitals in England and Wales that provide secondary care through outpatient gynaecology departments were eligible to participate in both the baseline and the repeat organisational survey. Hospitals were approached through the Clinical Directors of obstetrics and gynaecology, who then nominated an appropriate person to complete the questionnaire. The organisational questionnaire was available in a web-based format.

Among 202 eligible hospitals, 197 returned the repeat organisational survey in 2013 (a response rate of 97.5%). Three of these units reported that they no longer provide gynaecological services, five had not participated in the audit and nine had not completed the baseline organisational survey in 2010. The changes in the practice patterns for the remaining 180 hospitals are presented below. All analyses used descriptive statistics to summarise the responses to the survey.

2.1 Current organisation of services

Local protocols

The RCOG *Standards for Gynaecology*[5] emphasises that 'every organisation should clearly set out specific requirements relating to the management of excessive menstrual blood loss which interferes with a woman's physical, social, emotional and material quality of life.' Particular standards for HMB include:

- care pathways for women with HMB who have abnormal histopathological results
- locally agreed referral pathways between primary and secondary care.

Given these standards, and the recommendations in the guidance from NICE,[2] responders were asked whether their hospital had a local, written protocol. Of the 180 units, 174 responded to this question in both surveys. Overall, 90 hospitals (51.7%) reported that they have a written local protocol on the management of women with HMB, as compared with 29.9% of units in the baseline organisational survey. In particular:

- 67 units (38.5%) did not report a written protocol in either survey
- 55 units (31.6%) had introduced an HMB protocol in the last 3 years
- 20 units (11.5%) who had said they had a protocol in the baseline survey did not have a protocol in 2013.

Available facilities

The RCOG *Standards for Gynaecology*[5] state that 'there should be a dedicated one-stop menstrual bleeding clinic with facilities within the clinic for diagnostic investigations, including hysteroscopy and ultrasound.'

Of the 180 hospitals, 177 responded to this question in both surveys. In 2010, there were 64 hospitals (36.2%) that reported having a dedicated menstrual bleeding clinic (Table 2.1). By 2013, 20 hospitals had ceased to provide a dedicated menstrual bleeding clinic and 20 hospitals had introduced this; 44 hospitals (24.9%) had a dedicated clinic in both years. In 2013, 57 hospitals described the clinic as a 'one-stop' clinic (a clinic that provides both diagnosis and treatment plan at the same appointment).

Hospitals reported what facilities were available within the department to investigate women with HMB (Table 2.1). The majority of hospitals had ultrasound, hysteroscopy and endometrial biopsy, and the overall availability of these facilities had increased since 2010. There was one facility whose availability had decreased: 158 (87.8%) hospitals reported in 2013 that they had available day care diagnosis, as compared with availability in 172 (95.6%) hospitals in the baseline survey.

Table 2.1 Available facilities within gynaecology departments

Facilities	Number of hospitals (%*)	
	2013	2010
Dedicated menstrual bleeding clinic	64 (36.2%)	64 (36.2%)
'One-stop' clinic (provides both diagnosis and treatment plan at the same appointment)	57/64 (89.1%)	53/64 (82.8%)
Ultrasound (transvaginal scanning in the clinic)	150 (83.3%)	143 (79.4%)
Hysteroscopy (outpatient-based)	169 (93.9%)	155 (86.1%)
Day care diagnosis (inpatient-based) hysteroscopy plus endometrial biopsy	158 (87.8%)	172 (95.6%)
Endometrial biopsy (outpatient-based)	179 (99.4%)	176 (97.8%)

*Percentages are calculated after removing non-responders.

Treatment and services in secondary care

Responders were asked what investigations are considered at the initial consultation in their clinic for women with HMB being referred for the first time. In general, the responses followed the national recommendations.[2] An abdominal and pelvic examination was considered 'mostly' or 'always' by almost all hospitals (Table 2.2), whereas an objective measure of blood loss was considered 'never' or 'rarely' in most hospitals. Over half of hospitals considered taking a full blood count 'mostly' or 'always'. Of those that did not (84), 59% (of the 82 that responded to this question) expected a full blood count to have been carried out in primary care. There were only minor changes in the investigations 'always' or 'mostly' considered since the baseline survey in 2010.

Table 2.2 Investigations at first consultation: number of hospitals

Investigations 'always' or 'mostly' considered	Number of hospitals (%*)	
	2013	2010
Objective method of measuring blood loss	35 (19.4%)	20 (11.2%)
Full blood count	95 (53.1%)	108 (60.3%)
Ultrasound and other imaging	136 (76.0%)	135 (75.0%)
Pathology	91 (50.8%)	95 (53.1%)
Abdominal and pelvic examination	177 (98.3%)	179 (99.4%)

*Percentages are calculated after removing non-responders.

Waiting time from primary to secondary care

Responders were asked about their department's average waiting time between referral from GP to first outpatient appointment for women with HMB. The median (and interquartile range (IQR)) waiting time was similar in both years, with 6 (4, 8) weeks in 2013 and 6 (4, 6) weeks in 2010.

Available surgical and management options

Almost all hospitals reported that abdominal and vaginal hysterectomy were available surgical options at their hospitals (98.9% and 96.1%, respectively, in 2013) (Figure 2.1). Laparoscopically assisted hysterectomy was available at 90.6% of hospitals. Almost all hospitals (96.7%) offered one

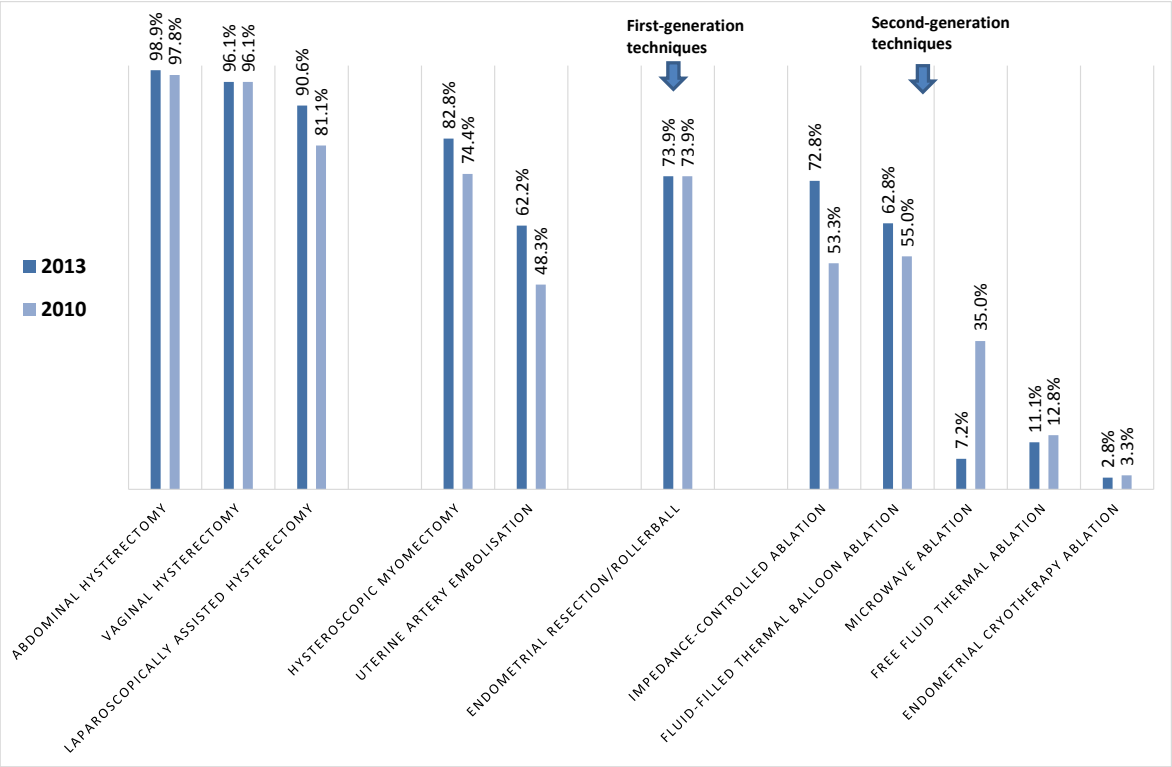


Figure 2.1 Available surgical options for women with HMB at NHS hospitals in England and Wales

or more second-generation ablation technique, increasing from 93.3% in 2010, in line with the recommendations in the NICE guidelines. Among these various techniques, impedance-controlled ablation was the most commonly available, followed by fluid-filled thermal balloon ablation. While both of the more common techniques became increasingly available, the availability of microwave ablation reduced from 35% of hospitals to 7% over the 3 years. Over 70% of hospitals still offered the first-generation rollerball ablation technique. The availability of myomectomy (82.8% in 2013 and 74.4% in 2010) and uterine artery embolisation (UAE) (62.2% in 2013 and 48.3% in 2010) were also included in the survey as these surgeries are sometimes performed in the treatment of fibroids.

Responders were asked to estimate the approximate percentage of women with HMB who had the following management options after their initial appointment in the gynaecology clinic:

- reassure and send back to GP
- offer medical treatment and send back to GP for follow-up
- insert a levonorgestrel-releasing intrauterine system (LNG-IUS)
- put on waiting list for EA
- put on waiting list for hysterectomy.

In general, the options against which hospitals reported the highest proportions were to insert an LNG-IUS (mean estimate 34.6%), to put women on a waiting list for EA (23.9%) and to offer medical treatment and send back to their GP (20.7%).

Information for patients

The RCOG standards[5] state that services should provide information leaflets to patients that include a description of each treatment option for HMB, together with outcomes and complications. The NICE guideline[2] similarly states that 'a woman with HMB referred to specialist care should be given information before her outpatient appointment.'

Of the responding hospitals, 84.4% provided an information leaflet, 10.6% referred patients to a website for information, and 12.2% did not provide written information (hospitals were able to tick multiple options). These proportions were 76.0%, 7.7% and 20.6%, respectively in 2010, indicating an improvement in the provision of written information to women with HMB in outpatient clinics.

2.2 Primary care services

The availability of referral systems for women with HMB did not significantly change since 2010, except for the introduction of a 'choose and book' system, which was reported by 122 (67.8%) of the 180 hospitals. Many hospitals reported referral routes other than from GPs, including accident and emergency departments (60.0%), other NHS professionals (57.8%), and other triage or PCT systems (24.4%). Only three hospitals (1.7%) reported that women could self-refer.

The RCOG standards[5] indicate that 'guidelines should be in place for direct referral to imaging services from primary care'. Almost all hospitals (98.9%) responded that GPs in their area could refer directly to imaging services. It was less common for GPs to be able to refer directly to pathology (43.3%) and other diagnostic procedures (21.0%). These referral patterns were very similar to the patterns in 2010. Over half of the hospitals (52.2%) reported that patients would 'always' or 'mostly' have had full blood count in primary care before being referred to hospitals, and about one-fifth reported that patients would 'always' or 'mostly' have had an ultrasound investigation. Hormonal assessment, liver function test and thyroid function test were less common investigations, which is consistent with NICE guidelines (which restricts the use of these investigations).

Almost all hospitals (89.3%) reported that the majority of their patients (60–100%) had received treatment in primary care (i.e. 0–40% had had no treatment in primary care). This was reported by 84.2% of hospitals in 2010. The most common treatments ('always' or 'mostly') offered to patients in primary care, as reported by hospitals, were tranexamic acid (42.4%) and a trial of treatment with mefenamic acid (36.7%).

2.3 Changes in organisation of services since 2010

In the 2013 organisational survey, hospitals were asked whether there had been any changes in their service delivery model for women with HMB since 2010. Forty-two hospitals (23.3%) reported a new service delivery model, and about half of the new delivery models were related to the introduction or expansion of outpatient hysteroscopy services.

Over half of hospitals noted that there had been changes in the management of HMB in primary care in the previous 3 years: 50 hospitals (27.8%) had new primary care pathways, 50 hospitals (27.8%) reported a higher proportion of women receiving care in primary care and 44 hospitals (24.4%) reported reduced referrals.

2.4 Summary

The repeat organisational audit carried out in 2013 showed small differences compared with the one that was carried out in 2010. These changes were as follows.

- More hospitals reported that they had a written protocol (51.7% in 2013 compared with 29.9% in 2010).
- There were only small changes in the overall availability of diagnostic and therapeutic facilities within gynaecological outpatient clinics, although there was some change in what individual hospitals reported they had available. In 2013, hospitals reported that 83.3% offered ultrasound and 93.9% hysteroscopy, compared with 79.4% and 86.1%, respectively, in 2010.
- There were only small changes in the investigations that hospitals reported to provide to women who are referred to an outpatient clinic for the first time.

- There was a small increase in the availability of second-generation EA techniques, from 93.3% in 2010 to 96.7% in 2013.
- More hospitals indicated that they provided women with an information leaflet in 2013 (84.4%) than in 2010 (76.0%).
- Referral patterns from GPs were largely unchanged. In 2013, almost all hospitals reported that GPs could refer directly to imaging services (98.9%).
- Over half of the hospitals indicated changes in the management of HMB in primary care, with the introduction of new care pathways, a higher proportion of women receiving treatment in primary care, and reduced referral rates of women with HMB being the most important changes.

In conclusion, the organisation of clinical services for women with HMB has remained relatively stable, with some improvements in places. The repeat organisation audit found small changes that all indicate a trend towards a further implementation of the NICE guideline,[2] the NICE quality standards[4] and the RCOG *Standards for Gynaecology*.[5]

3 Patients and methods for the prospective audit

3.1 Data collection

Data were collected for the prospective audit at two stages:

- baseline questionnaires given to consenting women aged between 18 and 60 years at the time of first outpatient clinic visit (1 February 2011 to 31 January 2012)
- follow-up questionnaires mailed to the women's home address 1 year after the first outpatient clinic visit (1 February 2012 to 31 January 2013).

The recruitment of women was described in detail in the *Second Annual Report*.[3] In brief, hospital staff were asked to identify eligible women from the referral letter in the notes before they attended clinic. These women were then asked to complete the baseline questionnaire before their consultation. The baseline questionnaire consisted of 58 questions on age, ethnicity, duration of condition, obstetric history, prior treatment received and comorbidities. The questionnaire also included a condition-specific HRQoL instrument and severity scores adapted from the UFS-QoL. The EQ-5D generic quality of life instrument was included to measure general HRQoL. Completed questionnaires and consent forms were placed in separate envelopes and a courier service was used to collect these from the participating hospitals on a monthly basis.

Women consenting to be contacted 1 year after their first outpatient gynaecology visit were sent a follow-up questionnaire by post, as described in the *Third Annual Report*.[6] The follow-up questionnaire consisted of 63 questions. Women completed questions on treatment received in the previous year, cause of HMB, new symptoms and standard of care received in secondary care. Both the adapted UFS-QoL and the EQ-5D instruments were also included in the follow-up questionnaire.

3.2 Linkage to HES and PEDW data

Data from the prospective audit was linked to HES, an administrative database that captures all inpatient admissions and day cases in English NHS acute trusts, and to PEDW, which records all episodes of inpatient and day case activity in NHS Wales hospitals.

Of the 15 325 women who completed a questionnaire at the time of their first outpatient clinic visit and who also met the inclusion criteria for the follow-up study, 15 294 (99.8%) could be linked to HES or PEDW. Of the 8517 women who completed a questionnaire 1 year later, 8493 (99.7%) could be linked.

The linkage enriched the data collected in the prospective audit and provided an additional dimension for analysing (and verifying) treatment received in secondary care, as well as providing additional information that was not recorded in the prospective audit, such as ethnicity and socio-economic deprivation. Of the responders, 9.2% were of non-white ethnicity, which is broadly representative of the demography of the UK.[10,11]

The Index of Multiple Deprivation (IMD) combines a number of indicators for economic, social and housing issues into a single deprivation score for each small area in England known as a Lower Super Output Area (LSOA). LSOAs are ranked relative to each other, from which quintile groups can be generated, where Level 1 represents the most deprived area and Level 5 represents the least deprived area.

When linked with the prospective audit, 94.9% (14 545/15 325) of women at baseline had IMD recorded in HES. When linked with responders to the follow-up questionnaire, 95.1% (8096/8517) had IMD recorded.

3.3 Statistical analyses

We summarised the results of the data for responding women for individual NHS providers (trusts and health boards). Statistics were defined as the proportion or number of women falling into specific pre-defined categories, typically reflecting the response categories to particular questions. Comparisons of factors were made using the two-sided *t* test for normally distributed data, the rank-sum test for non-normally distributed data and the chi-squared test for categorical data.

For women with missing data, we used multiple imputation to replace missing data. This method was used to reduce bias in our analysis and increase statistical power. Imputation by chained equations[12] was used to generate ten imputed data sets and statistical estimates were pooled using Rubin's combination rules for analysis.

Funnel plots were used to formally assess variation across NHS providers; that is, whether results at an individual NHS provider differ significantly from the national average. A funnel plot is a graphical method for comparing the performance of institutions using cross-sectional statistics.[13] This technique takes into account the number of responses from women referred to each institution, which is important because the extent to which the provider's result is expected to vary is related to the number of responses. The horizontal axis represents the number of women included in the analysis at each provider and the vertical axis measures the factor of interest.

The funnel plot contains five lines. The horizontal line represents the national average (all providers combined). The other two sets of dashed lines are control limits and define expected results that are two standard deviations (inner funnel) or three deviations (outer funnel) away from the national average. If a result falls outside the control limits, it is considered to be different from the national average at the 5% or 0.2% significance level, respectively. The funnel plots for outcomes were compiled using exact binomial limits. In this report, we follow the advice published by the Department of Health[14] and consider providers with a result outside the outer limits of the funnel as a 'potential outlier'.

Multivariable logistic and linear regression analysis was used to adjust results for potential confounding factors: ethnicity (white, non-white), baseline age, HMB-related conditions at baseline (HMB only, fibroids only, endometriosis only, both fibroids and endometriosis), baseline severity score, baseline HRQoL score, baseline EQ-5D score and deprivation quintile.

4 Treatments reported at 1 year after the first outpatient visit

4.1 Introduction

In this chapter, we present the treatments in secondary care that were reported by women 1 year after their first outpatient clinic visit. Variations in treatment are described across NHS trusts and health boards. In our *Third Annual Report*,[6] we presented this variation unadjusted for the baseline characteristics of the women. The treatments are now compared at the provider level with adjustment. In addition, the treatments the women received according to their ethnicity and socio-economic deprivation are also described.

The surgical treatments reported by the women are also compared with treatments recorded in HES and PEDW, to validate and assess patients as a source of information. We are not able to present a full comparison. Because of delays at the Health and Social Care Information Centre (HSCIC). we do not have an up-to-date extract of the HES database that covers the full follow-up period at the time of writing this report. Our HES extract includes admission up to 31 March 2012 whereas the follow-up period runs up to 31 January 2013. Similarly, our extract of the PEDW database includes admissions only up to 31 December 2013. As a result, we can only compare if treatments recorded in HES or PEDW were reported by the women themselves. Owing to the limitations in the available HES and PEDW data, the reverse comparison – comparing whether treatments reported by women are recorded in HES – is not meaningful as many treatments will have been delivered during the follow-up period for which we do not have HES or PEDW data.

4.2 Description of the women who received treatment in secondary care

Of the 8517 women who returned the follow-up questionnaire 1 year after their first outpatient clinic visit, 96.1% (8183) reported treatment received in secondary care. In the *Third Annual Report*,[6] we grouped the treatments into four mutually exclusive categories according to what was the likely 'last treatment'. First, women were considered to have had 'surgical treatment' if they reported to have had a surgical treatment (EA, hysterectomy, myomectomy or UAE) irrespective of other reported treatments. Second, the women were considered to have had 'other treatments' if they reported treatments except surgery or oral medication or IUS. Third, the remaining women were considered to have had oral medication or IUS or no treatment in secondary care but they may have had treatment prescribed by their GP.

The likely last treatments for these women were no treatment in 18.0% (1472), oral medication or IUS in 34.6% (2834), surgical treatment in 37.3% (3053) and other treatment in 10.1% (824). Of the women who reported no treatment in secondary care, almost half (640 women) had had no previous treatment in primary care. Some of the women not having received any treatment in secondary care may have been referred by their GP for further diagnostic tests and reassurance.

Women who reported having had surgical treatment were more likely to be between 35 and 50 years old than women in the other three treatment groups (Table 4.1). Women who had surgery also reported more severe symptoms and worse quality of life at their first outpatient clinic visit. Women who reported that they had received no treatment or whose likely last treatment was oral medication or IUS had fibroids and/or polyps less often than women who reported having had surgery or other treatments. Women who had no treatment reported the least severe symptoms and the best quality of life.

