Royal College of
Obstetricians and Gynaecologists

Bringing to life the best in women's health care

Ipsos MORI

Second Annual Report

July 2012

Funding provided by:

HQIP

Healthcare Quality
Improvement Partnership

National Heavy Menstrual Bleeding Audit

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

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We would like to thank all NHS trusts and staff members who provided information for the organisational audit and participated in the prospective audit. The National HMB Audit is only possible because of the dedication and commitment of NHS staff members 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.

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 project team consists of:

Royal College of Obstetricians and Gynaecologists

- Tahir Mahmood, Co-Chair of National HMB Audit project team
- Loveleen Bansi-Matharu, HMB Audit Lead
- Sara Johnson, Executive Director of of Quality and Knowledge
- Benedetta La Corte, ORCA Coordinator
- Allan Templeton, Professor and Honorary Clinical Director of the Office for Research and Clinical Audit (ORCA)

London School of Hygiene & Tropical Medicine

- Jan van der Meulen, Professor and Honorary Director of ORCA and Co-Chair of National HMB Audit project team
- David Cromwell, Senior Lecturer
- Ipek Gurol-Urganci, Lecturer
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Ipsos MORI

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- Chris Marshall, Senior Research Executive
- Tomasz Mludzinski, Senior Research Executive
- Jonathan Nicholls, Director of Health Research

Abbreviations

BMI	body mass index
GP	general practitioner
HES	Hospital Episode Statistics
HMB	heavy menstrual bleeding
HQIP	Healthcare Quality Improvement Partnership
HRQoL	health-related quality of life
LAC	local audit coordinator
LSHTM	London School of Hygiene & Tropical Medicine
NCAPOP	National Clinical Audit and Patient Outcomes Programme
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
ORCA	Office for Research and Clinical Audit
PCT	primary care trust
QoL	quality of life
RCOG	Royal College of Obstetricians and Gynaecologists
SHA	strategic health authority
UFS-QoL	Uterine Fibroid Symptom and Quality of Life
VAS	visual analogue scale

Glossary of terms

Adapted UFS-QoL

A disease-specific HRQoL instrument for women with HMB. It was adapted from the UFS-QoL[1] and validated for women with HMB in the pilot study for this audit.[2]

Clinical Reference Group

The Heavy Menstrual Bleeding Audit's Clinical Reference Group comprises representatives of the key stakeholders in heavy menstrual bleeding care. They advise the project team on particular aspects of the project and provide input from the wider clinical and patient community.

Clinician

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

Endometrial ablation

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.[3] 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.

Heavy menstrual bleeding (HMB)

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

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.

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.

Levonorgestrel-releasing intrauterine system (LNG-IUS)

A T-shaped plastic device placed in the uterus that steadily releases small amounts of levonorgestrel, a progesterone hormone.

Foreword

As the Lay Chair of the Clinical Reference Group for this study, I am delighted to introduce the Second Annual Report of the National Heavy Menstrual Bleeding Audit. This is a very significant study as it is the first audit in England and Wales using patient-reported outcomes in an outpatient setting as the measure. Heavy menstrual bleeding (HMB) is a serious condition, affecting an estimated 80 000 women in England and Wales each year, and yet there is very little information about how women feel about their condition and how they are treated.

In the first part of this audit, last year, we found that there was a wide variation in the extent to which different surgical treatments were used within strategic health authorities. While both the National Institute for Health and Clinical Excellence (NICE) and the RCOG have guidelines for the care of women with HMB, the variation seen in surgical rates indicated that the guidelines are not being followed consistently. For a lay person who trusts that medical consultants are working to best-practice guidelines, this is not good news.

The aims of this year's audit work were to assess the severity of menstrual problems and to identify whether there is variation in the treatment women receive at the primary care level. For the first time, this involved collecting information from women experiencing HMB. Gathering these data was no easy task and the efforts of the project team and hospital staff to ensure patients were aware of the study and participated should be recognised.

Over 16 000 questionnaires were completed and over 96% of these met the eligibility criteria. This is a good response and I would like to add my thanks again to everyone involved in submitting these questionnaires. However, we believe that this represents only about 20% of cases of HMB referred each year so there is some disappointment that we were not able to attract a greater response. Some hospitals were able to generate high response rates and some were not.