Table 4.1 Descriptive statistics of women according to likely last treatment reported in secondary care

Baseline characteristics	No treatment in secondary care (%)	Oral medication/ IUS (%)	Surgical treatment (%)	Other treatment (%)	Hysterectomy (subgroup of surgical treatment) (%)
n	1472	2834	3053	824	1118
Age (years), mean (sd)	43.9 (7.5)	43.1 (7.5)	44.3 (5.3)	42.4 (8.0)	44.9 (5.1)
Age group (years)					
18–34	11.6	12.6	4.9	16.6	3.6
35–39	11.4	10.9	11.1	12.3	8.7
40–44	23.0	26.1	29.9	24.8	28.7
45–49	31.7	32.9	39.7	28.8	43.0
≥50	22.3	17.4	14.4	17.6	16.0
HMB-related conditions					
HMB alone	54.1	53.3	42.1	42.2	34.2
Fibroids and/or polyps	39.2	40.2	49.9	46.2	56.6
Endometriosis with or without polyps	4.3	4.4	5.0	7.7	5.1
Fibroids and endometriosis with or without polyps	2.4	2.2	3.0	3.9	4.1
Severity score at baseline, mean (sd)	54.9 (22.0)	57.7 (20.6)	66.1 (19.7)	59.2 (21.1)	68.2 (19.5)
Severity score at baseline, quartiles					
<50	38.0	32.8	19.8	30.6	17.0
50–64.9	28.0	29.2	24.4	27.4	22.5
65–79.9	20.3	22.9	29.4	24.4	30.1
≥80	13.8	15.2	26.5	17.7	30.5
Missing: 1.3% (104)					
HRQoL score at baseline, mean (sd)	43.0 (23.6)	38.4 (21.5)	30.5 (20.0)	37.2 (21.5)	28.6 (20.1)
HRQoL score at baseline, quartiles					
<20	18.8	22.5	34.8	24.6	39.2
20–34.9	19.6	22.7	26.9	23.4	26.6
35–49.9	22.7	25.7	21.6	24.1	19.3
≥50	39.0	29.2	16.8	28.0	14.9
Missing: 3.6% (297)					
EQ-5D score at baseline, mean (sd)	0.709 (0.300)	0.708 (0.091)	0.666 (0.323)	0.682 (0.310)	0.627 (0.336)
EQ-5D score at baseline, quartiles					
<0.45	18.1	18.7	23.3	22.0	28.1
0.45–0.74	25.4	25.1	26.3	27.3	26.0
0.75–0.84	28.4	28.8	26.3	24.8	25.2
≥0.85	28.1	27.4	24.1	25.9	20.7
Missing: 7.9% (649)					
Ethnicity					
White	89.6	91.4	92.4	88.5	91.5
Non-white	10.4	8.6	7.6	11.5	8.5
Missing: 5.7% (465)					
Socio-economic deprivation (IMD)					
Quintile 1 (most deprived)	20.8	19.4	18.7	18.9	18.7
Quintile 2	21.1	19.1	19.8	20.1	18.3
Quintile 3	20.0	23.4	20.9	21.4	21.2
Quintile 4	19.6	19.7	22.1	20.7	23.4
Quintile 5 (least deprived)	18.5	18.4	18.6	18.9	18.3
Missing: 4.9% (398)					

Proportions shown unless otherwise stated.

4.3 Variation in treatment across NHS providers, adjusted for baseline factors

The variations in treatment that women received in the year after their first outpatient clinic visit were compared using funnel plots. These funnel plots display for each hospital the proportion of women who had no treatment in secondary care, oral medication/IUS, and surgical treatment adjusted for baseline characteristics. These adjustments were carried out using the multivariable regression models presented in Table 4.2.

Table 4.2 Treatments received in secondary care according to baseline patient characteristics

Baseline characteristics	*n*	No treatment		Oral medication/IUS		Surgical treatment	
		%	OR* (95% CI)	%	OR* (95% CI)	%	OR* (95% CI)
Age group (years)							
18–34	814	20.9	1.01 (1.00, 1.02)†	44.0	0.98 (0.98, 0.99)†	18.3	1.03 (1.02, 1.03)†
35–39	917	18.3		33.8		36.9	
40–44	2196	15.4		33.7		41.6	
45–49	2849	16.4		32.7		42.5	
≥50	1407	23.3		35.1		31.3	
HMB-related conditions							
HMB alone	3939	20.2	1	38.3	1	32.6	1
Fibroids and/or polyps	3621	15.9	0.72 (0.64, 0.82)	31.5	0.78 (0.71, 0.86)	42.1	1.43 (1.29, 1.58)
Endometriosis with or without polyps	404	15.6	0.77 (0.58, 1.03)	30.9	0.71 (0.57, 0.89)	37.9	1.27 (1.02, 1.58)
Fibroids and endometriosis with or without polyps	219	16.0	0.80 (0.55, 1.17)	27.9	0.69 (0.51, 0.93)	41.6	1.27 (0.96, 1.69)
Severity score at baseline, quartiles							
<50	2310	23.7	0.94 (0.90, 0.98)†	39.7	0.92 (0.89, 0.95)†	25.8	1.15 (1.11, 1.19)†
50–64.9	2180	18.5		37.5		33.8	
65–79.9	2022	14.5		31.7		44.0	
≥80	1567	12.7		27.1		51.1	
HRQoL score at baseline, quartiles							
<20	2097	12.7	1.15 (1.11, 1.20)†	29.3	1.01 (0.98, 1.05)†	48.8	0.88 (0.85, 0.91)†
20–34.9	1875	14.8		33.1		42.2	
35–49.9	1850	17.4		37.9		34.4	
≥50	2064	26.8		38.6		23.9	
EQ-5D score at baseline, quartiles							
<0.45	1555	15.6	0.98 (0.96, 1.00)†	31.7	1.01 (0.99, 1.03)†	41.9	1.01 (1.00, 1.03)†
0.45–0.74	1947	17.5		34.0		37.8	
0.75–0.84	2064	18.5		36.7		35.6	
≥0.85	1968	19.2		36.6		34.2	
Ethnicity							
White	7033	17.6	1	34.8	1	37.8	1
Non-white	685	21.0	1.31 (1.07, 1.61)	33.7	0.97 (0.82, 1.16)	32.1	0.74 (0.61, 0.88)
Socio-economic deprivation (IMD)							
Quintile 1 (most deprived)	1503	19.0	1	34.3	1	36.8	1
Quintile 2	1542	18.9	0.97 (0.81, 1.17)	32.9	0.93 (0.80, 1.08)	38.0	1.07 (0.92, 1.24)
Quintile 3	1684	16.3	0.79 (0.65, 0.95)	36.9	1.10 (0.95, 1.28)	36.8	1.04 (0.89, 1.20)
Quintile 4	1611	16.8	0.80 (0.67, 0.97)	32.5	0.90 (0.77, 1.06)	40.7	1.23 (1.05, 1.44)
Quintile 5 (least deprived)	1445	17.6	0.82 (0.68, 1.00)	33.8	0.95 (0.81, 1.12)	38.2	1.14 (0.98, 1.34)

* OR: Odds ratio calculated using a multivariable regression model with multiple imputation, adjusted for age, ethnicity, deprivation, HMB-related conditions at baseline, baseline severity score, baseline HRQoL score, baseline EQ-5D score.
† Odds ratio per unit increase in age, 10 unit increase in severity score, 10 unit increase in HRQoL score and 0.1 unit increase in EQ-5D score.
The percentages are calculated based on the total number of women who answered the relevant question.

These models suggest that women aged between 35 and 50 years, those who had HMB-related conditions, those with more severe symptoms and those with a worse quality of life were more likely to have surgical treatment. Opposite patterns could be observed for the association between baseline characteristics and no treatment in secondary care and oral medication/IUS.

The funnel plots in Figure 4.1 demonstrate that the results adjusted for baseline characteristics fall within the outer funnel limits for almost all providers, which indicates that most of the variation between them is likely to be the result of random fluctuations. However, the differences between providers were substantial. For example, the percentage of women who reported having had a surgical intervention varied from 20% to 60%.

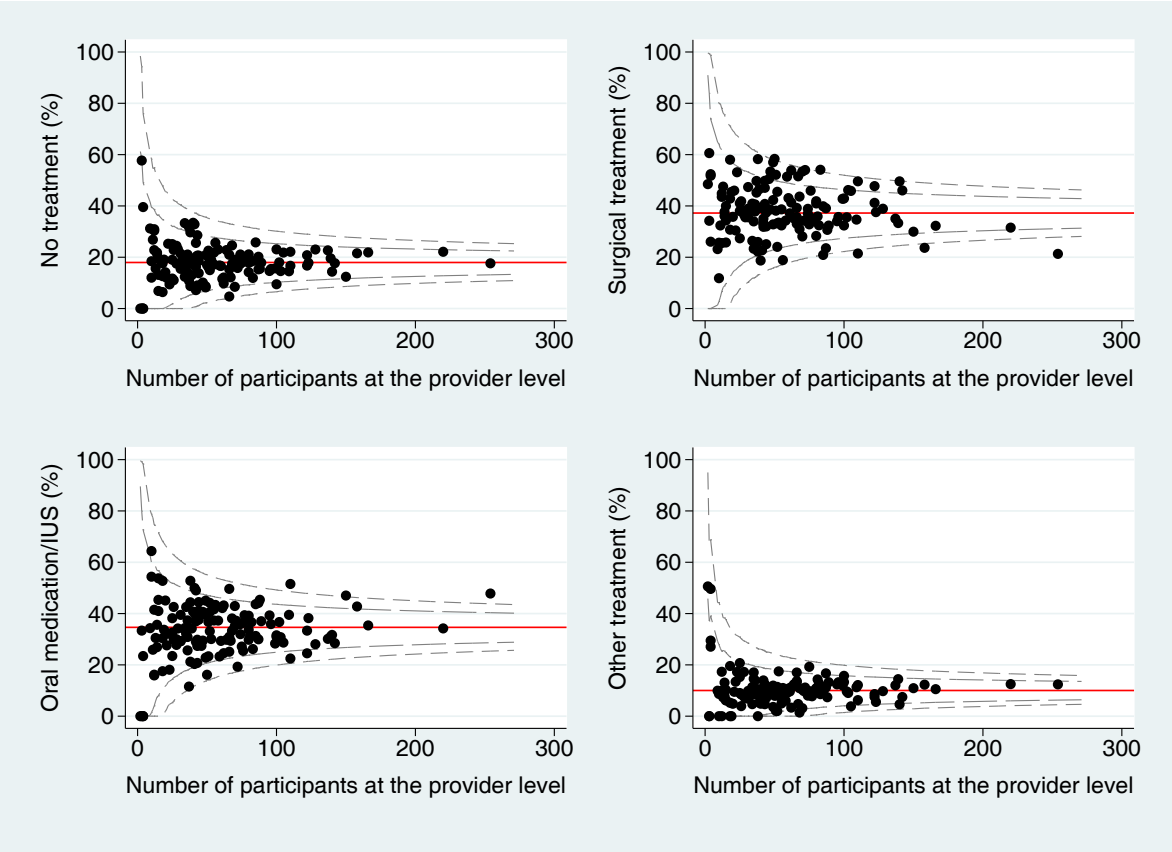


Figure 4.1 Variation in likely last treatment received in secondary care, adjusted for baseline factors

4.4 Variation in treatment according to ethnicity and socio-economic deprivation

The results of the multivariable regression analysis (Table 4.2) demonstrate that women from a non-white ethnic background were more likely to have no treatment in the year after their first outpatient clinic visit than women from a white ethnic background (OR 1.31) and less likely to receive surgical treatment (OR 0.74).

The impact of the women's socio-economic background was of the same magnitude. There is some indication that women from a less deprived background are more likely to have surgical treatment (OR 1.14) and less likely to have no treatment (OR 0.82) than women from a more deprived background.

4.5 Surgical treatments recorded in HES and PEDW compared with treatments reported by women at follow-up

The HES and PEDW records linked to patient-reported data were used to compare the treatments recorded with those reported by patients. In particular, we investigated whether women who had undergone a hysterectomy, myomectomy, UAE or EA according to HES or PEDW data reported these procedures themselves.

The linkage rate between HES and PEDW and the audit records of the 8517 women who had completed the 1-year follow-up questionnaire was high (91.4%). In the HES and PEDW data, women were considered to have had a hysterectomy or EA if any procedure field described either an abdominal or vaginal hysterectomy (OPCS Classification of Interventions and Procedures, version 4 (OPCS-4) codes Q07 and Q08, respectively) or an endometrial ablation (OPCS-4 codes Q16 and Q17).

Of the 542 women who had a hysterectomy recorded in HES and PEDW (OPCS-4 code Q07 or Q08), 95.4% reported this treatment themselves (Table 4.3). The corresponding percentages were lower for myomectomy (14.2% of 127 women according to OPCS-4 code Q09.2, Y75.2 or Y08.4), UAE (69.0% of 29 women according to OPCS-4 code L713 or Y53+Z96.6) and EA (75.4% of 1594 women according to OPCS-4 code Q16 or Q17). It is important to note that Table 4.3 demonstrates that the majority of women who had undergone a myomectomy according to HES and PEDW reported a hysterectomy (60.6%). Therefore, we also compared how many women who had had a surgical procedure (at least one of the four surgical procedures mentioned above) according to HES and PEDW reported such a procedure themselves. We found that this was the case for 85.3% of the women who had had a procedure according to HES or PEDW. These results demonstrate that most women accurately report whether or not that they had a surgical procedure, but that they are less accurate with regard to the type of procedure.

It important that the comparison of surgical procedures recorded in HES and PEDW and those reported by the women themselves be repeated when the HES and PEDW extract covering the full follow-up period becomes available (see above).

Table 4.3 Percentage of women reporting a surgical procedure according to whether the procedure was recorded in HES and PEDW

Patient-reported surgical procedure*	HES and PEDW (%)			
	Hysterectomy (*n* = 542)	Myomectomy (*n* = 127)	UAE (*n* = 29)	EA (*n* = 1594)
Hysterectomy	95.4	60.6	3.5	6.6
Myomectomy	2.0	14.2	0.0	5.8
UAE	0.2	0.8	69.0	0.9
EA	7.9	16.5	20.7	75.4
Other treatment, oral medication/IUS, no treatment	25.7	36.2	37.9	43.4

* Women may have ticked more than one treatment in the patient-reported data.

4.6 Summary

This chapter has described the likely 'last treatment' that women reported 1 year after their first gynaecological outpatient clinic visit. We found the following:

- About one in five women reported no treatment in secondary care, about one-third reported oral medication/IUS, about one-third reported surgery and one in ten reported other treatments. Women not having received treatment in secondary care may have been referred for further diagnostic tests and reassurance.

- Women aged between 35 and 50 years, those who had HMB-related conditions (i.e. fibroids, endometriosis), and those who had severe symptoms and a poor quality of life at their first outpatient clinic visit were most likely to report surgery.
- The differences between providers were substantial, with the percentage of women reporting surgical treatment varying from 20% to 60%. However, most of the variation between the providers in the treatments that women reported to have received is likely to be the result of random fluctuations.
- Women from a non-white ethnic background were more likely to report no treatment and less likely to have surgery than women from a white background.
- Women from a less deprived background were more likely to report surgical treatment and less like to report no treatment than women from a more deprived background, but these differences were relatively small.
- Most women accurately reported whether or not that they had had a surgical procedure, but they were less accurate about the type of procedure.

In conclusion, there is substantial variation between NHS providers in the treatment that women with HMB reported to have received in the year after their first outpatient clinic visit, even if differences in baseline characteristics (case mix) are taken into account. Women with HMB from a non-white ethnic background have surgical treatment less often than white women.

5 Patient-reported outcomes

5.1 Introduction

In this chapter, we present the outcomes that women reported 1 year after their first visit to a gynaecological outpatient clinic. The focus is on the severity of their symptoms and disease-specific HRQoL as measured with the adapted UFS-QoL. Both scores range from 0 to 100, with higher severity scores indicating greater symptom severity and higher HRQoL scores indicating better quality of life. In addition, we include the EQ-5D instrument as a generic measure of health, with a score ranging from 0 (death) to 1 (perfect health).

We compared outcomes across trusts and health boards with adjustment for the baseline characteristics as captured at the women's first hospital visit. In the *Third Annual Report*,[6] we had presented unadjusted outcomes. Outcomes are also presented according to the ethnic background of the women and the level of socio-economic deprivation.

5.2 Outcomes according to baseline characteristics and treatment

The outcomes reported by women 1 year after their first outpatient clinic visit – unadjusted for baseline characteristics – demonstrate that older women had less severe symptoms and a better quality of life (Table 5.1). Outcomes were slightly worse in women who reported having endometriosis. As could be expected, outcomes at 1 year were very strongly linked to symptom severity and specific and generic HRQoL reported at the first clinic visit.

Women from a non-white ethnic background as well as those from more socio-economically deprived areas reported more severe symptoms and poorer HRQoL.

The outcomes also varied according to the treatment that women reported (Table 5.1). The best HRQoL was reported by women who had had surgical treatment, and the worst by those who reported other treatments (i.e. treatments other than oral medication/IUS or surgery).

Table 5.1 Descriptive statistics of women 1 year after the first outpatient visit, by severity score, HRQoL score and EQ-5D score

Baseline characteristics and treatment reported in secondary care	*n*	Severity score at follow-up, mean (sd)	*n*	HRQoL score at follow-up, mean (sd)	*n*	EQ-5D score at follow-up, mean (sd)
Age group (years)						
18–34	830	42.4 (29.8)	824	56.2 (33.9)	856	0.701 (0.330)
35–39	933	33.5 (29.0)	924	66.4 (32.8)	951	0.745 (0.297)
40–44	2233	30.5 (28.5)	2194	69.1 (32.9)	2272	0.770 (0.290)
45–49	2895	28.2 (27.9)	2864	73.2 (31.5)	2959	0.806 (0.264)
≥50	1431	24.4 (26.2)	1417	77.3 (29.7)	1479	0.809 (0.269)
HMB-related conditions						
HMB alone	4018	30.1 (28.4)	3979	70.4 (32.5)	4108	0.770 (0.294)
Fibroids and/or polyps	3677	29.9 (28.5)	3628	70.8 (32.3)	3765	0.797 (0.266)
Endometriosis with or without polyps	409	34.4 (29.7)	404	66.2 (33.7)	420	0.720 (0.337)
Fibroids and endometriosis with or without polyps	218	29.9 (27.5)	212	69.3 (32.7)	224	0.778 (0.288)

(continued)

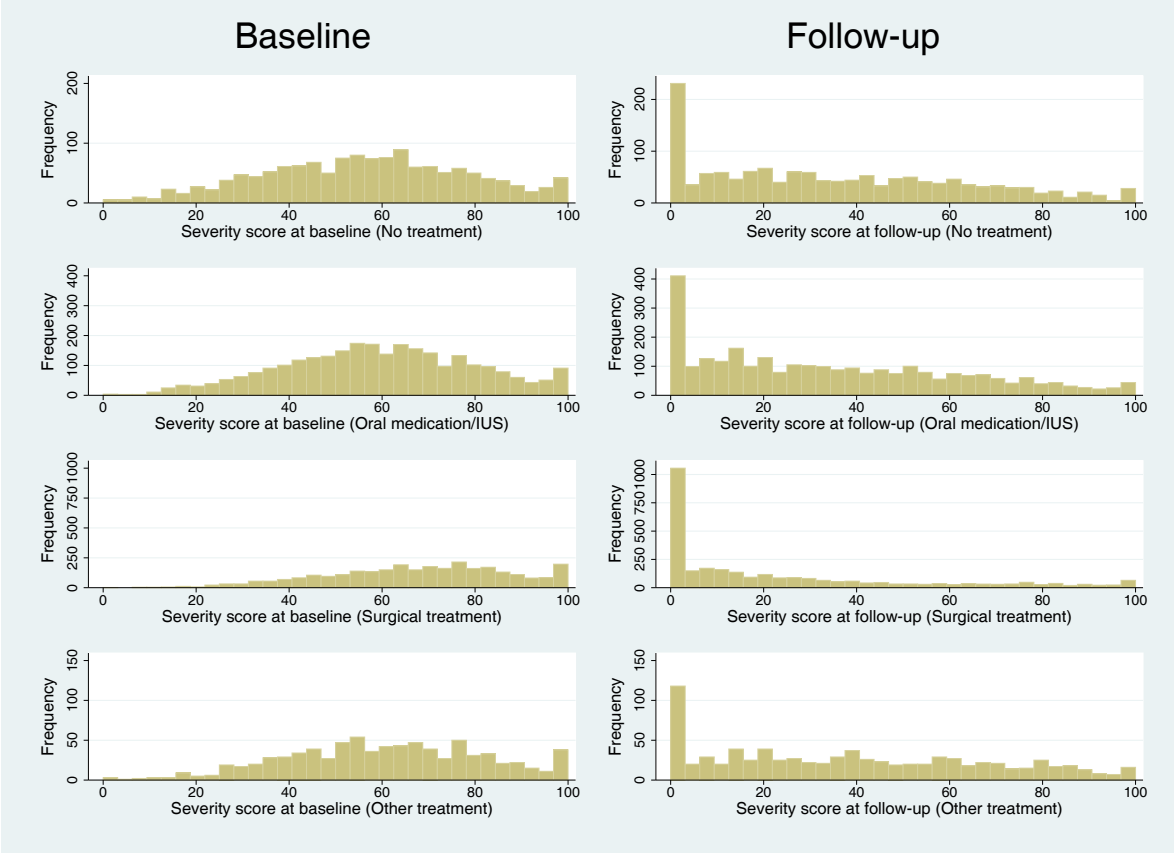
Table 5.1 (*continued*) Descriptive statistics of women 1 year after the first outpatient visit, by severity score, HRQoL score and EQ-5D score