Two findings stand out for me. Firstly, most of the women who participated in the study reported that they had been under primary care for over a year before they were referred to secondary care. Secondly, almost one-third of women had received no previous treatment before secondary referral despite 50% of them being in severe or very severe pain at the time of their first outpatient visit. This appears to be the picture across trusts.

Heavy menstrual bleeding has a significantly negative impact on women's quality of life, and it is of concern that such a high proportion of women are being referred to secondary care without any initial medical treatment. Again, the NICE guidelines, which appear very straightforward, do not seem to be consistently adhered to at the primary care level.

The next phase of the audit will follow up a year later the same women who completed the first questionnaire, to see what has happened to them in secondary care and how they feel about how they have been treated.

Mrs Angela Hyde
Clinical Reference Group Chair
Vice-Chair, RCOG Consumers' Forum

Executive summary

Heavy menstrual bleeding (HMB) is a common condition affecting more than one in five women of reproductive age. It is estimated to be the fourth most common reason that women are referred to gynaecological services and each year over 30 000 women in England and Wales undergo surgical treatment.

There have been substantial changes in the management of HMB over the last 10 years, with women increasingly having access to a wider range of medical therapies as well as to minimal-access surgical procedures such as endometrial ablation. These innovations have been incorporated into national clinical guidelines but information about how the NHS has responded is currently lacking. The National Heavy Menstrual Bleeding Audit, which began on 1 February 2010, is a 4-year audit that aims to describe the care received by women with HMB referred to NHS outpatient clinics in England and Wales, and to assess their experience of care. Specific audit objectives are to investigate any differences among NHS organisations in England and Wales in:

- the severity of menstrual problems experienced by women referred to NHS outpatient clinics and the care received prior to referral
- 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 this care had on their health and quality of life
- the effect of the treatments received in the first year after their outpatient visit on women's health and quality of life.

This Second Annual Report describes the results from the first year of the prospective audit of patient-reported outcomes. It focuses on women who attended outpatient gynaecology clinics with HMB symptoms for the first time between 1 February 2011 and 31 January 2012, describing their symptoms and the care received prior to referral.

Patient characteristics and clinical symptoms

The overall case ascertainment rate was 25.3%. This is likely to be an underestimate of the true rate as several issues regarding the denominator of the case ascertainment estimates have been identified.

The Hospital Episode Statistics (HES) outpatient database does not provide data at diagnostic level. On the basis of past studies, we therefore assumed that 10% of all recorded first visits to gynaecological outpatient clinics in previous years were for a complaint of HMB. This may have produced denominators that are too high for a number of reasons:

- a growing number of women are being treated solely in primary care
- a number of patients are now being referred to independent treatment centres rather than to NHS hospitals
- it is possible that we have included women who attended an outpatient clinic for a follow-up visit.

This report is based on the analysis of 15 812 questionnaires meeting the inclusion criteria. The median age of women who completed the questionnaires was 44 years and 87.8% were of white ethnicity. Nearly half (48.1%) of all women included in the analyses had known

fibroids, endometriosis and/or uterine polyps together with their HMB condition. Analyses focusing on clinical symptoms showed the following:

- overall, 74.0% of women had symptoms for over 1 year before being referred to secondary care; 71% of women with only HMB (i.e. without fibroids, polyps and/or endometriosis) had symptoms for over 1 year
- 54.2% of women reported severe or very severe pain at their first outpatient visit; this was considerably higher for those with endometriosis (75.8%) and for those with fibroids and endometriosis (66.0%)
- 83.5% of women would feel unhappy or terrible if their symptoms persisted over the next 5 years.

Primary care

While the majority of women were seen in primary care before referral to secondary care, 6.5% of women had not been seen by their general practitioner (GP) in the year prior to their first outpatient appointment. The proportion of women with more than four GP visits was higher among those of younger age, of non-white ethnicity and with longer duration of symptoms. Of those in severe or very severe pain, 21.3% had more than four GP visits, compared with 11.0% of those in moderate pain. Women with other comorbidities such as depression, high blood pressure and thyroid disorder were also more likely to have a greater number of GP visits. In relation to initial treatment in primary care prior to referral to secondary care:

- 31.1% of women had received no initial treatment in primary care and this percentage increased with older age (24.3% of those under 35 years compared with 36.6% of those over 50 years)
- women of non-white ethnicity, those who had fewer GP visits, those with HMB alone and those with HMB with fibroids (as opposed to those with HMB with endometriosis) were more likely to have had no previous treatment
- 26.0% of women in severe or very severe pain had had no previous treatment.