Baseline characteristics and treatment reported in secondary care	*n*	Severity score at follow-up, mean (sd)	*n*	HRQoL score at follow-up, mean (sd)	*n*	EQ-5D score at follow-up, mean (sd)
Severity score at baseline, quartiles						
<50	2364	22.4 (21.9)	2342	77.2 (26.5)	2406	0.853 (0.210)
50–64.9	2217	29.4 (26.1)	2198	70.9 (30.6)	2266	0.797 (0.261)
65–79.9	2043	33.2 (30.2)	2015	68.3 (34.0)	2095	0.758 (0.296)
≥80	1590	39.0 (34.5)	1565	62.0 (38.4)	1633	0.679 (0.352)
Missing	108		103		117	
HRQoL score at baseline, quartiles						
<20	2122	37.8 (33.8)	2097	59.3 (39.5)	2184	0.687 (0.349)
20–34.9	1895	31.1 (28.8)	1873	68.9 (32.9)	1939	0.779 (0.281)
35–49.9	1881	29.1 (26.2)	1861	72.5 (28.5)	1908	0.810 (0.241)
≥50	2117	22.4 (21.5)	2101	80.9 (22.4)	2159	0.855 (0.212)
Missing	307		291		327	
EQ-5D score at baseline, quartiles						
<0.45	1581	38.9 (32.3)	1550	61.4 (36.7)	1638	0.584 (0.382)
0.45–0.74	1979	30.7 (27.9)	1966	69.2 (32.7)	2020	0.750 (0.259)
0.75–0.84	2099	27.6 (26.5)	2082	73.6 (29.8)	2142	0.848 (0.193)
≥0.85	2001	23.6 (24.8)	1979	77.1 (28.6)	2025	0.917 (0.160)
Missing	662		646		692	
Ethnicity						
White	7131	29.1 (28.1)	7052	71.9 (31.9)	7281	0.789 (0.277)
Non-white	713	39.3 (30.0)	701	57.9 (34.1)	740	0.711 (0.324)
Missing	478		470		496	
Socio-economic deprivation (IMD)						
Quintile 1 (most deprived)	1538	37.4 (31.1)	1521	62.4 (34.9)	1591	0.692 (0.333)
Quintile 2	1579	31.6 (29.3)	1556	68.4 (33.7)	1616	0.751 (0.302)
Quintile 3	1706	29.5 (27.6)	1683	71.2 (31.6)	1742	0.792 (0.270)
Quintile 4	1626	26.9 (27.7)	1607	73.9 (31.6)	1654	0.809 (0.273)
Quintile 5 (least deprived)	1464	24.9 (25.3)	1449	75.8 (29.4)	1493	0.849 (0.214)
Missing	409		407		421	
Treatment reported in secondary care						
No treatment	1431	34.4 (27.6)	1409	65.0 (31.3)	1472	0.773 (0.283)
Oral medication/IUS	2796	33.5 (27.4)	2777	66.8 (32.2)	2834	0.771 (0.286)
Surgical treatment	2973	22.2 (28.0)	2920	79.7 (31.2)	3053	0.807 (0.275)
Other treatment	809	37.5 (28.9)	809	61.8 (32.8)	824	0.758 (0.283)
Missing	313		308		334	

The distributions are slightly skewed for some categories.

The difference in outcomes of women who reported surgical treatment and those in the other treatment group is relatively large. A comparison of the distributions of the baseline UFS-QoL severity and HRQoL scores reported at the first outpatient clinic visit and those reported at 1 year highlights the substantial improvement in these outcomes for all treatment groups (Figure 5.1). The shift is most prominent in the distributions of women who had surgical treatment, as they had on average the worst scores for symptom severity at the first visit and HRQoL and the best scores 1 year later.

(a) Severity score



(b) HRQoL score

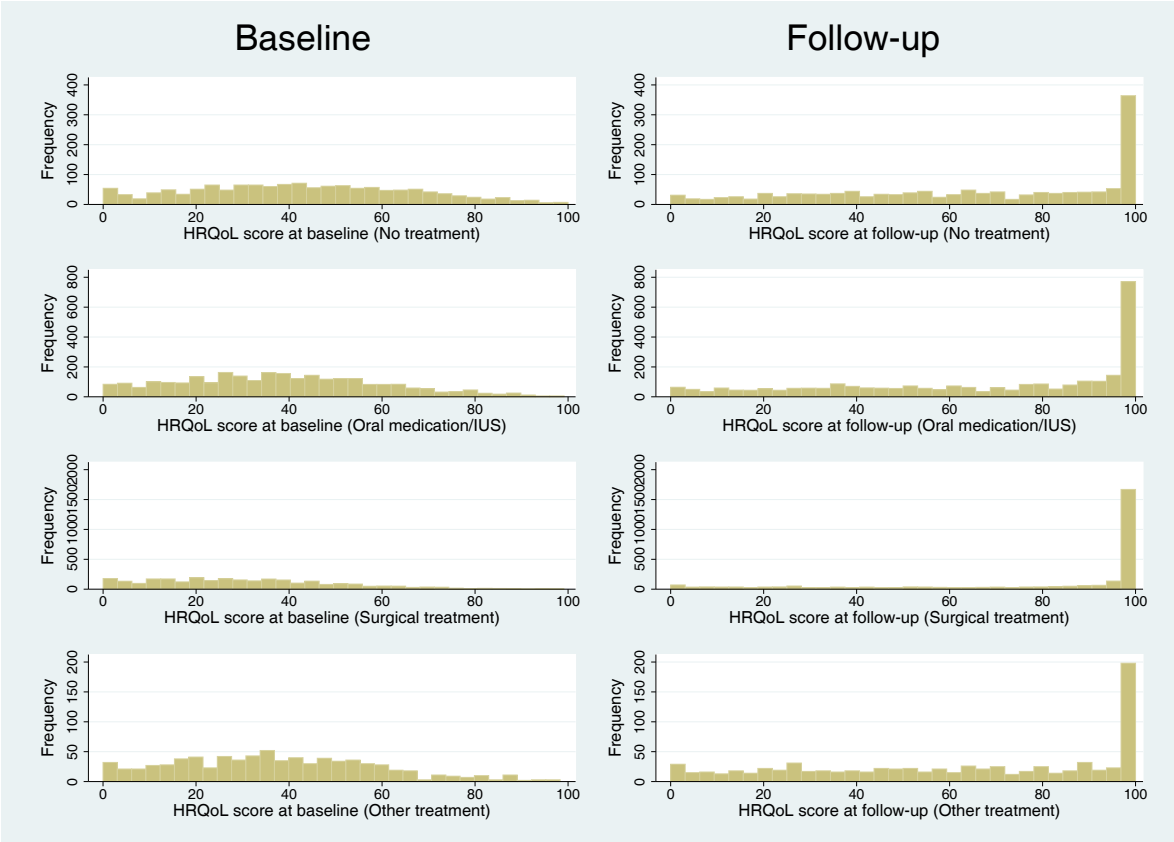


Figure 5.1 Distribution of severity score (a), HRQoL score (b) and EQ-5D score (c) at baseline and at follow-up, stratified by treatment reported in secondary care

(c) EQ-5D score

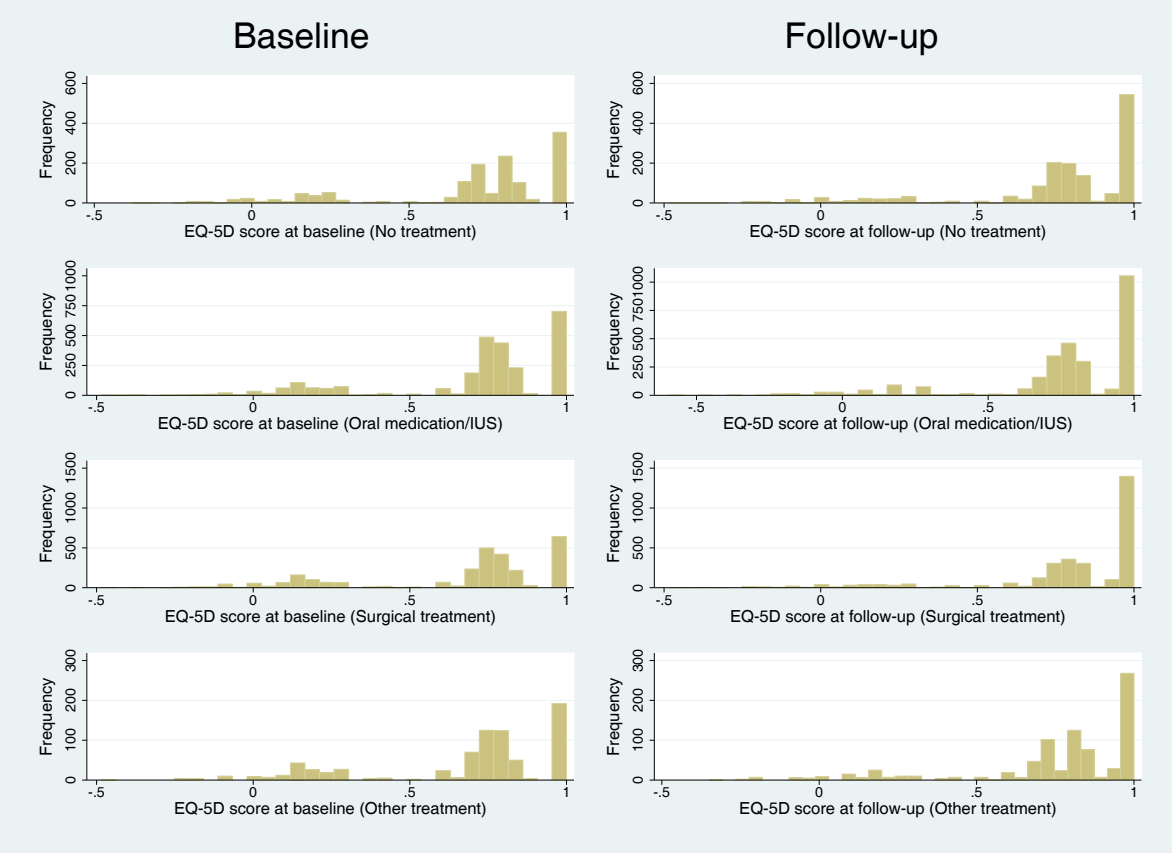


Figure 5.1 (*continued*) Distribution of severity score (a), HRQoL score (b) and EQ-5D score (c) at baseline and at follow-up, stratified by treatment reported in secondary care

5.3 Impact of treatment on symptom severity and quality of life

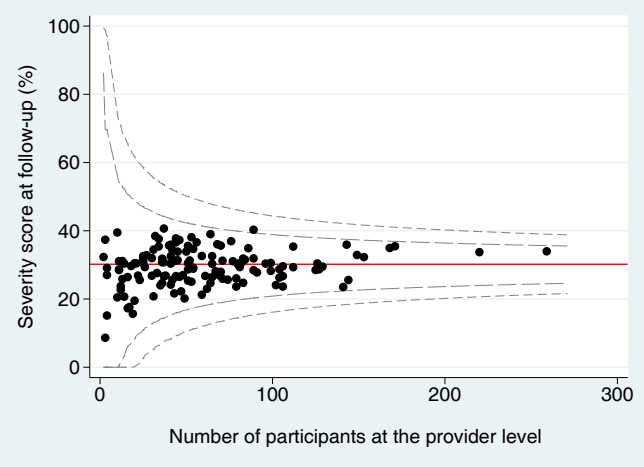
In the previous chapter, it was highlighted that women aged between 35 and 50 years, those who had HMB-related conditions (i.e. fibroids, endometriosis), and those who had severe symptoms and a poor quality of life at their first outpatient clinic visit were most likely to report having had surgery. To explore the impact of treatment, we compared the UFS-QoL symptom severity and disease-specific HRQoL scores as well as the EQ-5D generic HRQoL values according to treatment with adjustment for baseline characteristics. As explained in Chapter 3, we used multivariable linear regression to estimate these adjusted results.

With adjustment for baseline characteristics, including symptom severity and HRQoL reported at the first outpatient clinic visit, women who reported that they had had surgical treatment reported the least severe symptoms and the best quality of life. The difference in outcomes between women who reported no treatment and those who reported surgery was about 15 points for severity and 18 points for disease-specific HRQoL, which are both measured on a 100-point scale. Women who reported having received oral medication or IUS had better outcomes as well, compared with those who reported no treatment, but these differences were considerably smaller (between 2 to 3 points). A similar pattern of outcomes was observed for the EQ-5D generic HRQoL values.

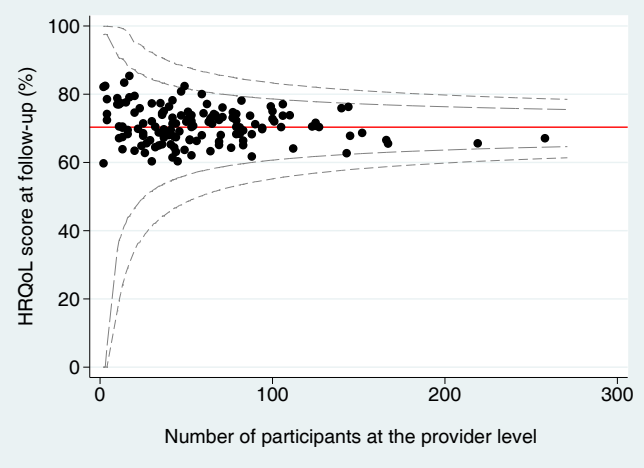
5.4 Variation in outcomes across NHS providers, adjusted for baseline factors

The adjusted severity scores, HRQoL scores and EQ-5D scores, 1 year following the first outpatient clinic visit, were compared across providers (Figure 5.2). The funnel plots demonstrate that that there is considerable variation between providers in the reported scores. For example, the mean

(a) Severity score



(b) HRQoL score



(c) EQ-5D score

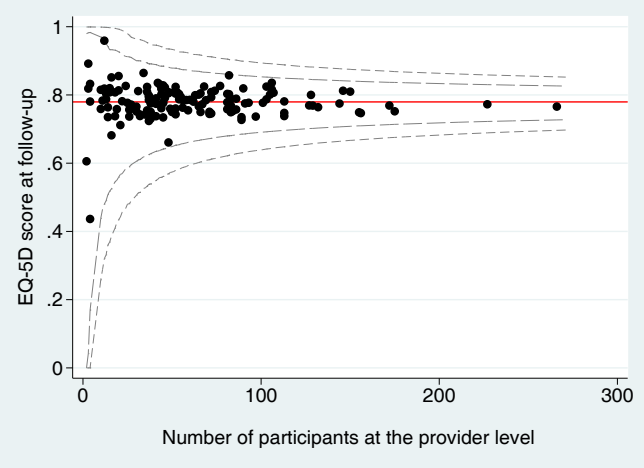


Figure 5.2 Severity score (a), HRQoL score (b) and EQ-5D score (c) at follow-up, adjusted for ethnicity and baseline factors

severity scores of the UFS-QoL ranged from 20 to 40 and the HRQoL score from 60 to 80. However, the results of all trusts and health boards fall within the inner funnel limits. It is important to note that the number of women who completed the follow-up questionnaire is lower than 100 for most providers. As a result, there is low statistical power to detect outcomes of individual providers as significantly different from the national mean.

5.5 Variation in outcomes according to ethnicity and socio-economic deprivation

The differences in outcomes of women according to their ethnic background or level of socio-economic deprivation decreased with adjustment for baseline characteristics (Table 5.2). However, even with adjustment, women from a non-white ethnic background and those from more socio-economically deprived areas reported more severe symptoms and worse HRQoL.

Table 5.2 Differences according to likely last treatment in severity score, HRQoL score and EQ-5D score 1 year after the first outpatient visit, with adjustment for baseline characteristics

Baseline characteristics and likely last treatment	Adjusted difference (95% CI)		
	Severity score (*n* = 8322)	HRQoL score (*n* = 8223)	EQ-5D score (*n* = 8517)
Treatment			
No treatment	0	0	0
Oral medication/IUS	−2.4 (−4.0, −0.7)	3.9 (2.0, 5.8)	0.004 (−0.012, 0.019)
Surgical treatment	−16.3 (−18.0, −14.6)	19.5 (17.6, 21.4)	0.060 (0.044, 0.076)
Other treatment	0.3 (−2.0, 2.5)	0.5 (−2.1, 3.0)	0.004 (−0.018, 0.025)
Ethnicity			
White	0	0	0
Non-white	6.0 (4.0, 8.1)	−9.3 (−11.7, −6.9)	−0.032 (−0.053, −0.012)
Socio-economic deprivation (IMD)			
Quintile 1 (most deprived)	0	0	0
Quintile 2	−3.3 (−5.2, −1.5)	3.2 (1.0, 5.3)	0.022 (0.005, 0.040)
Quintile 3	−3.9 (−5.8, −2.1)	4.1 (2.1, 6.2)	0.045 (0.028, 0.062)
Quintile 4	−4.9 (−6.7, −3.0)	4.9 (2.8, 7.0)	0.042 (0.025, 0.060)
Quintile 5 (least deprived)	−6.0 (−7.9, −4.0)	5.8 (3.6, 8.0)	0.068 (0.050, 0.086)

In the *Second Annual Report*,[3] we described that women from a non-white ethnic background and those from more deprived areas had more severe symptoms and a poorer HRQoL at their first gynaecological outpatient clinic visit. However, even with adjustment for these baseline differences, there was an effect of ethnicity and socio-economic deprivation on the 1-year outcomes. This suggests that white women and those from less deprived areas experienced a greater improvement of their conditions.

5.6 Summary

In this chapter, we described symptom severity and disease-specific and generic HRQoL as reported by the women 1 year after their first visit to a gynaecological outpatient clinic. We found the following:

- Women with HMB had large improvements in their condition in the year after their first gynaecological outpatient clinic visit.
- Overall, outcomes were better in older women and in those who reported better HRQoL at the first outpatient clinic visit.
- Women who reported being told that they had endometriosis reported poor outcomes.
- There were large differences according to treatment. Women who reported having had surgical treatment reported on average better outcomes than those who reported other treatments. Adjustment for baseline characteristics increased these differences even further.
- There was considerable variation in outcomes across providers. However, this variation is consistent with the variation that can be expected as a result of random fluctuations. No

trust or health board had outcomes that are statistically significantly different from the national mean.

- Women from a white ethnic background and those from less socio-economically deprived areas experienced a greater improvement of their condition in the year after their first outpatient clinic visit than their non-white and more deprived counterparts.

In conclusion, women, especially those who had had surgical treatment, reported large improvements in their symptoms and HRQoL in the year after their first outpatient clinic visit. There is no evidence of systematic variation across providers in these outcomes. Improvements were greatest in women from a white ethnic background and those from less socio-economically deprived areas.

6 Experience in secondary care

6.1 Introduction

The questionnaire that women completed 1 year after their first gynaecology outpatient clinic visit contained a number of questions about their experience in secondary care. These questions were derived from the NHS inpatient surveys, supplemented with questions used in earlier national clinical audits.

In the *Third Annual Report*,[6] we compared the overall rating that women assigned to the care they had received across the hospitals. In this report, we also compare, across providers, women's satisfaction with the information received and their involvement in the decision-making process. The experience in secondary care is also presented according to the treatment women received, their ethnic background and the level of socio-economic deprivation.