Among those who had received initial treatment, the most frequent treatment received was medication (other than the pill) (32.6%) and the pill (15.3%).

Variation among trusts

There was no significant difference among trusts in the medical care that women had received at primary care, or in the clinical symptoms seen in women before referral to secondary care. In particular, there was little evidence to suggest that differences in the proportion of patients with no GP visits or no previous treatment varied at trust level. While differences among trusts in quality of life scores (both disease specific and general) were evident, there was little evidence of systematic variation among trusts.

Review of prospective audit

The HMB audit is unique among other national clinical audits as the audit aims to include all patients with a particular clinical problem at their first outpatient clinical visit. Given the lower than expected case ascertainment rates, the project team undertook a qualitative telephone survey of the participating NHS hospitals to examine how participation could be improved. Shortage of staff, motivation of consultants, motivation of patients and the outpatient clinic environment were highlighted as factors that may have contributed to the lower than expected case ascertainment rates.

Conclusion

The patient-reported outcomes component of the audit has shown that women being referred to secondary care are mostly those with prolonged duration of symptoms and in severe or very severe pain. One-third of women had received no previous treatment. While most of these factors did vary at patient level, variation was not seen at NHS trust level. Therefore, referral practice from primary care does not seem to contribute to the wide variation in surgical practice seen in secondary care.

1 Introduction

1.1 The National Heavy Menstrual Bleeding Audit

Heavy menstrual bleeding (HMB) affects more than one in five women of reproductive age. One in three women seen for the first time in secondary care will undergo surgical treatment. This equates to approximately 30 000 women in England and Wales undergoing surgical treatment for HMB each year.

The Royal College of Obstetricians and Gynaecologists (RCOG), in partnership with the London School of Hygiene & Tropical Medicine (LSHTM) and Ipsos MORI, a leading research company in the UK, is conducting the National HMB Audit. The audit began on 1 February 2010. The overall aims of this 4-year audit are to describe the care received by women with HMB referred to NHS outpatient clinics in England and Wales and to assess women's experience of care.

The audit has two components:

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

The first component, which was completed in August 2010, collected information from hospitals to evaluate the organisation of hospital gynaecological services, current referral patterns and local protocols with regard to the management of HMB. Further information on this component can be found in the First Annual Report (www.rcog.org.uk/files/rcog-corp/NationalHMBAudit_1stAnnualReport_May2011.pdf).[2] For convenience, a short summary is provided at the end of this Introduction (see Section 1.3).

The second component of the audit started on 1 February 2011. Eligible women who had consented to participate in the audit were asked to complete a questionnaire at their first gynaecology outpatient visit (the baseline questionnaire). Questions included were on the severity of the condition, the impact its symptoms had on quality of life and the treatments they had received in primary care. The recruitment of women for this phase of the audit finished on 31 January 2012. These women will be followed up after 1 year to collect information on the treatments received since their outpatient visit, patient-reported outcomes and quality of life.

The prospective audit has required a novel method. The audit could not rely on the standard approach of asking hospitals to submit clinical data because it is not possible to audit services for HMB reliably without measuring the effect of care on women's quality of life. How treatment has affected a woman's quality of life can only be measured by collecting data from the patients themselves. In addition, we will also use the information provided by the women themselves about the treatment that they receive in the year following their first outpatient visit.

In this Second Annual Report, we describe the patient-reported outcomes from the baseline questionnaire. We also describe the audit methodology, and the benefits and shortfalls of conducting an audit of this nature. Specific audit aims considered in this report are:

- the severity of menstrual problems experienced by women referred to NHS outpatient clinics and variation in severity among NHS organisations in England and Wales
- variation in quality of life of referred women
- variation in treatments received in primary care among women with HMB.