In contrast to the comparison of patient-reported outcomes, these comparisons are not adjusted for differences in women's baseline characteristics as we take the view that it should be expected that all women have an equally good care experience – irrespective of their age and clinical profile.

6.2 Variation in women's experience in secondary care across NHS providers

Of the 8517 women who returned the follow-up questionnaire 1 year after their first outpatient clinic visit, 97.0% (8264) reported on their satisfaction with the information received, 97.4% (8299) reported on their involvement in the decision-making process and 97.8% (8333) rated the overall care received.

There was considerable variation in the percentage of women who reported being 'very satisfied' or 'somewhat satisfied' with the information that they had received from their hospital (Figure 6.1). This percentage ranges for most providers from 60% to 95%, with a national mean of 81.4%. Results from all providers fell within the funnel limits and therefore no trust or health board was identified as a potential outlier. However, the number of women in most trusts and health boards who completed the questionnaire is less than 100, which reduces the statistical power of the comparison.

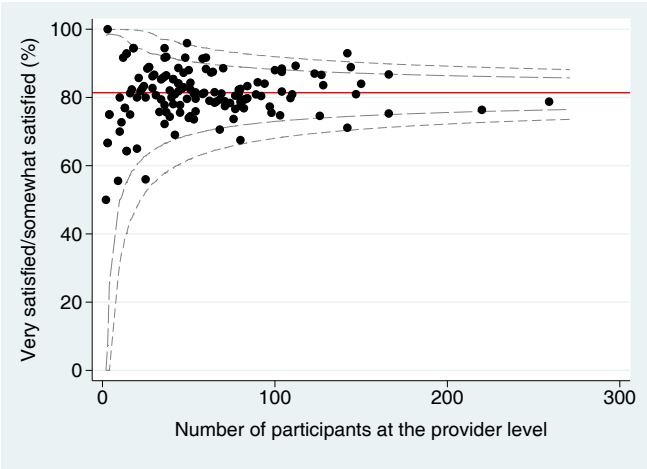


Figure 6.1 Proportion of women reporting being very satisfied or somewhat satisfied with the information received from their hospital

The percentage of women who reported that they 'definitely' had been involved as much as they wanted in decisions about their care varied by provider from about 40% to 80%, with a national mean of 61.1% (Figure 6.2). The results of two larger providers were above the outer limit of the funnel, suggesting that in these providers more women felt that they were involved in the decision making about their treatment than can be expected based on the average national results.

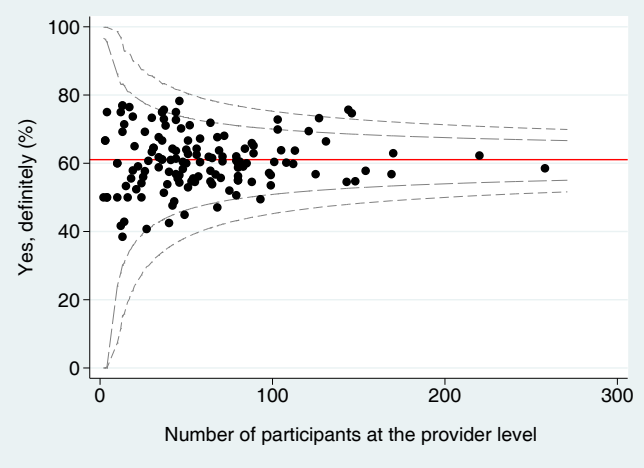


Figure 6.2 Proportion of women reporting being definitely involved with decisions about their care

The percentage of women who rated their care as 'good', 'very good' or 'excellent' varied from about 80% to 100% across most providers, with a national mean of 90.3% (Figure 6.3). Some lower percentages were observed for a number of smaller providers. However, we could not detect trusts or health boards that should be considered as potential outliers as the results for all providers are within the funnel limit.

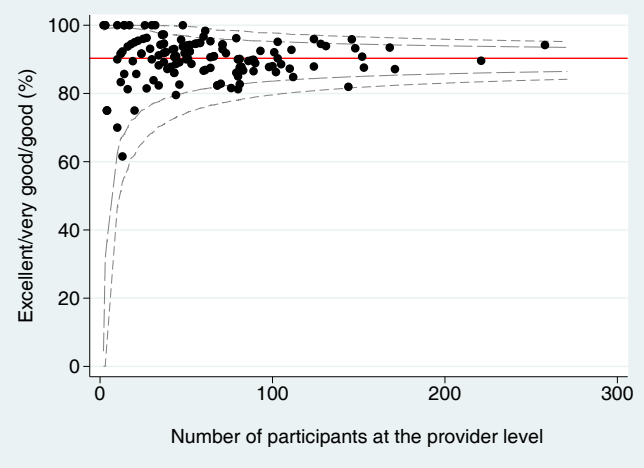


Figure 6.3 Proportion of women rating overall care as excellent, very good or good

6.3 Variation in women's experiences according to treatment

Women who had surgery reported more frequently than women in the non-surgical treatment groups that they were satisfied with the information they had received and that they had been involved in the decision making about their treatment (Table 6.1). Women who had surgery also reported more frequently that they rated their care at least as 'good' although the differences with the non-surgical treatment groups are relatively small.

Table 6.1 Experiences of women in secondary care, by ethnicity, deprivation and treatment

Baseline characteristics and treatment reported in secondary care	Satisfied with the information received from the hospital			Involved in decisions about care and treatment			Overall care received from the hospital		
	n (8264)	Very/ somewhat satisfied (%)	Not satisfied (%)	*n* (8299)	Yes, definitely (%)	Yes, to some extent/ no (%)	*n* (8333)	Excellent/ very good/ good (%)	Fair/ poor (%)
Ethnicity									
White	7083	82.0	18.0	7111	62.4	37.7	7133	90.6	9.4
Non-white	713	77.1	22.9	721	50.6	49.4	724	88.1	11.9
Missing	468			467			476		
Socio-economic deprivation (IMD)									
Quintile 1 (most deprived)	1542	80.7	19.3	1550	58.7	41.4	1556	90.6	9.4
Quintile 2	1562	81.1	19.0	1574	59.8	40.2	1576	88.3	11.7
Quintile 3	1689	81.5	18.5	1700	59.4	40.7	1709	90.6	9.4
Quintile 4	1608	82.2	17.8	1608	64.2	35.8	1620	90.4	9.6
Quintile 5 (least deprived)	1458	82.4	17.6	1457	64.0	36.0	1462	91.9	8.1
Missing	405			410			410		
Treatment reported in secondary care									
No treatment	1413	70.1	29.9	1405	50.5	49.5	1428	87.3	12.8
Oral medication/ IUS	2761	79.3	20.8	2769	58.2	41.8	2774	90.3	9.7
Surgical treatment	2979	89.2	10.8	2999	71.8	28.2	3002	92.6	7.4
Other treatment	801	79.9	20.1	814	51.8	48.2	816	87.3	12.8
Missing	310			312			313		

6.4 Variation in women's experiences according to ethnicity and socio-economic deprivation

Women from a white ethnic background reported more often than those from a non-white background that they were 'satisfied' or 'very satisfied' with the information that they had received from the hospital, they felt 'definitely' involved in the decision making, and they rated their care as 'good', 'very good' or 'excellent' (Table 6.1). These differences were largest with respect to decision making.

The impact of socio-economic deprivation on women's experiences was relatively small, with women from less deprived backgrounds reporting experiences that were slightly better.

6.5 Summary

In this chapter, we described the experience that women had in the year after their first visit to a gynaecological outpatient clinic. We found the following:

- 90% of the women rated the care they had received as 'good', 'very good' or 'excellent'.
- About 60% of the women reported that they were 'satisfied' or 'very satisfied' with the information they had received from the hospital and 60% felt 'definitely' involved in the decision making about their treatment. The percentages varied considerably among providers but no trusts or health boards were identified as potential outliers with a bad result.
- Women from a non-white ethnic background were less satisfied with the information they had received and felt less involved in the decision making.
- The impact of socio-economic background on the experiences reported by women was small.

In conclusion, the audit found considerable variation across providers in women's experience of care received in the year after their first outpatient clinic visit, but no trust or health board was identified as a potential outlier. Women from a non-white ethnic background were less positive than white women with respect to the information they received and their involvement in the decision making about their treatment.

7 Validity and generalisability of the National HMB Audit results

7.1 Introduction

The National HMB Audit is the first national study that uses patient-reported information collected during an outpatient clinic visit. This chapter presents three separate analyses of the validity and generalisability of the results:

- the view of clinicians on the appropriateness and validity of using patient-reported data
- a case note review of a random sample of patients from 17 units, comparing the information reported by 309 patients with their medical records
- a comparison of the characteristics of the 15 325 women who attended the initial gynaecology outpatient clinic and also met the inclusion criteria for the follow-up study across providers with low, mid and high case ascertainment.

7.2 Patients as a source of information: clinicians' view

In the repeat organisational survey (Appendix 3), 154 (85.6%) of the 180 responding clinicians agreed (i.e. 'strongly agreed' or 'agreed') that patients (rather than clinicians) are an appropriate source of information for clinical audits of care aimed at improving a patient's quality of life. A significant majority of the responders also agreed that the information reported by patients with HMB was valid, albeit that more responders (83.9%) agreed that patient-reported information about symptoms was valid than about treatments (78.9%) and outcomes (77.8%).

7.3 Data validation: case note review

In the fourth year of the audit, 17 participating units representing all regions in England and Wales took part in a case note review. The hospitals selected included units with low and high case ascertainment rates, and also those with both teaching and non-teaching status. Twenty patients were selected from each unit using a random number generator. The short case note review collected information about HMB-related symptoms, their duration and previous treatment (as recorded in the case notes at the time of the women's first visit to a gynaecological outpatient clinic), as well as the causes of HMB and the treatments received (as recorded in the case notes during the year after the first clinic visit). The reviews were completed by clinical staff (Appendix 2).

We received 309 of the 340 expected case note reviews (90.9%). In this report, we compare the duration of symptoms recorded in the case notes at the women's first outpatient clinic visit with the duration reported by the women themselves. The duration could not be found in the case notes for 35 women (11.3%) and was not reported by 9 women themselves (2.9%) (Table 7.1). Of the 162 women whose duration of symptoms was recorded as more than 1 year in their case notes, 140 (86.4%) reported a similar duration themselves. Of the 99 women whose duration of symptoms was recorded as between 2 months and 1 year in the case notes, 34 (34.3%) reported a similar duration but 56 (56.6%) reported a duration of more than 1 year. These results indicate that, on average, women themselves report a duration of HMB symptoms that is longer than the duration of symptoms recorded in the case notes.

A comparison of the causes of HMB recorded in the case notes in the year after the first outpatient clinic visit and those reported by the women themselves indicated that 86 women had uterine fibroids recorded in their case notes and that 65 of these (75.6%) reported these themselves

Table 7.1 Agreement of patient-reported data with the case notes: duration of symptoms

		Patient-reported data				
		Less than 2 months	2 months to 1 year	More than 1 year	*Don't know/ missing*	Total
Case notes	Less than 2 months	3	5	5	*0*	13
	2 months to 1 year	7	34	56	*2*	99
	More than 1 year	1	17	140	*4*	162
	Don't know/missing	*0*	*7*	*25*	*3*	*35*
	Total	11	63	226	*9*	309

(Table 7.2). With respect to other conditions, 35 women had polyps of the lining of the womb recorded in their case notes, with 25 (71.4%) reporting these themselves; 20 women had hormonal imbalance recorded in their case notes, with three (15%) reporting this themselves; and 10 women had endometriosis recorded in their case notes, with five (50%) reporting it themselves. It is also important to note that all these specific causes of HMB were more frequently reported by the women themselves than recorded in the case notes. This was especially the case for hormonal imbalance and endometriosis.

Table 7.2 Agreement of patient-reported data with the case notes: causes of HMB 1 year after the first outpatient clinic visit

	Patient-reported data							
	Uterine fibroids				Polyps of the lining of the womb			
		No	Yes	Total		No	Yes	Total
Case notes	No	194	29	223	No	248	26	274
	Yes	21	65	86	Yes	10	25	35
	Total	215	94	309	Total	258	51	309
	Hormonal imbalance				Endometriosis			
		No	Yes	Total		No	Yes	Total
	No	265	24	289	No	276	23	299
	Yes	17	3	20	Yes	5	5	10
	Total	282	27	309	Total	281	28	309

Table 7.3 shows that according to the case notes 146 women had oral medication and/or IUS, with 97 of these (66.4%) reporting this themselves. Ninety women had surgical treatment according to the case notes, with 73 of these (81.1%) reporting this themselves. A more detailed analysis looking at specific surgical procedures demonstrated that the agreement between what is recorded in the case notes and what women reported themselves was strong for hysterectomy (40 women according to case notes, with 35 of these (87.5%) reporting it themselves), and slightly weaker for EA (45 according to case notes, with 33 of these (73.3%) reporting it themselves). With respect to EA, it is also important to note that it was more frequently reported by the women themselves than reported in the case notes. The frequency of other surgical procedures recorded in the case notes of the 309 women included in this review was so low (only seven had myomectomy and five had UAE recorded) that a comparison with procedures reported by women themselves is not meaningful. These comparisons confirm again that women's own reports on surgical treatments correspond well with what can be found in case notes, especially for hysterectomy. However, their recollection about other types of treatment suggests that perhaps they did not receive full information about their treatments.

Table 7.3 Agreement of patient-reported data with the case notes: treatments received in the year after the first outpatient clinic visit

Treatments	Number of cases		Observed agreement
	Case notes	Patient-reported data	
Prior treatments (baseline)			
No treatment	75	97	73.4%
Oral medication (including the pill)	179	166	62.8%
IUS	57	56	90.2%
Treatments in the last year (follow-up)			
No treatment	20	54	82.5%
Oral medication (including the pill)	77	96	65.4%
IUS	89	105	75.4%
EA	45	62	86.7%
Hysterectomy	40	44	95.5%

The observed agreement is the proportion of patients that have case notes and patient-reported data as yes, yes or no, no. It was not calculated for myomectomy or UAE because of the small numbers reported as yes (frequencies shown below).

(a) Oral medication/IUS

		Patient-reported data		
		No	Yes	Total
Case notes	No	91	72	163
	Yes	49	97	146
	Total	140	169	309

(b) Surgical treatment

		Patient-reported data		
		No	Yes	Total
Case notes	No	178	41	219
	Yes	17	73	90
	Total	195	114	309

(c) Types of surgical treatment

		Patient-reported data						
		EA				Hysterectomy		
		No	Yes	Total		No	Yes	Total
Case notes	No	235	29	264	No	260	9	269
	Yes	12	33	45	Yes	5	35	40
	Total	247	62	309	Total	265	44	309
		Myomectomy				UAE		
		No	Yes	Total		No	Yes	Total
Case notes	No	294	8	302	No	301	3	304
	Yes	3	4	7	Yes	2	3	5
	Total	197	12	309	Total	303	6	309

7.4 Representation of women included in the HMB audit: comparison of characteristics of women treated by NHS trusts with low, mid and high case ascertainment

In our *Third Annual Report*,[6] we estimated that the case ascertainment for the audit was 31.9%. However, it was also observed that case ascertainment varied considerably across providers. To explore whether this variation in case ascertainment may have an impact on the validity of the results for the individual providers, we compared women's baseline characteristics reported in the questionnaire completed at their first visit to the gynaecology outpatient clinic. The characteristics were compared across providers. We ranked providers by their case ascertainment and then categorised them as 'low' (lower quartile, ascertainment <20%), 'mid' (interquartile, ascertainment between 20% and 45%) or 'high' (upper quartile, ascertainment >45%).

Table 7.4 shows that there are only very little differences in most characteristics of the women grouped according to case ascertainment. However, women from providers with high case ascertainment were more often from a non-white ethnic background and a more deprived area than the women in the other groups. This demonstrates that it is important to adjust for case mix, especially ethnicity and socio-economic deprivation, to ensure that the comparison of treatments received in the year after the women's first outpatient clinic visit and the outcomes reported after a year is affected as little as possible by differences in case ascertainment across providers.

Table 7.4 Baseline descriptive statistics of women, by providers with low, mid and high case ascertainment

Baseline characteristics	Case ascertainment (%)		
	Low (<20%)	Mid (20–45%)	High (>45%)
n	1462	7139	6724
Age (years), mean (sd)	42.5 (7.6)	42.4 (7.5)	42.2 (7.8)
Age group (years)			
18–34	14.4	14.5	15.4
35–39	11.3	13.5	12.6
40–44	27.4	26.3	26.7
45–49	32.7	31.6	30.7
≥50	14.2	14.2	14.7
HMB-related conditions			
HMB alone	52	51.7	51.9
Fibroids and/or polyps	39.8	40.5	40.1
Endometriosis with or without polyps	5.7	5.1	5.7
Fibroids and endometriosis with or without polyps	2.5	2.6	2.4
Severity score at baseline, mean (sd)	62.1 (21.0)	62.3 (21.1)	61.1 (21.5)
Severity score at baseline, quartiles			
<50	29.1	27.7	29.6
50–64.9	25.8	27	27.3
65–79.9	25.7	25.3	24.4
≥80	19.4	20.1	18.7
Missing: 2.2% (335)			
HRQoL score at baseline, mean (sd)	34.4 (22.3)	34.4 (21.9)	35.1 (22.5)
HRQoL score at baseline, quartiles			
<20	27.6	26.2	27
20–34.9	22.9	24	23.5
35–49.9	22.1	24.2	22.6
≥50	27.4	25.6	27
Missing: 4.8% (739)			

(*continued*)

Table 7.4 (*continued*) Baseline descriptive statistics of women, by providers with low, mid and high case ascertainment

Baseline characteristics	Case ascertainment (%)		
	Low (<20%)	Mid (20–45%)	High (>45%)
EQ-5D score at baseline, mean (sd)	0.651 (0.333)	0.655 (0.328)	0.652 (0.329)
EQ-5D score at baseline, quartiles			
<0.45	20.7	20.8	21.1
0.45–0.74	27	25.5	25.9
0.75–0.84	27.1	27.7	27.1
≥0.85	25.2	26	25.9
Missing: 9.9% (1523)			
Ethnicity			
White	91	89.2	86.8
Non-white	9	10.8	13.2
Missing: 6.8% (1042)			
Socio-economic deprivation (IMD)			
Quintile 1 (most deprived)	22.6	20.6	26.8
Quintile 2	22.2	20.5	22.9
Quintile 3	19.8	21.1	19.4
Quintile 4	16.7	20.1	17.6
Quintile 5 (least deprived)	18.7	17.6	13.3
Missing: 5.1% (780)			

Proportions shown unless otherwise stated.

7.5 Summary

In this chapter, we presented some evidence for the validity and generalisability of the National HMB Audit results. We found the following:

- 86% of clinicians think that women with HMB (rather than clinicians) are an 'appropriate source' of information about care aimed to improve quality of life. 84% of clinicians agree that patient-reported information about symptoms is valid, with slightly lower percentages agreeing about the validity of patient-reported information on treatment (79%) and outcomes (78%).
- A comparison with information derived from a case note review revealed that women themselves reported slightly longer duration of symptoms, that there are considerable differences between the causes of HMB recorded in case notes and by women themselves (with the greatest discrepancies observed for hormonal imbalance and endometriosis), and that women's own report of surgical treatment, especially hysterectomy, corresponds reasonably well with case notes.
- Women treated in trusts or health boards with high case ascertainment were more often from a non-white ethnic background and from a more socio-economically deprived area, indicating the importance of adjusting comparisons of treatments and outcomes for these characteristics.

In conclusion, clinicians strongly supported patient-reported data as a source of information for the National HMB Audit. However, discrepancies between women's own reports and information recorded in case notes, as well as differences in ethnic and socio-economic background of women accessing providers with different levels of case ascertainment, have to be taken into account when interpreting the Audit's results.

8 Patterns of surgical treatment

8.1 Introduction

Many women with HMB will receive surgical treatment either because the condition severely affects their quality of life or because other therapies were not tolerated or were deemed to be ineffective. The main surgical treatment options are EA or hysterectomy.

In this chapter, we describe patterns of surgical treatment for women with HMB. The analysis covers the period between 1 April 2009 and 31 March 2012 in England and Wales. The trends in the use of EA and hysterectomy and the regional surgical rates are compared with the patterns of surgical care in the previous 3 years (April 2006 to March 2009).