1.2 Summary of treatment options for women with HMB

Medical therapies are the recommended first-line treatments for HMB. These include oral drug regimens, such as oral contraceptives, tranexamic acid and the nonsteroidal anti-inflammatory drug mefenamic acid, and levonorgestrel-releasing intrauterine systems. In cases where first-line treatment proves ineffective or where HMB severely affects quality of life, surgical alternatives are indicated.[4]

Hysterectomy was typically the only surgical option available before the mid-1990s. Although it is a definitive treatment, 4% of women who undergo hysterectomy experience physical complications.[5] Hysterectomy is also associated with emotional complications and high economic cost.[6] The introduction of endometrial ablation in the late 1980s resulted in a decline in the number of hysterectomies performed and an increase in the number of endometrial ablations performed.[7] First-generation endometrial ablation techniques included endometrial laser ablation and rollerball ablation. Second-generation techniques, which include fluid-filled thermal ball, microwave, cryotherapy and radiofrequency balloon ablation, have been common practice in the UK from 1998.[7] Endometrial ablation is less invasive and has been shown to be more effective than hysterectomy in randomised controlled trials.[8,9] Although short-term complications have been reported for most techniques (particularly for first-generation techniques),[10,11] second-generation techniques are widely accepted as being safer than, and at least as effective as, first-generation techniques. Furthermore, second-generation endometrial ablation techniques are now seen by many as a conservative alternative to hysterectomy.[5]

1.3 Summary of findings from the First Annual Report

The results of the organisational audit and a description of patterns of surgical treatment for women with HMB across England and Wales were included in the First Annual Report.[2]

For the organisational audit, all NHS acute trusts in England and Wales with outpatient gynaecology departments were sent a questionnaire on issues relating to the availability of facilities, local treatment protocols and patterns of primary and secondary care. All trusts responded. In summary, the results of the audit showed that 38% of hospitals had a dedicated menstrual bleeding clinic and over 80% of hospitals had availability of ultrasound, hysteroscopy and endometrial biopsy. Only 30% of hospitals had a local written protocol regarding the care and management of women with HMB.

The Hospital Episode Statistics (HES) database was used to analyse patterns of surgical treatment for women with HMB in England. The annual rate of surgery for women with HMB between April 2003 and March 2006 was 143 per 100 000. This increased to 152 per 100 000 between April 2006 and December 2009. There was wide variation in surgical rates among strategic health authorities (SHAs) in both time periods. Between April 2003 and March 2006, surgical rates ranged from 71 to 220 procedures per 100 000 women, and between April 2006 and December 2009, surgical rates ranged from 70 to 255 procedures per 100 000 women. Surgical rates also varied widely among primary care trusts (PCTs), ranging from 14 to 392 per 100 000 women. This level of variation is similar to rates observed previously,[12] although the actual rate of surgery has increased with more women having endometrial ablations. Figure 1.1 shows the geographical distribution of relative rates of surgery for English and Welsh PCTs after April 2006. The pale areas have rates of surgery that are significantly lower than expected, while the dark areas have rates higher than expected on the basis of the national average.