8.2 Methods

The analysis used data from HES and PEDW, administrative databases that capture all inpatient admissions and day cases in NHS secondary care services. We restricted the sample to women aged between 25 and 59 years at the time of surgery and included the first surgical procedure only.

A woman was defined as undergoing surgery for HMB if the first diagnosis field indicated 'excessive, frequent and irregular menstruation' (International Classification of Diseases and Related Health Problems, 10th edition (ICD-10) codes N92.0, .1, .4–.9) or 'other abnormal uterine and vaginal bleeding' (ICD-10 codes N93.8, .9) and if any procedure field described either an abdominal or vaginal hysterectomy (OPCS-4 codes Q07 and Q08, respectively) or an endometrial ablation (OPCS-4 codes Q16 and Q17).

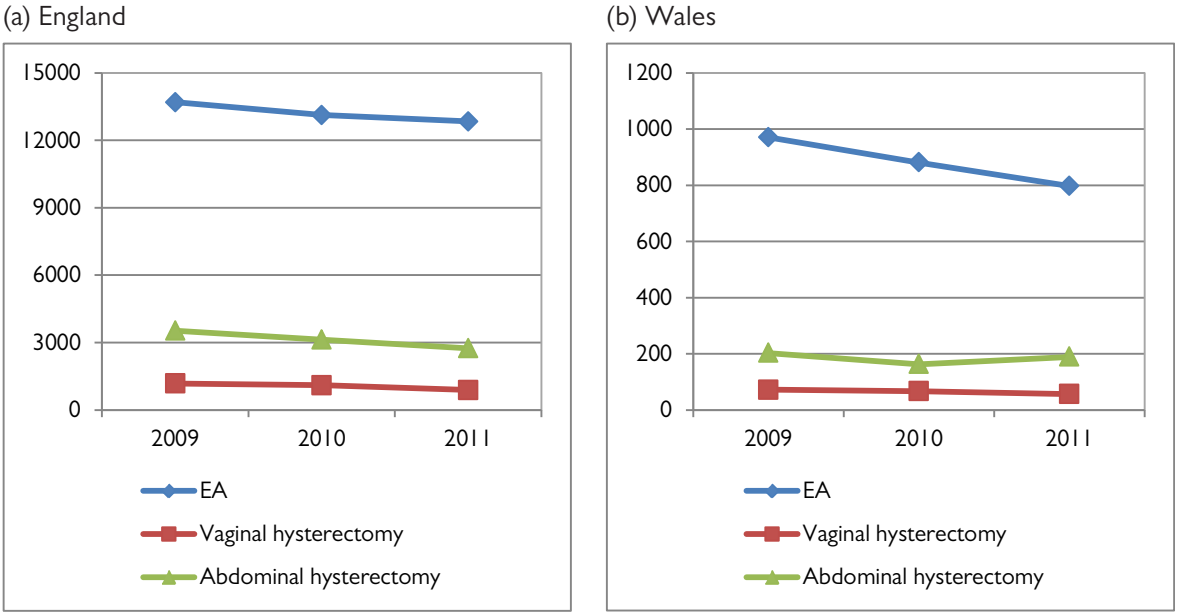
Since 1 April 2013, the regional structure of the NHS in England has consisted of clinical commissioning groups, NHS area teams and NHS commissioning regions. This new structure has replaced the SHAs and PCTs that had been in operation since 2006. For comparability with previous reports, the analysis below uses the old SHA and PCT structure. NHS Wales comprises seven LHBs, which are responsible for delivering all NHS healthcare services within a geographical area. The current LHBs were created on 1 October 2009 following the reorganisation of the 22 LHBs that had existed since 2003. For the analysis below, women were allocated to the current LHBs to take account of the reorganisation of the services.

For English SHAs and PCTs, age-standardised procedure rates were derived by dividing the observed number of procedures by the number that would be expected if the region had the same age-specific rates as England, and then multiplying this ratio by the English procedure rate. For the seven LHBs in Wales, a similar method was applied by dividing the observed number of procedures by the number that would be expected if the region had the same age-specific rates as Wales, and then multiplying this ratio by the Welsh procedure rate. Both SHA and LHB rates were standardised using 5-year age bands. PCT rates were standardised using two age groups – under 40 and over 40 years of age. Reference female populations were derived from the 2011 Office for National Statistics (ONS) population figures and all rates are expressed per 100 000 women/year.

8.3 Patterns of surgical treatment over time

Among the 137 581 women admitted with a primary diagnosis of HMB in England between April 2009 and March 2012, 52 245 women (38.0%) received surgical treatment. There were a total of 3171 vaginal hysterectomies, 9415 abdominal hysterectomies and 39 659 EAs. The annual numbers of all three procedures decreased over this time period (Figure 8.1).

In Wales, 11 344 women were admitted with a primary diagnosis of HMB in the corresponding time period. Of these, 3399 women (29.9%) received surgical treatment, with 196 vaginal hysterectomies, 555 abdominal hysterectomies and 2648 EAs. The annual numbers of EAs decreased over this time period, but the numbers of vaginal and abdominal hysterectomies remained stable (Figure 8.1).



Figures 8.1 Number of surgical operations for women with HMB in England (a) and Wales (b), April 2009 to March 2012

In both countries, the median age for EA was 43 years (IQR 39 to 47). The median age for hysterectomy in England was 42 years (IQR 37 to 46) and in Wales it was 41 years (IQR 39 to 47) (Table 8.1).

Table 8.1 Annual rate of surgery for women with HMB, by age group, between 2006 and 2012 in England and Wales

Age group (years)	Annual surgery rate (per 100 000 women)							
	England				Wales			
	2006/7 to 2008/9		2009/10 to 2011/12		2006/7 to 2008/9		2009/10 to 2011/12	
	EA	Hysterectomy	EA	Hysterectomy	EA	Hysterectomy	EA	Hysterectomy
25–29	10.9	5.6	9.5	4.6	17.1	4.8	15.6	4.4
30–34	43.5	23.6	38.2	16.7	71.7	29.6	67.7	27.9
35–39	126.6	60.8	116.6	42.1	170.2	68.5	190.2	76.6
40–44	229.1	96.4	229.8	71.4	287.2	87.2	293.8	89.2
45–49	220.3	83.2	222.3	64.3	277.7	59.8	256.4	55.3
50–54	75.2	27.2	77.8	20.8	98.1	21.6	91.1	20.1
55–59	8.7	4.0	6.6	3.5	8.9	3.3	9.5	3.5

8.4 Regional variations in surgical treatment

In England, the annual surgical rate for women with HMB was 139/100 000 women between April 2009 and March 2012. In Wales, the corresponding figure was 164/100 000 women. Among the ten English SHAs, the annual surgical rate ranged from 57 to 229 procedures/100 000 women, and among PCTs from 18 to 312 procedures/100 000 women (Figure 8.2). Among Welsh LHBs, this rate ranged from 146 to 214 procedures/100 000 women.

The proportion of women having surgery who underwent EA ranged from 71% to 85% within the ten English SHAs. Among Welsh LHBs, this proportion ranged from 70% to 87%.

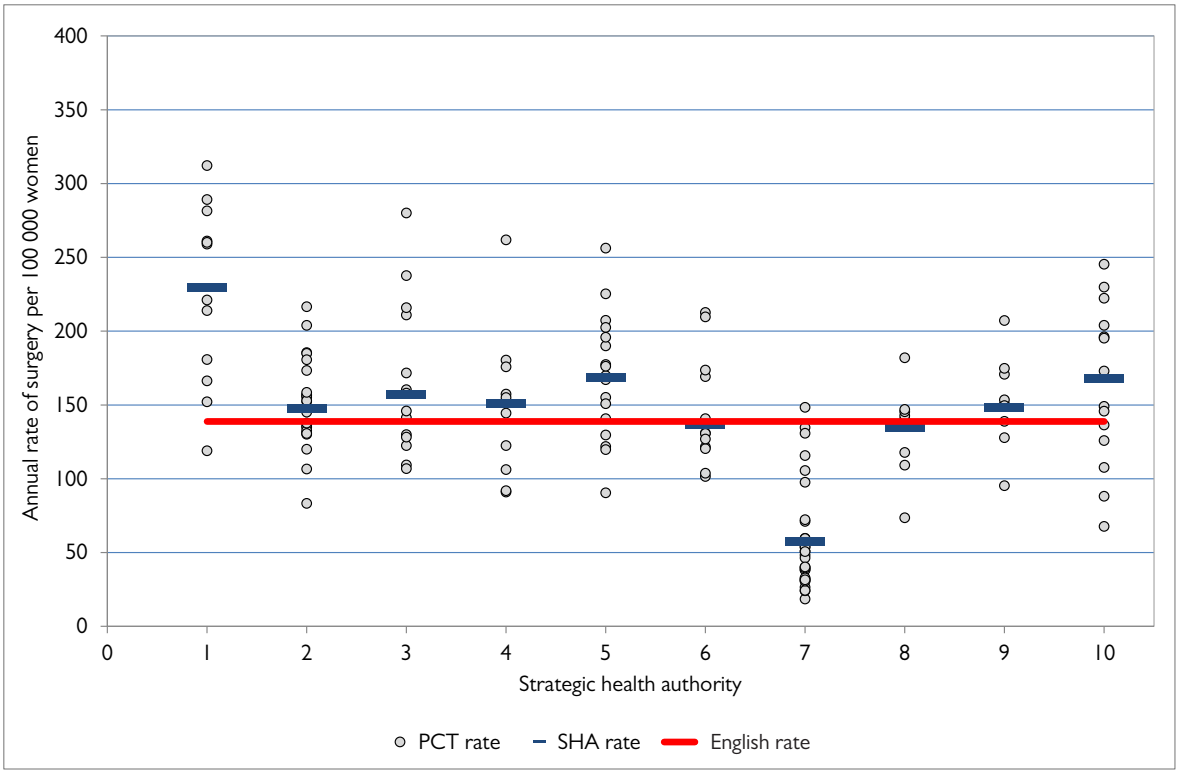


Figure 8.2 Annual rates of surgery at PCT and SHA level in England for women with HMB admitted to NHS trusts between 1 April 2009 and 31 March 2012; rates are expressed per 100 000 women and are standardised for age

The geographical distribution of relative rates of surgery for English PCTs and Welsh LHBs between April 2009 and March 2012 is shown in Figure 8.3. The pale areas have rates of surgery that are significantly lower than expected, while in the dark areas rates are higher than expected.

8.5 Comparison with patterns of treatment from 2006 to March 2009 in English NHS trusts

In the *First Annual Report*,[7] we reported an annual rate of surgical treatment of 152 procedures/100 000 women for the period from 2006 to 2009 in England (figures for Wales are not available), with corresponding annual rates across SHAs varying from 70 to 255 and across PCTs from 14 to 392 procedures/100 000 women. In comparison with the figures for the period April 2009 to March 2012 given in Section 8.4 above, there has been a slight decrease in the rate of surgical treatment but no reduction in the regional variation.

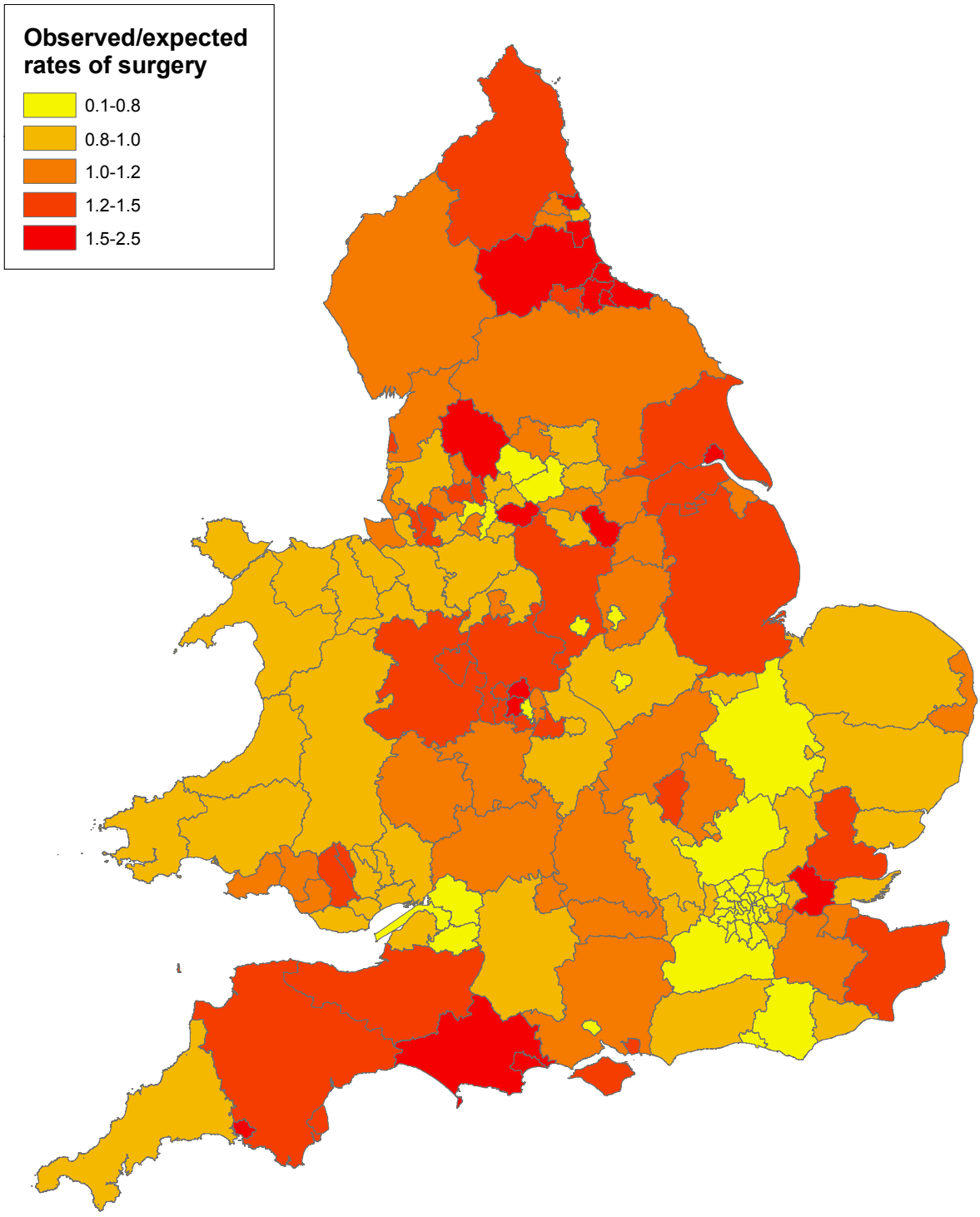


Figure 8.3 Relative rates of surgery for women with HMB in English PCTs and Welsh LHBs between April 2009 and March 2012 the relative rates are expressed as observed divided by expected number of procedures, and areas with values lower than 1 have lower than expected rates

8.6 Summary

In this chapter, we assessed regional variations in the rate of surgical treatment for women with HMB in England and Wales. We found the following:

- 38% of women who were admitted to an English NHS hospital with a diagnosis of HMB between April 2009 and March 2012 had a surgical procedure, with about three-quarters of these being EAs.
- In Wales, 30% of women admitted with HMB had a surgical procedure, and also about three-quarters of these were EAs.
- In the same period in England, the annual surgical rate for women with HMB was 139/100 000 women. In Wales, the corresponding figure was slightly higher at 164/100 000 women.
- There was a slight decrease in the annual rate of surgical treatment in England across the ten English SHAs (comparing the period 2006–2009 with the period 2009–2012) but the variation among SHAs and PCTs remained the same.
- There was a decrease in the use of EA between April 2009 and March 2012 in both England and Wales.

9 Conclusions

9.1 Introduction

Heavy menstrual bleeding (HMB) is a common condition, affecting around 25% of women aged between 30 and 50. About 20%[15] of the 1.2 million referrals to specialist gynaecologist services concern women with HMB. The National HMB Audit aimed to use patient-reported outcomes as indicators for the quality of care women received in the year after their first referral to a gynaecology outpatient clinic.

Patient-reported outcomes are a source of data for the audit as HMB has a major adverse effect on women's HRQoL: it impacts on physical, emotional and social wellbeing, and is a major cause of absence from work. A recent review[16] suggested that women with HMB have an HRQoL score below the 25th percentile for the general female population.

9.2 Treatments, outcomes and experiences in the year after the first outpatient clinic visit

In this *Final Report* of the Nation HMB Audit, we report the following:

- The organisation of clinical services for women with HMB has remained stable over the period of the audit: about one-third have a dedicated menstrual bleeding clinic, nearly all of which are a 'one-stop' clinic.
- There is considerable variation across providers in the treatment that women with HMB report. For example, the percentage of women who reported surgical treatment (EA, hysterectomy, myomectomy or UAE) varied between 20% and 60% across providers. Reasons as to why women might have received no treatment in secondary care could include them wanting to retain fertility or having been referred primarily for reassurance.
- There is also variation across providers in the outcomes that women reported, but the level of variation is smaller than that observed for treatment. On average, most women reported large improvements in their condition 1 year after their first outpatient clinic visit, irrespective of the type of treatment they received. The largest improvements were seen in women who had surgical treatment.
- Overall, women's experiences with care were very good, with 90% of them rating the care received in the year after their first outpatient clinic visit as at least 'good'. There was again considerable variation across providers. The average percentage of women who were satisfied with the information they had received was 81% and the percentage who felt that they had definitely been involved in the decision making about their care was 61%. These percentages varied considerably across providers.
- The women's ethnic background had a considerable impact on the treatments they received as well as on their outcomes and experience of care. Women from a non-white ethnic background were less likely to have surgery. They also reported smaller improvements in their condition, they were less satisfied with the information they received and they felt less involved in the decision making about their care. These findings may in part be attributable to cultural differences.
- The treatment in the year after the first outpatient clinic visit also varied according to the women's socio-economic background. Women from a more deprived background were less likely to have surgical treatment and they reported smaller improvements in their condition. Differences in the overall experience of care by socio-economic background were relatively small.

- The annual rate of surgical treatment for HMB is 139/100 000 women in England and 164/100 000 women in Wales. Patterns of treatment varied considerably across SHAs and PCTs in England and across LHBs in Wales. The overall rate of surgery has marginally reduced compared with the period 2006–2009, but the regional variation has remained unchanged.

Additional key findings in earlier reports are the following:

- Almost half of the women who attended their first outpatient gynaecological visit for an HMB complaint reported that they had additional problems, including fibroids, endometriosis and/or polyps.
- Nearly one-third of women reported that they had had no treatment for their HMB in primary care. However, it should be noted that immediate referral can be an appropriate option, for example for women with extensive fibroids or for women seeking further diagnostic tests and reassurance.

9.3 Validity and generalisability of audit results

In this *Final Report*, we have explored the validity and generalisability in a number of ways. We found the following:

- Women report accurately (compared with HES and PEDW data) whether or not they had a surgical procedure, but they are less accurate about the type of procedure.
- When compared with case notes, women themselves report slightly longer duration of symptoms. Their own account of the likely cause of their HMB differs considerably. The case note review confirmed that women accurately report whether they had surgical treatment, with the greatest agreement for hysterectomy.
- Women who were treated in trusts and health boards with a high case ascertainment more often had a non-white ethnic background and lived in more socio-economically deprived areas.

9.4 Strength and weaknesses of the National HMB Audit

In our original proposal, we stated as the audit's philosophy that we would combine prospectively collected patient-reported outcomes with administrative data in order to minimise the burden on clinical staff. As a consequence, we have used information reported by patients, supplemented with data from HES in England and PEDW in Wales.

The overall case ascertainment was 31.9%, which is much lower than the initial target of 70%. In addition, the response rate to the follow-up questionnaire was 55.6%, which again is lower than the target of 70%. Our assessment of the low case ascertainment and response rates demonstrates that younger age, non-white ethnicity and more deprived socio-economic status are important determinants of non-participation and non-response. The surveys were only available in the English language, which may have precluded non-English speakers from participating. As a first step, these factors need to be taken into account when comparing providers and different ways of managing women with HMB.

In the 2013 organisational survey, hospitals were also asked about the factors that contributed to a recruitment rate lower than expected in the audit. The main factors mentioned by hospitals were lack of availability of dedicated staff for patient recruitment, lack of patient motivation, lack of clinical support, difficulty identifying eligible patients, insufficient time for patients to compete the questionnaire before their appointment, and lack of availability of private space to complete the questionnaire. These comments need to be considered for national clinical audits in the future that rely on the collection of patient-reported information from outpatient clinics.