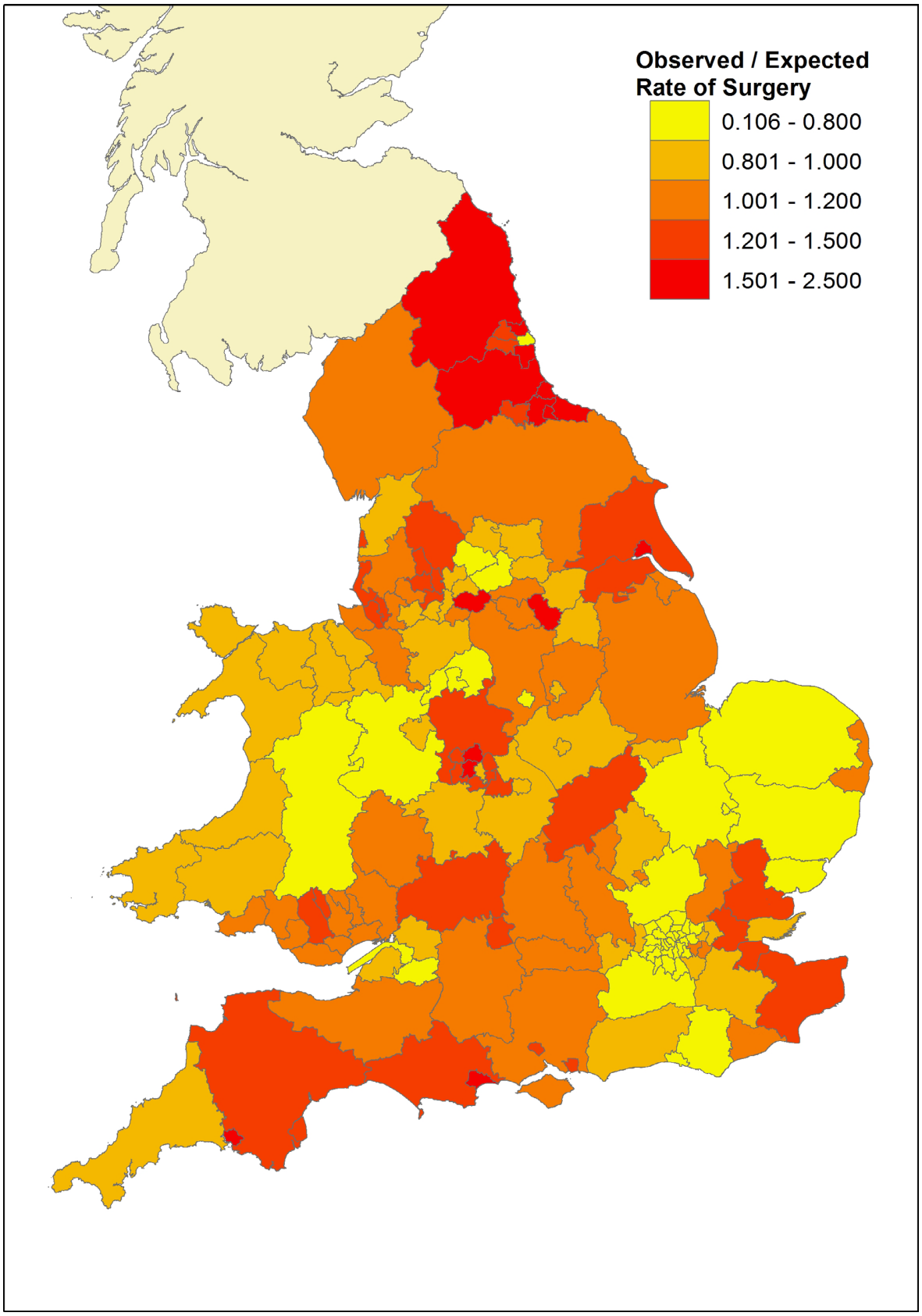

Figure 1.1 Relative rates of surgery for women with HMB in English and Welsh primary care trusts between April 2006 and December 2009

2 The National Heavy Menstrual Bleeding Audit

2.1 Background to the audit

Clinical guidelines on the treatment of HMB have been available in England and Wales since 1995. The latest of these was published by the National Institute for Health and Clinical Excellence (NICE) in 2007,[4] and further standards were published by the RCOG in 2008.[13] These documents provide guidance on both the treatment of HMB and how services should be organised.

Little is known on how hospitals in England and Wales have responded to these guidelines. There is, however, evidence to suggest significant variation of practice in secondary care. There is also a lack of information on women's symptoms, patterns of care and quality of life indicators. This information is needed to make recommendations on how to improve the care received by women with HMB.

2.2 Aim and objectives

The overall aim of the HMB Audit is to assess patient outcomes and experience of care for women with HMB referred to NHS outpatient clinics in England and Wales. Specifically, the audit objectives are to compare results among NHS trusts. The audit investigates:

- 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 visit have had on women's health and quality of life.

The audit will provide comparative information for clinicians and will highlight whether the care received by women with HMB is consistent with recommended practice. The audit will also identify areas in which improvements could potentially be made.

The audit will also support other initiatives by:

- providing information on the uptake of the NICE guideline and RCOG *Standards for Gynaecology* across England and Wales
- generating a source of national information that commissioners can use to refine their purchasing strategy
- exploring whether outcome indicators collected through this audit could be used to support revalidation of clinicians as prescribed by the General Medical Council
- informing the development of national quality matrices through the use of patient-reported outcome measures
- producing information on the impact that new patient-centred arrangements may have on the current service-delivery model, treatment patterns and patient experience as detailed in the Department of Health project *Delivering Care Closer to Home*.

2.3 Design of the audit

The audit has been funded by the Health Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). The audit is being led by the Office for Research and Clinical Audit (ORCA) at the RCOG, which is a collaboration between the RCOG and LSHTM. On this project, the ORCA team works in partnership with Ipsos MORI, a leading opinion and market research organisation. Additional team members from the Department of Health Services Research and Policy at LSHTM provide expertise in questionnaire development and health outcome measurement.

The audit began on 1 February 2010 and will run for 4 years. It has two main components: an organisational audit and a patient-based prospective audit of the patterns and outcomes of care.

Organisational audit

The results of the organisational audit were published in the First Annual Report in May 2011.[2] The aim of the organisational audit was to describe the provision of gynaecological services for women with HMB at NHS acute trusts in England and Wales and to examine important structural issues that would influence the care received by individual women. It collected information on the local organisation of services, access to diagnostic and therapeutic facilities, and the availability of patient information. Trusts were also asked to send their local protocols to allow for a review of how NHS trusts had responded to NICE guidance and the RCOG service standards.

Audit of patient care and patient-reported outcomes

The main component of the audit is a prospective audit of the care received by women with HMB and of their patient-reported outcomes. All women aged between 18 and 60 years in England and Wales who had a new referral for HMB to an outpatient gynaecology department were eligible for participation. Women who had visited a gynaecological outpatient clinic for HMB within the previous 12 months were excluded.

Patient recruitment took place between 1 February 2011 and 31 January 2012. Consenting women were asked to complete a questionnaire that included questions on the severity of 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. Owing to the personal nature of the questions, women were required to complete questionnaires on their own. Therefore, women with insufficient English comprehension or a cognitive or visual impairment that precluded self-completion were excluded.

Women are sent a follow-up questionnaire 1 year after recruitment (starting on 1 February 2012) to gather information on their treatment history, their care experience, and their symptoms and quality of life at that time. This patient-reported information will be linked to HES data to give a rich description of patient care and outcomes.

3 Methodology

3.1 Data collection

There are two phases of data collection:

- baseline questionnaires given to consenting women at the time of first outpatient visit (February 2011 to January 2012)
- follow-up questionnaires mailed to the women's home address 1 year after the baseline questionnaire was completed (February 2012 to January 2013)

In this report, we focus on the first phase of data collection.

The outpatient questionnaire consisted of 58 questions on age, ethnicity, duration of condition, obstetric history, previous treatments and comorbidities. The questionnaire included a condition-specific quality of life (QoL) instrument. This instrument is an adapted version of the UFS-QoL. The original UFS-QoL consists of 37 items (eight symptom items and 29 health-related QoL items). The questionnaire was adapted by changing the word 'fibroids' to 'heavy menstrual bleeding (i.e. heavy period)' and also by changing specific words so that they were appropriate for UK English. The adaptation of this questionnaire as well as its evaluation was described in detail in the First Annual Report.[2]

The EQ-5D generic QoL instrument was included to measure general health-related quality of life (Appendix 3). We also used a question asking women how satisfied they were with their HMB symptoms. This was adapted from a question that was originally devised for men with lower urinary tract symptoms.[14]

3.2 Collection of data from patients

Before starting data collection, each hospital participating in the audit was sent a set of patient packs. This consisted of large envelopes containing questionnaire booklets (including tear-off consent forms), envelopes for storing completed questionnaires and envelopes for storing completed consent forms. Hospitals were also advised to choose a local audit coordinator (LAC). The role of the LAC did vary among trusts but was generally three-fold:

- to identify eligible women
- to hand out questionnaires and explain the consent process
- to receive completed questionnaires.

Ideally, women were identified before the clinic from the referral letter in the notes, and asked to fill out the questionnaire before their consultation.

LACs were asked to ensure that the consent forms had been filled in, signed and separated from the questionnaire. The completed questionnaire and consent form were then placed in the envelopes provided.

Women willing to take part in the audit were asked to tear off the completed consent form from the questionnaire after completing it, place the questionnaire in the envelope provided, and return both the completed questionnaire and consent form to the LAC. Women could take the information leaflet (handed to them with the questionnaire) home with them.