In this context, it is important to note that, of the clinicians who responded to our repeat organisation survey, a majority (around 80%) agreed that patients (rather than clinicians) are an appropriate source of information for an audit about clinical services for women with HMB. They also agreed that the information provided by women was valid and there was a strong support for using patient-reported information about their symptoms.

An important limitation in what we can report in this *Final Report* (compared with what we proposed to do) is the lack of a full investigation of the treatments that women received according to HES and PEDW data. In this report, there is a restricted comparison of treatments as reported in HES and PEDW compared with those reported by the women themselves. While this is indicative of the agreement between the two data sets, this comparison is of limited value given that we were unable to obtain HES and PEDW extracts for the full audit period, which would mean including episodes until 31 January 2013.

The HES extract that we had access to at the time of writing this report ran until 31 March 2012, and the PEDW extract until 31 December 2012. The limiting factor for the HES data has been a delay in obtaining up-to-date extracts from the HSCIC, which, owing to a number of large developments with regard to the handling of national electronic healthcare data, has been inundated with the rapidly increasing number of request for data extracts and linkage.

The proposed analyses that depend on data linkage, including describing the variation in treatments that women received across hospitals as well as investigating the accuracy with which women themselves describe the treatment they had, will need to be investigated after the publication of this report.

Lastly, one of the surprising observations of the National HMB Audit was that it is difficult to ascertain how many of the eligible patients will ultimately participate in the audit. As explained in the *Third Annual Report*,[6] we used three different sources to estimate the total number of eligible women (i.e. providers' own estimates obtained through the audit's organisational survey; outpatient HES and PEDW data, with the assumption that 10% of all first-time referrals would be for HMB; and inpatient HES and PEDW data, with the assumption that, overall, one-third of women referred for HMB would have a surgical procedure). We found that these sources produced different estimates at the national level but also at the provider level.

9.5 Determinants of high-quality care

The RCOG *Standards for Gynaecology*[5] indicate that written protocols should be in place for speedy and evidence-based management of HMB. These standards also highlight the importance of being able to provide a one-stop menstrual bleeding clinic with facilities for diagnostic gynaecology, including hysterectomy and ultrasound. Information leaflets should be available that describe all possible treatment options, together with their outcomes and complications.

We explored to what extent these organisational arrangements of clinical services had an impact on the outcomes and experiences reported by women 1 year after their first gynaecology outpatient clinic visit. We used the findings of the organisational audit (Chapter 2) and the treatments (Chapter 4), outcomes (Chapter 5) and experiences (Chapter 6) that were reported by the women themselves.

Table 9.1 demonstrates that there are only relatively small differences in the treatments, outcomes and experiences of women according to the organisational arrangements of the hospitals. For example, women treated in hospitals that have a written protocol had slightly higher rates of surgical treatment but the outcomes and experiences reported by the women themselves were similar. Hospitals with a one-stop clinic also seemed to have slightly higher surgical rates and women treated in these hospitals reported slightly higher HRQoL and lower symptoms severity, as well as a better overall experience. Average waiting times from primary to secondary care did not seem to have an impact on treatments, outcomes and experiences. Hospitals that provided written information for patients seemed to have slightly higher rates of surgical treatment.

These findings indicate that women treated in hospitals that have implemented the recommendations included in the RCOG *Standards for Gynaecology*[5] have outcomes and experiences that are a little better, but the differences are small. However, they also suggest that it is unlikely that outcomes and experiences can be improved by individual measures in isolation, and that it is the whole panoply of services for women with HMB that together determine the quality of their care.

Table 9.1 Determinants of high-quality care: a comparison of outcomes, treatments and experiences reported by women according to organisational characteristics observed in the repeat organisational survey

	Proportion of women (%)	Treatments at 1 year		Outcomes at 1 year		Patient experience: patients rating care received as excellent/very good/good (%)
		Rate of EA (%)	Rate of any surgery (%)	Mean HRQoL score	Mean symptom severity score	
n	8089	8089	8089	7803	7899	8089
Organisation of clinical services						
Availability of written protocol						
No	45.5	16.9	34.3	70.1	30.3	88.3
Yes	54.5	19.6	36.8	70.4	30.4	88.3
One-stop clinic						
No	60.5	17.7	35.7	69.7	30.8	87.8
Yes	39.5	19.5	36.0	71.1	29.6	89.2
Average waiting time from primary to secondary care						
4 weeks or less	33.1	18.4	35.4	71.2	29.6	87.0
5 to 7 weeks	38.0	17.4	35.1	70.0	30.6	89.1
8 weeks or more	29.0	18.7	35.2	69.8	30.6	88.5
Information for patients						
No written information	12.8	17.5	33.7	69.7	31.1	87.4
Leaflet	87.2	18.5	35.9	70.3	30.2	88.3

9.6 Implications for service delivery

Overall, 90% of women with HMB reported that they rated the care they received from hospitals in the year after their first outpatient clinic visit as good or excellent. The majority of women experienced substantial improvement in their symptoms.

However, the National HMB Audit demonstrates that care can be further improved. The audit's findings are important because they allow an assessment of the extent to which the NICE clinical guidelines[2] and quality standards[4] and the RCOG *Standards for Gynaecology*[5] are being followed in clinical practice. Comparing the results of the audit with the recommendations in these documents, we conclude the following:

- The existing referral pathways between primary and secondary care should be reviewed given that nearly one-third of women who reported that they had not received any treatment for their HMB in primary care. This review should carefully explore the reason why some women do not receive treatment in primary care as, in a number of cases, immediate referral is an appropriate option, for example for women with extensive fibroids.
- Care provided to women of non-white ethnicity and those from more socio-economically deprived areas should be reviewed as these women were less likely to have surgical treatment and they reported smaller improvements in their condition than white women and those from a less deprived background. A greater awareness of cultural differences and enhancing access to dedicated menstrual care may further improve how the individual needs of women are being met.
- For women with severe symptoms and a poor quality of life, surgical treatment (if appropriate) could be considered sooner as this audit found that it produced the greatest improvement.
- Information for patients should be further improved. About 10% of the hospitals reported that they do not provide written patient information on HMB and the treatment options that are available.

- Written protocols for the management of women with HMB should be more widely available as only about 50% of hospitals reported having such a protocol in place.
- The organisation of gynaecology outpatient clinics may need to be reviewed given that only one-third of hospitals reported that they had a dedicated menstrual bleeding clinic (with about 90% of these being one-stop clinics).
- Trusts and health boards should continue to compare themselves against their peers with regard to the treatments they offer to women with HMB, given the considerable variation that we observed across providers in treatments offered in secondary care. The results of each of the participating providers presented in Appendix 5 can be used for this purpose.

References

1. Shapley M, Jordan K, Croft PR. An epidemiological survey of symptoms of menstrual loss in the community. *Br J Gen Pract* 2004;54:359–63 [www.ncbi.nlm.nih.gov/pmc/articles/PMC1266170/].
2. National Collaborating Centre for Women's and Children's Health, National Institute for Health and Clinical Excellence (NICE). *Heavy Menstrual Bleeding*. Clinical Guideline No. 44. London: NICE; 2007 [www.nice.org.uk/Guidance/CG44].
3. Royal College of Obstetricians and Gynaecologists, London School of Hygiene & Tropical Medicine, Ipsos MORI. *National Heavy Menstrual Bleeding Audit*. Second Annual Report. London: RCOG; 2012 [www.rcog.org.uk/files/rcog-corp/NationalHMBAudit_2ndAnnualReport_11.07.12_forweb.pdf].
4. National Institute for Health and Care Excellence. *Heavy Menstrual Bleeding*. NICE Quality Standard 47. London: NICE; 2013 [www.nice.org.uk/guidance/QS47].
5. Royal College of Obstetricians and Gynaecologists. *Standards for Gynaecology*. Report of a Working Party. London: RCOG Press; 2008 [www.rcog.org.uk/womens-health/clinical-guidance/standards-gynaecology].
6. Royal College of Obstetricians and Gynaecologists, London School of Hygiene & Tropical Medicine, Ipsos MORI. *National Heavy Menstrual Bleeding Audit*. Third Annual Report. London: RCOG; 2013 [www.rcog.org.uk/files/rcog-corp/NationalHMBAudit_3rdAnnualReport_September2013.pdf].
7. Royal College of Obstetricians and Gynaecologists, London School of Hygiene & Tropical Medicine, Ipsos MORI. *National Heavy Menstrual Bleeding Audit*. First Annual Report. London: RCOG; 2011 [www.rcog.org.uk/files/rcog-corp/NationalHMBAudit_1stAnnualReport_May2011.pdf].
8. Royal College of Obstetricians and Gynaecologists, London School of Hygiene & Tropical Medicine, Ipsos MORI. *National Heavy Menstrual Bleeding Audit Addendum: Patterns of Surgical Treatment for Women with Heavy Menstrual Bleeding in Wales*. London: RCOG; 2012 [www.rcog.org.uk/files/rcog-corp/HMBAuditAddendum_forweb.pdf].
9. Cromwell DA, Mahmood TA, Templeton A, van der Meulen JH. Surgery for menorrhagia within English regions: variation in rates of endometrial ablation and hysterectomy. *BJOG* 2009 Sep;116(10):1373–9 [onlinelibrary.wiley.com/doi/10.1111/j.1471-0528.2009.02284.x/pdf].
10. Office for National Statistics. *Social Focus in Brief: Ethnicity 2002*. London: ONS; 2002 [www.ons.gov.uk/ons/rel/ethnicity/social-focus-in-brief--ethnicity/full-report/full-report---ethnicity.pdf].
11. Office for National Statistics. *Ethnicity and National Identity in England and Wales 2011*. London: ONS; 2012 [www.ons.gov.uk/ons/dcp171776_290558.pdf].
12. Royston P. Multiple imputation of missing values: update. *Stata J* 2005;5:188–201 [www.stata-journal.com/article.html?article=st0067_1].
13. Spiegelhalter DJ. Funnel plots for comparing institutional performance. *Stat Med* 2005;24:1185–202.
14. Department of Health. *Patient Reported Outcome Measures (PROMs) in England: A Methodology for Identifying Potential Outliers*. London: Department of Health; 2011 [www.gov.uk/government/publications/patient-reported-outcome-measures-proms-in-england-a-methodology-for-identifying-potential-outliers--2].

15. National Institute for Health and Clinical Excellence. *Heavy Menstrual Bleeding: Draft Scope for Consultation*. London: NICE; 2004 [www.nice.org.uk/guidance/cg44/resources/draft-consultation-scope2].

16. Liu Z, Doan QV, Blumenthal P, Dubois RW. A systematic review evaluating health-related quality of life, work impairment, and health-care costs and utilization in abnormal uterine bleeding. *Value Health* 2007 ;10:183–94.

Appendix 1

Clinical Reference Group, Project Board and Clinical Advisors

Members of the Clinical Reference Group

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Allan Templeton FRCOG	Project team
Jan van der Meulen	Project team Co-Chair

Members of the Project Board

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Anna Carluccio	Project team
Anita Dougall	Project team
Stefan Durkacz	Project team
Ipek Gurol-Urganci	Project team
Angela Hyde	Chair of Clinical Reference Group
Sara Johnson	Project team
Amit Kiran	Project team
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Samantha McIntyre	Healthcare Quality Improvement Partnership
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Clinical Advisors

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Appendix 2

Acknowledgement of providers and clinical staff

Thank you to those who contributed to the repeat organisational survey and the case note review exercise.

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Graham Foat	Ormskirk & District General Hospital
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Bruce Ramsay	Peterborough City/Stamford Hospitals
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Veena Kaul	Pontefract General Infirmary
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Tracy Wareham	Southmead Hospital
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Philip Morgan	St Helens/Whiston Hospitals
Pandelis Athanasias	St Helier Hospital
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Kristina Naidoo	St Mary's Hospital (Manchester)
Katy Clifford	St Mary's Hospital (London)
Adrian Green	St Mary's Hospital (Isle of Wight)
Martin Mills	St Michael's Hospital
Saikat Banerjee	St Peter's Hospital
AM Simons	St Richard's Hospital
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Tunde Dada	Stoke Mandeville Hospital
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Hanny Stockman	Tameside Hospital
Jonathan Hindley	Torbay Hospital
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Lawrence Anyanwu	University Hospital (Coventry)
Dan Zamblera	University Hospital Lewisham
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Ambreen Rauf	Warrington Hospital
Laurie Irvine	Watford Hospital
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Funlayo Odejinmi	Whipps Cross University Hospital
Christine Link	Withybush General Hospital
Rhonda Flemming	Whittington Hospital
Mamta Pathak	Worcestershire Royal Hospital
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Appendix 3

Repeat organisational survey

Instructions for completing and returning survey

1. **Please ensure that one survey is completed for each outpatient gynaecology department within your trust. All questions refer to individual hospitals, not the trust as a whole.**
2. **Completion of this survey may require a multi-professional effort. We would be grateful if the Clinical Director could take responsibility for ensuring that the survey is fully completed and returned to the RCOG.**
3. **The survey has 25 questions and will take approximately 10 minutes to complete depending on availability of relevant information.**
4. **Please answer all questions, unless instructed by '→ *go to'* instruction next to some tick boxes. If there is no '→ *go to'* instruction, please proceed to the next question.**
5. **Please complete the survey online at http://www.surveymonkey.com/s/rcoghmb by 31st July 2013.**
6. **If you want, you can print a copy of the completed questionnaire for your reference.**
7. **If you have any questions about this survey, please contact the HMB Audit Lead, Dr Amit Kiran, at amit.kiran@lshtm.ac.uk or telephone 0207 927 2279.**

1. **Outpatient Gynaecology Department**

Hospital _____

NHS Trust _____

2. **Details of Person Completing the Survey**

Your name _____

Job title/role _____

Department _____

Hospital _____

Trust _____

Telephone _____

Email _____

Services and Care for Women with Heavy Menstrual Bleeding

3. Does your department have a **written** protocol or guideline regarding the care and management of women with heavy menstrual bleeding?

   ☐ No
   ☐ Yes

4. Does your department have a dedicated heavy menstrual bleeding clinic (i.e., a clinic that is designed only to see patients with menstrual bleeding issues)?

   ☐ No→ *go to question 7.*
   ☐ Yes

5. If yes, would you describe the heavy menstrual bleeding clinic as a 'one-stop' clinic (a clinic that provides both diagnosis and treatment plan at the same appointment)?

   ☐ No→ *go to question 7.*
   ☐ Yes

6. If yes, what proportion of women with heavy menstrual bleeding are first seen in the heavy menstrual bleeding clinic? (*Please tick <u>one</u> box*)

Almost all	Most	Around half	Minority	Very few
☐	☐	☐	☐	☐

7. Which of the following facilities are available within the department to investigate patients with heavy menstrual bleeding? (*Tick all that apply*)

   ☐ Ultrasound (Transvaginal ultrasound scanning in the clinic)
   ☐ Hysteroscopy (outpatient based)
   ☐ Endometrial biopsy (outpatient based)
   ☐ Day care diagnosis, hysteroscopy plus endometrial biopsy (inpatient based)
   ☐ Other *(Please specify)*_____

8. What investigations are considered at the **first consultation** in your clinic of a woman with heavy menstrual bleeding who has been referred for the first time? (*Tick all investigations that apply*)

	Always	Mostly	Sometimes	Rarely	Never
Objective method of assessing blood loss	☐	☐	☐	☐	☐
Full blood count	☐	☐	☐	☐	☐
Ultrasound and other imaging	☐	☐	☐	☐	☐
Pathology (e.g., endometrial biopsy)	☐	☐	☐	☐	☐
Abdominal and pelvic examination	☐	☐	☐	☐	☐
Other (*Please specify*) _____	☐	☐	☐	☐	☐

9. What surgical treatment options does your trust offer women with heavy menstrual bleeding? (*Tick all that apply*)

- ☐ Endometrial cryotherapy ablation
- ☐ Fluid filled thermal balloon ablation
- ☐ Free fluid thermal ablation
- ☐ Impedance control ablation
- ☐ Microwave ablation
- ☐ Endometrial resection/roller ball ablation
- ☐ Uterine artery embolisation
- ☐ Laparoscopic assisted hysterectomy
- ☐ Abdominal hysterectomy
- ☐ Vaginal hysterectomy
- ☐ Hysteroscopic myomectomy (Resection/Laser)
- ☐ Other (*Please specify*)_____

Referral

10. What referral systems are available to women with heavy menstrual bleeding in your local area? (How are women referred to care in your department?) (*Tick all that apply)*

- ☐ GP referral
- ☐ Referral by other NHS professionals
- ☐ Other triage or PCT referral system
- ☐ A&E department referral
- ☐ Patients approach clinic directly; no referral required
- ☐ Other (*Please specify*)_____

11. What baseline investigations would generally have been carried out in primary care prior to patients' referral to your department? (*Tick all investigations that apply)*

	Always	Mostly	Sometimes	Rarely	Never	Don't know
Full blood count	☐	☐	☐	☐	☐	☐
Liver function test	☐	☐	☐	☐	☐	☐
Hormonal assessment	☐	☐	☐	☐	☐	☐
Thyroid function test	☐	☐	☐	☐	☐	☐
Ultrasound	☐	☐	☐	☐	☐	☐
Other (*Please specify*) _____	☐	☐	☐	☐	☐	☐
None of these	☐	☐	☐	☐	☐	☐

12. When women with heavy menstrual bleeding come to your clinic for the first time, what treatments have they typically already had in primary care, or that have been self administered? (*Tick all treatments that apply)*

	Always	Mostly	Sometimes	Rarely	Never
Combined oral contraceptives (COCs)	☐	☐	☐	☐	☐
Injected long-acting progestogens	☐	☐	☐	☐	☐
Levonorgestrel-releasing intrauterine system (LNG-IUS) (e.g., Mirena)	☐	☐	☐	☐	☐
Trial of treatment with Mefenamic Acid	☐	☐	☐	☐	☐
Oral progestogens	☐	☐	☐	☐	☐
Tranexamic acid	☐	☐	☐	☐	☐
Self treatment	☐	☐	☐	☐	☐
Other (*Please specify*) _____	☐	☐	☐	☐	☐

13. What proportion of women who are referred for the first time to your clinic for heavy menstrual bleeding have had not had any treatment in primary care? (*Please tick <u>one</u> box*)

- ☐ All or almost all (app. 91-100%)
- ☐ Most (app. 60-90%)
- ☐ Around half (app. 41-59%)
- ☐ Minority (app. 10-40%)
- ☐ Very few (<10%)

14. In general, what are the most common reasons for patients with heavy menstrual bleeding to be referred for the first time to your outpatient department? *(Tick all reasons that apply)*

	Always	Mostly	Sometimes	Rarely	Never
Failure to respond to medical treatment in primary care	☐	☐	☐	☐	☐
Patient seeking definite treatment (e.g., hysterectomy)	☐	☐	☐	☐	☐
Patient requesting referral to a specialist	☐	☐	☐	☐	☐
Other (*Please specify*) _____	☐	☐	☐	☐	☐

15. What is the average waiting time between referral from GP to first outpatient appointment in your clinic for women with heavy menstrual bleeding?

☐☐ weeks OR ☐ Not sure

16. Considering the outcome of the first visit in your clinic for women with heavy menstrual bleeding, please estimate the proportion of women who would have the following management options?

Management options after first consultation	Approximate percentage (*Please round to nearest 10%*)
Reassure and send back to GP	
Offer medical treatment and send back to GP for follow-up	
Insert LNG-IUS (e.g., Mirena)	
Put on waiting list for endometrial ablation	
Put on waiting list for hysterectomy	
Other (*Please specify*) _____	

17. Can GPs in your area refer women with heavy menstrual bleeding directly for the following diagnostic procedures? (*Tick all that apply)*

☐ Imaging
☐ Pathology
☐ Other diagnostic procedures (*Please specify*)_____
☐ Not applicable, GPs cannot directly refer for any services

Information for patients

18. Does your department provide written information for women with complaints of heavy menstrual bleeding? (*Tick all that apply*)

- ☐ Leaflet
- ☐ Website (*Please specify*)_____
- ☐ Other (*Please specify*)_____
- ☐ Not applicable, unit does not provide information

19. If the department provides written information about heavy menstrual bleeding, when do you typically provide this information? (*Please tick <u>one</u> box*)

- ☐ Prior to first visit
- ☐ At first visit prior to seeing a clinician
- ☐ At first visit while seeing a clinician
- ☐ After first visit
- ☐ No typical time
- ☐ Other (*Please specify)*_____

20. Who in your department is **most** likely to provide written information about heavy menstrual bleeding to patients? (*Please tick <u>one</u> box*)

- ☐ Consultant gynaecologist
- ☐ SAS or associate specialist gynaecologist
- ☐ Doctor in training
- ☐ Nurse practitioner
- ☐ Nurse
- ☐ Healthcare assistant
- ☐ Receptionist
- ☐ Other (*Please specify*)_____

21. The audit was based on patient reported symptoms, treatments and outcomes. Do you think the information reported by patients with heavy menstrual bleeding is valid?

Type of information	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Symptoms	☐	☐	☐	☐	☐
Treatments	☐	☐	☐	☐	☐
Outcomes	☐	☐	☐	☐	☐

22. Do you think that patients (rather than clinicians) are an appropriate source of information for clinical audits into care aimed at improving a patient's quality of life? (*Please tick <u>one</u> box*)

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
☐	☐	☐	☐	☐

23. The overall recruitment rate in the audit was lower than expected. Which of the following factors led to difficulties in the recruitment of patients in your outpatient department? (*Tick all factors that apply*)

	Always	Mostly	Sometimes	Rarely	Never
Local clinical support	☐	☐	☐	☐	☐
Identification of eligible patients	☐	☐	☐	☐	☐
Availability of staff to administer questionnaires	☐	☐	☐	☐	☐
Availability of sufficiently private space for participants to complete the questionnaire	☐	☐	☐	☐	☐
Insufficient time to complete the questionnaire before the appointment	☐	☐	☐	☐	☐
Patient motivation	☐	☐	☐	☐	☐
Support from the HMB audit team	☐	☐	☐	☐	☐
Other	☐	☐	☐	☐	☐

24. Do you have any suggestions to improve recruitment in future national audits in gynaecology?

☐ No

☐ Yes (please write here): _____

_____

_____

_____

25. What has changed in your service delivery model for women with heavy menstrual bleeding since 2010? (*Tick all that apply*)

☐ New service delivery model

☐ Introduction of new departmental protocols

☐ Introduction of new primary care pathways

☐ Increased proportion of women receiving care being delivered in the primary care

☐ Reduced number of referrals to my the trust

If your trust has introduced a new service delivery model, please describe the model briefly:

_____

_____

_____

Appendix 4

Case note review questionnaire

Royal College of Obstetricians and Gynaecologists
Bringing to life the best in women's health care

The National Heavy Menstrual Bleeding Audit in the NHS

Please confirm the patients unique project identification number (this is not the NHS number)
☐☐☐☐☐☐☐☐☐☐

Please confirm the patients date of birth (day/month/year)
☐☐/☐☐/☐☐☐☐

Please indicate answers by ticking (✓) the relevant box or boxes.

Q.1 How long did this patient have symptoms of HMB before her first outpatient visit?
Please tick one.

- ☐ 2 months or less
- ☐ More than 2 months, but less than 1 year
- ☐ More than 1 year
- ☐ Don't know

Q.2. Did this patient have previous treatments for HMB before her first outpatient visit?
Please tick all that apply.

- ☐ None
- ☐ The Pill (oral contraception)
- ☐ Other medication (not the pill)
- ☐ Intrauterine system (for example Mirena)
- ☐ Endometrial ablation (treatment to remove the lining of uterus or womb)
- ☐ Other treatment
- ☐ Don't know

Q.3 Did this patient have any of the following suspected/diagnosed at her first outpatient visit? Please tick all that apply.

- ☐ Uterine fibroids
- ☐ Endometriosis
- ☐ Polyps of the uterus (womb) or cervix
- ☐ A bleeding disorder
- ☐ Adenomyosis
- ☐ Heart disease (for example angina, heart attack or heart failure)
- ☐ High blood pressure
- ☐ Lung disease (for example asthma, chronic bronchitis or emphysema)
- ☐ Diabetes
- ☐ Depression
- ☐ Thyroid disorder
- ☐ Kidney disease
- ☐ Cancer (within the last 5 years)

Q.4 What treatment did this patient get in the year following the first outpatient visit?
Please tick all that apply.

- □ No treatment
- □ Oral medication (including the pill)
  - □ From hospital
  - □ From GP or Family Planning Clinic
- □ Intrauterine system (for example Mirena)
  - □ From hospital
  - □ From GP or Family Planning Clinic
- □ Endometrial ablation (treatment to remove the lining of uterus or womb)
  - □ Diathermy
  - □ Balloon
  - □ Laser
  - □ Microwave
  - □ Fluid filled
- □ Hysterectomy
- □ Myomectomy
- □ Uterine artery embolisation
- □ Other treatment _____
- □ Don't know

Q.5 What was the cause of HMB reported in one year after the first outpatient visit?
Please tick all that apply.

- □ Dysfunctional uterine bleeding
- □ Hormonal imbalance
- □ Polyps of the lining of the womb
- □ Endometriosis
- □ Uterine fibroids
- □ No obvious cause
- □ Other cause _____
- □ Don't know

Thank you for completing this questionnaire

Appendix 5

Provider-level descriptive statistics

Inclusion criteria:

- NHS providers that completed both organisational surveys (131 NHS hospitals trusts, comprising 180 hospitals)
- patients that completed both baseline and follow-up questionnaires and are from the selected hospitals (8089 of 8517 responders).

Table A5.1 Organisational services (repeat organisational survey 2013)

Provider name	Written protocol	Dedicated HMB one-stop clinic	Average waiting time between referral from GP to first outpatient clinic visit	Written information (leaflet) provided
	Yes, No	Yes, No	Weeks	Yes, No
Abertawe Bro Morgannwg University Health Board	No	No	26	Yes
Airedale NHS Trust	Yes	Yes	N/A	Yes
Aneurin Bevan Health Board	No	No	36	No
Ashford and St Peter's Hospitals NHS Trust	No	Yes	6	Yes
Barking, Havering and Redbridge University Hospitals NHS Trust	Yes	Yes	12	Yes
Barnet and Chase Farm Hospitals NHS Trust	No	No	18	Yes
Barnsley Hospital NHS Foundation Trust	Yes	No	8	Yes
Barts Health NHS Trust	Yes	Yes	6.5	Yes
Basildon and Thurrock University Hospitals NHS Foundation Trust	Yes	Yes	12	Yes
Bedford Hospital NHS Trust	No	No	6	Yes
Betsi Cadwaladr University Health Board	Yes	Yes	19.3	Yes
Birmingham Women's NHS Foundation Trust	No	Yes	8	Yes
Blackpool Fylde and Wyre Hospitals NHS Foundation Trust	Yes	No	6	No
Bradford Teaching Hospitals NHS Foundation Trust	Yes	Yes	4	Yes
Brighton and Sussex University Hospitals NHS Trust	Yes	No	N/A	Yes
Buckinghamshire Hospitals NHS Trust	No	No	8	No
Burton Hospitals NHS Foundation Trust	No	No	N/A	No
Calderdale and Huddersfield NHS Foundation Trust	Yes	No	6	Yes
Cambridge University Hospitals NHS Foundation Trust	Yes	No	5	Yes
Central Manchester University Hospitals NHS Foundation Trust	No	Yes	N/A	Yes
Chelsea and Westminster Hospital NHS Foundation Trust	No	No	N/A	No
Chesterfield Royal Hospital NHS Foundation Trust	No	No	3	No
City Hospitals Sunderland NHS Foundation Trust	Yes	No	5.7	Yes
County Durham and Darlington NHS Foundation Trust	No	No	6	Yes
Croydon Health Services NHS Trust	Yes	No	4	Yes
Cwm Taf Health Board	Yes	Yes	26	Yes
Dartford and Gravesham NHS Trust	No	No	6	Yes
Derby Hospitals NHS Foundation Trust	Yes	Yes	4	Yes
Doncaster & Bassetlaw Hospitals NHS Foundation Trust	No	No	4	Yes

Provider name	Written protocol	Dedicated HMB one-stop clinic	Average waiting time between referral from GP to first outpatient clinic visit	Written information (leaflet) provided
	Yes, No	Yes, No	Weeks	Yes, No
Ealing Hospital NHS Trust	No	No	4	Yes
East and North Hertfordshire NHS Trust	No	No	7	Yes
East Cheshire NHS Trust	Yes	No	3	Yes
East Lancashire Hospitals NHS Trust	Yes	No	6	No
East Sussex Hospitals NHS Trust	Yes	No	8	Yes
Epsom and St Helier University Hospitals NHS Trust	Yes	No	4	Yes
Frimley Park NHS Foundation Trust	Yes	No	5	Yes
Gateshead Health NHS Foundation Trust	No	No	4	No
George Eliot Hospital NHS Trust	No	Yes	4	Yes
Great Western Hospitals NHS Foundation Trust	Yes	Yes	24	Yes
Guy's and St Thomas' NHS Foundation Trust	Yes	Yes	6	Yes
Hampshire Hospitals NHS Foundation Trust	Yes	Yes	10	Yes
Heart of England NHS Foundation Trust	Yes	No	5.3	Yes
Heatherwood and Wexham Park Hospitals Trust	Yes	No	6	Yes
Hereford Hospitals NHS Trust	Yes	Yes	10	No
Hinchingbrooke Healthcare NHS Trust	Yes	No	N/A	Yes
Homerton University Hospital NHS Foundation Trust	No	No	4	Yes
Hull & East Yorkshire Hospitals NHS Trust	Yes	Yes	6	Yes
Hywel Dda Health Board	Yes	Yes	23	Yes
Imperial College Healthcare NHS Trust	Yes	Yes	4.5	Yes
Ipswich Hospital NHS Trust	Yes	No	4	Yes
Isle of Wight NHS Trust	No	No	6	No
James Paget University Hospitals NHS Foundation Trust	No	No	12	Yes
King's College Hospital NHS Foundation Trust	Yes	No	3	Yes
Kingston Hospital NHS Trust	No	No	4	Yes
Lancashire Teaching Hospitals NHS Trust	No	No	8	No
Leeds Teaching Hospitals NHS Trust	No	No	6	Yes
Liverpool Women's NHS Foundation Trust	Yes	Yes	5	Yes
Luton and Dunstable Hospital NHS Foundation Trust	No	No	4	Yes
Maidstone and Tunbridge Wells NHS Trust	Yes	Yes	8	Yes
Medway NHS Foundation Trust	No	Yes	10	Yes
Mid Cheshire Hospitals NHS Foundation Trust	No	No	4	Yes
Mid Essex Hospital Services NHS Trust	Yes	Yes	3	Yes
Mid Staffordshire General Hospitals NHS Trust	No	No	5	Yes
Mid Yorkshire Hospitals NHS Trust	Yes	No	6	Yes
Milton Keynes Hospital NHS Foundation Trust	Yes	No	6	Yes
Norfolk and Norwich University Hospital NHS Trust	No	Yes	4	Yes
North Bristol NHS Trust	Yes	No	N/A	Yes
North Cumbria Acute Hospitals NHS Trust	Yes	No	6	Yes
North Middlesex University Hospital NHS Trust	Yes	No	3	Yes
North Tees and Hartlepool NHS Trust	Yes	Yes	4	Yes
North West London Hospitals NHS Trust	No	No	2	Yes
Northampton General Hospital NHS Trust	Yes	Yes	4	Yes
Northern Devon Healthcare NHS Trust	No	No	6	No
Northern Lincolnshire & Goole Hospitals NHS Foundation Trust	Yes	Yes	3	Yes
Northumbria Healthcare NHS Foundation Trust	No	Yes	5	Yes
Oxford Radcliffe Hospitals NHS Trust	Yes	Yes	5	Yes
Pennine Acute Hospitals NHS Trust	No	No	4	Yes

Provider name	Written protocol	Dedicated HMB one-stop clinic	Average waiting time between referral from GP to first outpatient clinic visit	Written information (leaflet) provided
	Yes, No	Yes, No	Weeks	Yes, No
Peterborough and Stamford Hospitals NHS Foundation Trust	Yes	No	4	Yes
Plymouth Hospitals NHS Trust	Yes	Yes	6	Yes
Poole General Hospital NHS Foundation Trust	Yes	Yes	6	Yes
Portsmouth Hospitals NHS Trust	Yes	No	8	Yes
Royal Berkshire Foundation Trust	No	No	6	Yes
Royal Cornwall Hospitals NHS Trust	No	No	10	Yes
Royal Devon & Exeter NHS Foundation Trust	No	Yes	5	Yes
Royal Free Hampstead NHS Trust	No	No	N/A	Yes
Royal United Hospital Bath NHS Trust	Yes	No	5	Yes
Salisbury Hospital NHS Foundation Trust	No	No	8	No
Sandwell & West Birmingham Hospitals NHS Trust	Yes	Yes	3.5	Yes
Sheffield Teaching Hospitals NHS Trust	Yes	No	5	Yes
Sherwood Forest Hospitals NHS Trust	Yes	No	3	Yes
Shrewsbury & Telford Hospital NHS Trust	Yes	Yes	12	Yes
South Devon Healthcare NHS Foundation Trust	Yes	No	5	No
South Tees Hospitals NHS Trust	Yes	Yes	5.5	Yes
South Tyneside NHS Foundation Trust	No	No	5	No
South Warwickshire General Hospitals NHS Trust	No	No	6	Yes
Southampton University Hospitals NHS Trust	No	Yes	4	Yes
Southend University Hospital NHS Foundation Trust	Yes	No	4	Yes
Southport & Ormskirk Hospital NHS Trust	No	No	6	Yes
St George's Healthcare NHS Trust	No	No	10	Yes
St Helens & Knowsley Hospitals NHS Trust	Yes	No	8	Yes
Stockport NHS Foundation Trust	No	No	4	Yes
Tameside Hospital NHS Foundation Trust	Yes	Yes	2	Yes
Taunton and Somerset NHS Foundation Trust	No	Yes	8	Yes
The Hillingdon Hospital NHS Trust	Yes	No	3	Yes
The Lewisham Hospital NHS Trust	Yes	No	8	Yes
The Newcastle upon Tyne Hospitals NHS Foundation Trust	Yes	Yes	8	Yes
The Princess Alexandra Hospital NHS Trust	No	No	4	Yes
The Queen Elizabeth Hospital King's Lynn NHS Trust	No	No	18	No
The Royal Bolton Hospital NHS Foundation Trust	Yes	No	1	Yes
The Royal Bournemouth and Christchurch NHS Foundation Trust	Yes	Yes	6	Yes
The Royal Wolverhampton Hospitals NHS Trust	No	Yes	12	Yes
The Whittington Hospital NHS Trust	No	Yes	6	Yes
United Lincolnshire Hospitals NHS Trust	Yes	Yes	8	Yes
University College London Hospitals NHS Foundation Trust	Yes	Yes	8	No
University Hospital of North Staffordshire NHS Trust	No	No	N/A	Yes
University Hospitals Bristol NHS Foundation Trust	No	No	8	Yes
University Hospitals Coventry and Warwickshire NHS Trust	Yes	Yes	4	Yes
University Hospitals of Leicester NHS Trust	Yes	Yes	5	No
University Hospitals of Morecambe Bay NHS Trust	No	No	5	Yes
University Hospitals of South Manchester NHS Foundation Trust	No	No	6	Yes
Walsall Hospitals NHS Trust	No	Yes	5	No

Provider name	Written protocol	Dedicated HMB one-stop clinic	Average waiting time between referral from GP to first outpatient clinic visit	Written information (leaflet) provided
	Yes, No	Yes, No	Weeks	Yes, No
Warrington and Halton Hospitals NHS Foundation Trust	No	Yes	4	Yes
West Hertfordshire Hospitals NHS Trust	Yes	No	6	Yes
West Middlesex University Hospital NHS Trust	Yes	No	8	Yes
Western Sussex Hospitals NHS Trust	No	Yes	5.5	Yes
Weston Area Health NHS Trust	Yes	No	6	Yes
Wirral University Teaching Hospital NHS Foundation Trust	No	No	4	Yes
Worcestershire Acute Hospitals NHS Trust	Yes	No	6.3	Yes
Wrightington, Wigan and Leigh NHS Foundation Trust	Yes	Yes	3	Yes
Yeovil District Hospital NHS Foundation Trust	Yes	No	8	Yes
York Teaching Hospital NHS Foundation Trust	No	No	12	Yes

Table A5.2 Patient-reported characteristics at the first outpatient clinic visit (baseline)

Provider name	Case ascertainment (%)	Actual cases (*n*)	Case ascertainment category* (Low, Mid or High)	Overall health of women (Excellent/very good) (%)	Women with at least one HMB-related condition (%)	Women who reported no previous treatment in primary care (%)
Abertawe Bro Morgannwg University Health Board	27.2	113	Mid	48.2	51.3	36.1
Airedale NHS Trust	48.8	52	High	42.3	42.3	24
Aneurin Bevan Health Board	50.6	89	High	40.9	48.3	33.3
Ashford and St Peter's Hospitals NHS Trust	2.5	4	Low	25	50	0
Barking, Havering and Redbridge University Hospitals NHS Trust	22.1	36	Mid	19.4	66.7	30.6
Barnet and Chase Farm Hospitals NHS Trust	24.4	16	Mid	40	62.5	18.8
Barnsley Hospital NHS Foundation Trust	41.7	66	Mid	35.4	48.5	25.8
Barts Health NHS Trust	32.4	81	Mid	21.8	55.6	42.3
Basildon and Thurrock University Hospitals NHS Foundation Trust	7.7	18	Low	23.5	66.7	38.9
Bedford Hospital NHS Trust	23.5	26	Mid	34.6	30.8	24
Betsi Cadwaladr University Health Board	50.5	266	High	48.7	44	37.8
Birmingham Women's NHS Foundation Trust	9.6	30	Low	27.6	60	25
Blackpool Fylde and Wyre Hospitals NHS Foundation Trust	34.7	71	Mid	47.9	43.7	25.7
Bradford Teaching Hospitals NHS Foundation Trust	31.9	16	Mid	37.5	56.3	12.5
Brighton and Sussex University Hospitals NHS Trust	24.6	52	Mid	37.3	63.5	32.7

Provider name	Case ascertainment (%)	Actual cases (*n*)	Case ascertainment category* (Low, Mid or High)	Overall health of women (Excellent/ very good) (%)	Women with at least one HMB-related condition (%)	Women who reported no previous treatment in primary care (%)
Buckinghamshire Hospitals NHS Trust	21.9	37	Mid	48.6	67.6	32.4
Burton Hospitals NHS Foundation Trust	31	41	Mid	37.5	56.1	29.3
Calderdale and Huddersfield NHS Foundation Trust	35	71	Mid	34.8	45.1	28.6
Cambridge University Hospitals NHS Foundation Trust	36.7	45	Mid	37.8	51.1	20.9
Central Manchester University Hospitals NHS Foundation Trust	6.8	14	Low	14.3	64.3	35.7
Chelsea and Westminster Hospital NHS Foundation Trust	3.8	3	Low	66.7	66.7	66.7
Chesterfield Royal Hospital NHS Foundation Trust	27.5	60	Mid	35	48.3	29.3
City Hospitals Sunderland NHS Foundation Trust	39.4	93	Mid	44.1	31.2	37.1
County Durham and Darlington NHS Foundation Trust	13.7	37	Low	35.1	21.6	36.1
Croydon Health Services NHS Trust	20.5	12	Mid	50	58.3	45.5
Cwm Taf Health Board	33.1	83	Mid	46.3	39.8	31.6
Dartford and Gravesham NHS Trust	8.9	20	Low	35	70	45
Derby Hospitals NHS Foundation Trust	26.5	91	Mid	32.6	60.4	26.7
Doncaster & Bassetlaw Hospitals NHS Foundation Trust	58.4	156	High	35.9	46.2	31.6
Ealing Hospital NHS Trust	62.3	45	High	20.5	48.9	27.5
East and North Hertfordshire NHS Trust	11.7	27	Low	44.4	59.3	33.3
East Cheshire NHS Trust	81.5	82	High	45.7	53.7	31.7
East Lancashire Hospitals NHS Trust	63.5	113	High	42	41.6	33.3
East Sussex Hospitals NHS Trust	70.2	172	High	37.7	52.3	37.3
Epsom and St Helier University Hospitals NHS Trust	22.8	42	Mid	47.6	61.9	40.5
Frimley Park NHS Foundation Trust	16.2	18	Low	50	66.7	38.9
Gateshead Health NHS Foundation Trust	45.1	38	High	42.1	44.7	24.3
George Eliot Hospital NHS Trust	4.9	4	Low	75	50	50
Great Western Hospitals NHS Foundation Trust	35.4	86	Mid	51.8	40.7	25.3
Guy's and St Thomas' NHS Foundation Trust	79.8	155	High	33.6	68.4	32.9
Hampshire Hospitals NHS Foundation Trust	29.9	97	Mid	47.4	60.8	28.1
Heart of England NHS Foundation Trust	27.8	90	Mid	37.8	51.1	32.6
Heatherwood and Wexham Park Hospitals Trust	15.9	21	Low	19	61.9	40
Hereford Hospitals NHS Trust	12	15	Low	40	46.7	46.7
Hinchingbrooke Healthcare NHS Trust	42.2	50	Mid	44	54	22.4
Homerton University Hospital NHS Foundation Trust	41.7	16	Mid	18.8	93.8	12.5

Provider name	Case ascertainment (%)	Actual cases (*n*)	Case ascertainment category* (Low, Mid or High)	Overall health of women (Excellent/ very good) (%)	Women with at least one HMB-related condition (%)	Women who reported no previous treatment in primary care (%)
Hull & East Yorkshire Hospitals NHS Trust	19.7	67	Low	38.5	49.3	37.9
Hywel Dda Health Board	28.7	77	Mid	39	58.4	32.4
Imperial College Healthcare NHS Trust	31.8	68	Mid	41.2	77.9	28.4
Ipswich Hospital NHS Trust	49.1	127	High	46.5	52	30.4
Isle of Wight NHS Trust	50	56	High	33.9	51.8	29.6
James Paget University Hospitals NHS Foundation Trust	54.9	101	High	39.6	48.5	28
King's College Hospital NHS Foundation Trust	24.3	54	Mid	37	72.2	28.8
Kingston Hospital NHS Trust	79.3	66	High	43.1	72.7	27.3
Lancashire Teaching Hospitals NHS Trust	21.1	46	Mid	44.4	32.6	43.5
Leeds Teaching Hospitals NHS Trust	9.4	34	Low	29.4	61.8	35.3
Liverpool Women's NHS Foundation Trust	60.4	175	High	39.8	53.1	39.5
Luton and Dunstable Hospital NHS Foundation Trust	61.4	83	High	31.7	48.2	18.8
Maidstone and Tunbridge Wells NHS Trust	34.6	74	Mid	41.1	52.7	34.2
Medway NHS Foundation Trust	13.2	27	Low	37	48.1	48
Mid Cheshire Hospitals NHS Foundation Trust	6.4	10	Low	40	50	40
Mid Essex Hospital Services NHS Trust	41.4	113	Mid	35.4	40.7	30.6
Mid Staffordshire General Hospitals NHS Trust	23.8	41	Mid	34.1	43.9	39
Mid Yorkshire Hospitals NHS Trust	56.1	81	High	35	43.2	24.7
Milton Keynes Hospital NHS Foundation Trust	49.5	83	High	50.6	65.1	27.2
Norfolk and Norwich University Hospital NHS Trust	57.3	227	High	36.3	59.9	24.7
North Bristol NHS Trust	13.4	38	Low	32.4	68.4	28.9
North Cumbria Acute Hospitals NHS Trust	38.9	52	Mid	36	51.9	19.2
North Middlesex University Hospital NHS Trust	2	3	Low	33.3	33.3	66.7
North Tees and Hartlepool NHS Trust	50.3	129	High	43.4	35.7	24.6
North West London Hospitals NHS Trust	48	41	High	39	68.3	24.3
Northampton General Hospital NHS Trust	33.3	63	Mid	42.6	50.8	30.6
Northern Devon Healthcare NHS Trust	27.7	25	Mid	48	40	28
Northern Lincolnshire & Goole Hospitals NHS Foundation Trust	32.1	69	Mid	31.9	56.5	27.3
Northumbria Healthcare NHS Foundation Trust	33	109	Mid	43.1	42.2	38.9
Oxford Radcliffe Hospitals NHS Trust	9.9	43	Low	42.9	41.9	20.9
Pennine Acute Hospitals NHS Trust	10.8	16	Low	43.8	50	25
Peterborough and Stamford Hospitals NHS Foundation Trust	30.2	72	Mid	42.9	65.3	22.5

Provider name	Case ascertainment (%)	Actual cases (*n*)	Case ascertainment category* (Low, Mid or High)	Overall health of women (Excellent/ very good) (%)	Women with at least one HMB-related condition (%)	Women who reported no previous treatment in primary care (%)
Plymouth Hospitals NHS Trust	13.1	48	Low	38.3	56.3	10.6
Poole General Hospital NHS Foundation Trust	24.3	38	Mid	55.3	55.3	21.1
Portsmouth Hospitals NHS Trust	47.9	72	High	41.7	59.7	24.3
Royal Berkshire Foundation Trust	26.9	36	Mid	48.6	66.7	45.7
Royal Cornwall Hospitals NHS Trust	6.8	19	Low	52.6	63.2	22.2
Royal Devon & Exeter NHS Foundation Trust	31.2	107	Mid	51.4	43.9	29.8
Royal Free Hampstead NHS Trust	26.7	37	Mid	25.7	70.3	22.2
Royal United Hospital Bath NHS Trust	35.4	30	Mid	53.3	66.7	10.7
Salisbury Hospital NHS Foundation Trust	7.5	10	Low	44.4	50	40
Sandwell & West Birmingham Hospitals NHS Trust	63.6	86	High	25.6	44.2	29.3
Sheffield Teaching Hospitals NHS Trust	37.4	132	Mid	43.5	53.8	23.3
Sherwood Forest Hospitals NHS Trust	22.4	52	Mid	32.7	42.3	25.5
Shrewsbury & Telford Hospital NHS Trust	31.6	81	Mid	52.5	42	29.1
South Devon Healthcare NHS Foundation Trust	26.8	62	Mid	54.8	54.8	49.2
South Tees Hospitals NHS Trust	46.1	150	High	48	44.7	20.1
South Tyneside NHS Foundation Trust	43.9	44	Mid	54.5	45.5	39.5
South Warwickshire General Hospitals NHS Trust	12.9	13	Low	46.2	61.5	76.9
Southampton University Hospitals NHS Trust	34.2	13	Mid	38.5	53.8	30.8
Southend University Hospital NHS Foundation Trust	35.5	65	Mid	50.8	44.6	30.8
Southport & Ormskirk Hospital NHS Trust	35.5	30	Mid	50	46.7	20
St George's Healthcare NHS Trust	89.7	54	High	44.2	57.4	40.7
St Helens & Knowsley Hospitals NHS Trust	26.4	29	Mid	48.3	48.3	27.6
Stockport NHS Foundation Trust	45.8	59	High	44.8	61	40.7
Tameside Hospital NHS Foundation Trust	19.5	49	Low	31.3	36.7	38.3
Taunton and Somerset NHS Foundation Trust	52.1	106	High	46.2	51.9	28.2
The Hillingdon Hospital NHS Trust	79.2	56	High	38.2	66.1	40
The Lewisham Hospital NHS Trust	16.9	11	Low	63.6	27.3	54.5
The Newcastle upon Tyne Hospitals NHS Foundation Trust	68.1	146	High	42.7	39.7	28.9
The Princess Alexandra Hospital NHS Trust	1.1	2	Low	50	50	100
The Queen Elizabeth Hospital King's Lynn NHS Trust	12.5	22	Low	40.9	63.6	9.1
The Royal Bolton Hospital NHS Foundation Trust	59.7	105	High	36.2	54.3	38.1
The Royal Bournemouth and Christchurch NHS Foundation Trust	52.3	72	2.875	59.2	34.7	30.6

Provider name	Case ascertainment (%)	Actual cases (*n*)	Case ascertainment category* (Low, Mid or High)	Overall health of women (Excellent/ very good) (%)	Women with at least one HMB-related condition (%)	Women who reported no previous treatment in primary care (%)
The Royal Wolverhampton Hospitals NHS Trust	29.6	32	Mid	31.3	50	22.6
The Whittington Hospital NHS Trust	40.4	58	Mid	34.5	67.2	48.2
United Lincolnshire Hospitals NHS Trust	44	106	Mid	41	53.8	32.4
University College London Hospitals NHS Foundation Trust	39.4	35	Mid	26.5	80	38.2
University Hospital of North Staffordshire NHS Trust	15.6	36	Low	38.9	63.9	34.3
University Hospitals Bristol NHS Foundation Trust	37.8	44	Mid	48.8	63.6	26.2
University Hospitals Coventry and Warwickshire NHS Trust	41.6	81	Mid	41.3	40.7	23.1
University Hospitals of Leicester NHS Trust	39.1	89	Mid	36	53.9	43.7
University Hospitals of Morecambe Bay NHS Trust	17.6	46	Low	54.3	41.3	31.1
University Hospitals of South Manchester NHS Foundation Trust	49	55	High	36.5	49.1	29.6
Walsall Hospitals NHS Trust	8.6	12	Low	66.7	25	36.4
Warrington and Halton Hospitals NHS Foundation Trust	68.3	84	High	48.2	60.7	28
West Hertfordshire Hospitals NHS Trust	18.5	24	Low	50	70.8	31.8
West Middlesex University Hospital NHS Trust	52.9	48	High	25	62.5	38.3
Western Sussex Hospitals NHS Trust	28.5	82	Mid	37.8	69.5	25
Weston Area Health NHS Trust	21.8	20	Mid	55	50	40
Wirral University Teaching Hospital NHS Foundation Trust	89.7	103	High	48.5	51.5	17
Worcestershire Acute Hospitals NHS Trust	31.3	99	Mid	40.4	56.6	34
Wrightington, Wigan and Leigh NHS Foundation Trust	28.1	26	Mid	34.6	30.8	28
Yeovil District Hospital NHS Foundation Trust	42.1	51	Mid	54.2	56.9	27.5
York Teaching Hospital NHS Foundation Trust	28.1	82	Mid	41.3	47.6	28.8

* Case ascertainment: low = lower quartile with ascertainment less than 20%; mid = interquartile with ascertainment of 20% to 45%; high = upper quartile with ascertainment of more than 45%.

Table A5.3 Patient-reported outcomes 1 year after the first outpatient clinic visit (follow-up)

Provider name	Women who received surgical treatment* (%)	Mean HRQoL at follow-up*	Women satisfied with the care received in hospital (excellent/very good/good) (%)
Abertawe Bro Morgannwg University Health Board	21.5	64.1	84.8
Airedale NHS Trust	52.1	74.9	94.1
Aneurin Bevan Health Board	23.5	61.8	89.8
Ashford and St Peter's Hospitals NHS Trust	51.7	72.4	75.0
Barking, Havering and Redbridge University Hospitals NHS Trust	40.9	70.5	82.4
Barnet and Chase Farm Hospitals NHS Trust	25.7	77.6	93.8
Barnsley Hospital NHS Foundation Trust	33.0	63.3	90.9
Barts Health NHS Trust	32.8	70.3	86.1
Basildon and Thurrock University Hospitals NHS Foundation Trust	30.7	69.5	94.4
Bedford Hospital NHS Trust	38.6	64.9	100.0
Betsi Cadwaladr University Health Board	21.3	67.1	94.2
Birmingham Women's NHS Foundation Trust	37.4	65.6	93.1
Blackpool Fylde and Wyre Hospitals NHS Foundation Trust	28.1	66.1	82.4
Bradford Teaching Hospitals NHS Foundation Trust	39.1	71.4	81.3
Brighton and Sussex University Hospitals NHS Trust	33.2	72.0	92.2
Buckinghamshire Hospitals NHS Trust	45.2	74.0	97.2
Burton Hospitals NHS Foundation Trust	46.6	68.3	87.8
Calderdale and Huddersfield NHS Foundation Trust	30.9	65.1	93.0
Cambridge University Hospitals NHS Foundation Trust	31.9	61.5	79.5
Central Manchester University Hospitals NHS Foundation Trust	25.5	63.9	85.7
Chelsea and Westminster Hospital NHS Foundation Trust	60.6	59.7	100.0
Chesterfield Royal Hospital NHS Foundation Trust	51.4	80.0	86.7
City Hospitals Sunderland NHS Foundation Trust	30.7	71.2	86.5
County Durham and Darlington NHS Foundation Trust	49.7	74.4	97.3
Croydon Health Services NHS Trust	23.2	77.0	83.3
Cwm Taf Health Board	34.0	72.3	96.2
Dartford and Gravesham NHS Trust	42.9	79.5	95.0
Derby Hospitals NHS Foundation Trust	32.3	73.7	88.9
Doncaster & Bassetlaw Hospitals NHS Foundation Trust	30.0	68.7	87.6
Ealing Hospital NHS Trust	33.1	71.3	86.0
East and North Hertfordshire NHS Trust	27.4	62.8	81.5
East Cheshire NHS Trust	28.3	73.1	85.0
East Lancashire Hospitals NHS Trust	34.7	73.7	92.8
East Sussex Hospitals NHS Trust	32.3	65.5	87.1
Epsom and St Helier University Hospitals NHS Trust	35.0	76.4	92.9
Frimley Park NHS Foundation Trust	58.0	79.1	100.0
Gateshead Health NHS Foundation Trust	25.9	65.3	91.9
George Eliot Hospital NHS Trust	26.1	78.5	75.0
Great Western Hospitals NHS Foundation Trust	54.1	78.1	86.7
Guy's and St Thomas' NHS Foundation Trust	33.3	67.8	90.8
Hampshire Hospitals NHS Foundation Trust	35.7	69.8	92.5
Heart of England NHS Foundation Trust	39.1	68.3	89.9
Heatherwood and Wexham Park Hospitals Trust	46.0	63.4	85.7
Hereford Hospitals NHS Trust	36.1	70.2	100.0
Hinchingbrooke Healthcare NHS Trust	58.4	63.7	91.8
Homerton University Hospital NHS Foundation Trust	40.0	68.3	81.3
Hull & East Yorkshire Hospitals NHS Trust	35.1	73.4	90.9

Provider name	Women who received surgical treatment* (%)	Mean HRQoL at follow-up*	Women satisfied with the care received in hospital (excellent/very good/good) (%)
Hywel Dda Health Board	38.9	64.3	81.6
Imperial College Healthcare NHS Trust	39.2	74.2	90.6
Ipswich Hospital NHS Trust	47.7	70.5	87.9
Isle of Wight NHS Trust	33.5	72.1	88.7
James Paget University Hospitals NHS Foundation Trust	34.0	70.2	87.8
King's College Hospital NHS Foundation Trust	32.8	70.4	92.3
Kingston Hospital NHS Trust	35.6	71.9	87.5
Lancashire Teaching Hospitals NHS Trust	32.0	67.6	90.9
Leeds Teaching Hospitals NHS Trust	47.4	77.3	88.2
Liverpool Women's NHS Foundation Trust	23.7	66.6	93.5
Luton and Dunstable Hospital NHS Foundation Trust	45.9	70.4	82.7
Maidstone and Tunbridge Wells NHS Trust	54.0	73.3	91.8
Medway NHS Foundation Trust	41.8	67.8	96.3
Mid Cheshire Hospitals NHS Foundation Trust	25.7	77.0	70.0
Mid Essex Hospital Services NHS Trust	49.6	73.8	87.3
Mid Staffordshire General Hospitals NHS Trust	18.7	68.0	87.2
Mid Yorkshire Hospitals NHS Trust	35.0	62.7	81.5
Milton Keynes Hospital NHS Foundation Trust	41.0	69.4	90.1
Norfolk and Norwich University Hospital NHS Trust	31.5	65.6	89.6
North Bristol NHS Trust	37.8	69.7	94.6
North Cumbria Acute Hospitals NHS Trust	38.1	66.7	90.0
North Middlesex University Hospital NHS Trust	34.2	82.5	100.0
North Tees and Hartlepool NHS Trust	41.2	70.7	94.5
North West London Hospitals NHS Trust	22.2	65.3	92.1
Northampton General Hospital NHS Trust	43.1	74.4	98.4
Northern Devon Healthcare NHS Trust	41.1	68.6	91.7
Northern Lincolnshire & Goole Hospitals NHS Foundation Trust	51.5	72.5	82.4
Northumbria Healthcare NHS Foundation Trust	37.6	71.6	95.2
Oxford Radcliffe Hospitals NHS Trust	49.8	69.6	86.0
Pennine Acute Hospitals NHS Trust	47.1	78.2	93.8
Peterborough and Stamford Hospitals NHS Foundation Trust	34.2	73.8	82.9
Plymouth Hospitals NHS Trust	50.5	80.8	100.0
Poole General Hospital NHS Foundation Trust	58.3	75.0	92.1
Portsmouth Hospitals NHS Trust	43.6	68.0	94.4
Royal Berkshire Foundation Trust	40.6	77.4	97.2
Royal Cornwall Hospitals NHS Trust	45.5	85.4	89.5
Royal Devon & Exeter NHS Foundation Trust	46.2	77.1	95.1
Royal Free Hampstead NHS Trust	39.6	67.3	89.2
Royal United Hospital Bath NHS Trust	36.7	72.1	90.0
Salisbury Hospital NHS Foundation Trust	11.8	78.8	90.0
Sandwell & West Birmingham Hospitals NHS Trust	39.9	68.4	89.5
Sheffield Teaching Hospitals NHS Trust	38.9	70.4	93.9
Sherwood Forest Hospitals NHS Trust	42.3	82.4	94.0
Shrewsbury & Telford Hospital NHS Trust	35.4	74.2	81.3
South Devon Healthcare NHS Foundation Trust	41.3	77.1	96.7
South Tees Hospitals NHS Trust	46.1	76.3	93.2
South Tyneside NHS Foundation Trust	22.7	64.4	90.7
South Warwickshire General Hospitals NHS Trust	43.5	70.5	91.7
Southampton University Hospitals NHS Trust	47.5	77.4	92.3
Southend University Hospital NHS Foundation Trust	37.1	71.4	86.9
Southport & Ormskirk Hospital NHS Trust	38.6	73.8	93.1

Provider name	Women who received surgical treatment* (%)	Mean HRQoL at follow-up*	Women satisfied with the care received in hospital (excellent/very good/good) (%)
St George's Healthcare NHS Trust	24.1	66.5	92.3
St Helens & Knowsley Hospitals NHS Trust	37.4	63.1	89.7
Stockport NHS Foundation Trust	18.9	68.0	94.8
Tameside Hospital NHS Foundation Trust	53.4	69.1	93.8
Taunton and Somerset NHS Foundation Trust	45.9	70.4	88.6
The Hillingdon Hospital NHS Trust	32.4	62.1	94.6
The Lewisham Hospital NHS Trust	32.4	67.1	100.0
The Newcastle upon Tyne Hospitals NHS Foundation Trust	49.6	75.9	95.9
The Princess Alexandra Hospital NHS Trust	48.5	82.1	100.0
The Queen Elizabeth Hospital King's Lynn NHS Trust	30.5	69.9	95.5
The Royal Bolton Hospital NHS Foundation Trust	35.6	72.0	86.3
The Royal Bournemouth and Christchurch NHS Foundation Trust	53.4	76.1	94.4
The Royal Wolverhampton Hospitals NHS Trust	38.9	60.3	100.0
The Whittington Hospital NHS Trust	34.3	66.3	94.8
United Lincolnshire Hospitals NHS Trust	42.9	75.0	90.3
University College London Hospitals NHS Foundation Trust	26.4	68.8	91.2
University Hospital of North Staffordshire NHS Trust	23.3	65.0	94.3
University Hospitals Bristol NHS Foundation Trust	40.8	73.1	90.9
University Hospitals Coventry and Warwickshire NHS Trust	37.0	73.1	86.3
University Hospitals of Leicester NHS Trust	20.9	65.1	87.8
University Hospitals of Morecambe Bay NHS Trust	25.1	67.4	89.1
University Hospitals of South Manchester NHS Foundation Trust	38.7	70.7	94.5
Walsall Hospitals NHS Trust	44.8	70.6	91.7
Warrington and Halton Hospitals NHS Foundation Trust	32.4	66.4	90.0
West Hertfordshire Hospitals NHS Trust	53.1	75.9	91.7
West Middlesex University Hospital NHS Trust	33.3	60.3	82.6
Western Sussex Hospitals NHS Trust	41.8	74.7	87.7
Weston Area Health NHS Trust	35.8	74.6	75.0
Wirral University Teaching Hospital NHS Foundation Trust	42.8	76.4	92.1
Worcestershire Acute Hospitals NHS Trust	32.4	72.8	87.5
Wrightington, Wigan and Leigh NHS Foundation Trust	38.0	71.5	96.0
Yeovil District Hospital NHS Foundation Trust	57.0	72.8	90.2
York Teaching Hospital NHS Foundation Trust	35.9	68.3	90.0

* Adjusted for ethnicity, baseline age, HMB-related conditions at baseline, baseline severity score, baseline HRQoL score, baseline EQ-5D score and IMD.