3.3 Sending questionnaires and consent forms back to the project team

A courier service was used to collect completed questionnaires and consent forms from the participating hospitals on a monthly basis. An email reminder was sent to the LAC from Ipsos MORI 7 days before the monthly collection to confirm collection arrangements.

3.4 Calculating the expected number of women with HMB complaints seen at outpatient clinics for the first time (the 'expected' denominator)

To estimate case ascertainment at each clinic, the monthly expected denominator was calculated using HES outpatient data and results from the organisational audit. Among all gynaecology appointments, the number of first face-to-face appointments that the women attended and where they were seen by a healthcare professional were calculated. Past studies suggested that it is reasonable to expect that 10% of first gynaecology visits are for a complaint of HMB.[15]

A woman may have attended a visit that was recorded as a 'first appointment' but may not have been eligible for the audit because she may have been seen for HMB in another secondary care setting in the previous 12 months. Hence the denominator was further reduced by on average 30% after taking into account patient-level outpatient gynaecology appointment histories. Denominators were calculated at trust level for all trusts, and at unit level where the required information was available.

This denominator was compared with that obtained in the organisational audit and the lesser of the two was defined to be the unit or trust denominator as appropriate. All units were contacted to confirm denominators; denominators were revised if units were able to demonstrate that the defined denominator was inaccurate, by, for example, providing the number of women seen for HMB complaints over the previous 3–6 months.

3.5 Statistical analyses

While most analyses were of a descriptive nature, funnel plots were used to statistically assess variation among trusts in various outcomes of interest. These plots test whether the results at an individual NHS trust differ significantly from the national average (results observed if all NHS trusts are combined). In all funnel plots shown, the horizontal axis represents the number of women included in the audit at each trust and the vertical axis measures the outcome of interest.

The horizontal line in the funnel plots shows the national average (all trusts combined). The control limits, at 95% and 99.8% levels, represent the expected variation in proportions assuming that all variation is random. If a result falls outside the control limits, it is considered to be different from the national average at a 0.05 or a 0.002 significance level, respectively. The funnel plots for proportions use exact binomial limits, and logistic regression was used to calculate results adjusted for differences in case mix. Linear regression was used to calculate adjusted results for outcomes measured as continuous variables (for example, QoL scores).

4 Audit participation and case ascertainment rates

4.1 Participation and case ascertainment

Of the 221 hospitals (comprising 154 trusts) that were included in the organisational audit, 199 hospitals (comprising 148 trusts) took part in the patient-reported outcomes component of the HMB Audit. Case ascertainment for each trust was determined by dividing the number of women who had completed the questionnaire by the expected denominator each month. The overall case ascertainment rate was 25.3%. Case ascertainment varied considerably among trusts (Appendix 2): five trusts (3.4%) had case ascertainment rates of over 70%, and 16 trusts (10.8%) had case ascertainment rates between 50% and 70%. Twenty-five (16.9%) had case ascertainment rates of less than 10%.

4.2 Completeness of data

In total, 16 439 women completed the questionnaire and 15 812 (96.2%) of these questionnaires met the inclusion criteria. For the purpose of measuring completeness of data, the questions in the questionnaire were categorised into 13 categories; a category was considered as being 'complete' if *all* questions within the category were answered. The 13 categories used were:

1. Symptoms, previous treatment and pregnancy (eight questions)
2. Comorbidities (one question)
3. General health (two questions)
4. HMB-specific QoL – severity (eight questions)
5. HMB-specific QoL – concern (five questions)
6. HMB-specific QoL – activity (seven questions)
7. HMB-specific QoL – energy (seven questions)
8. HMB-specific QoL – control (five questions)
9. HMB-specific QoL – self-consciousness (three questions)
10. HMB-specific QoL – sexual functioning (two questions)
11. General QoL (EQ-5D) (five questions)
12. Visual analogue scale (VAS) (one question)
13. Demographics (four questions).

Figure 4.1 shows the proportion of women with complete data in each category. The level of completeness was excellent for all categories. In particular, the level of completeness was 90% or higher for the following categories: comorbidities, general health, HMB-specific QoL questions on concern, self-consciousness and sexual functioning, general QoL questions (EQ-5D) and the VAS.

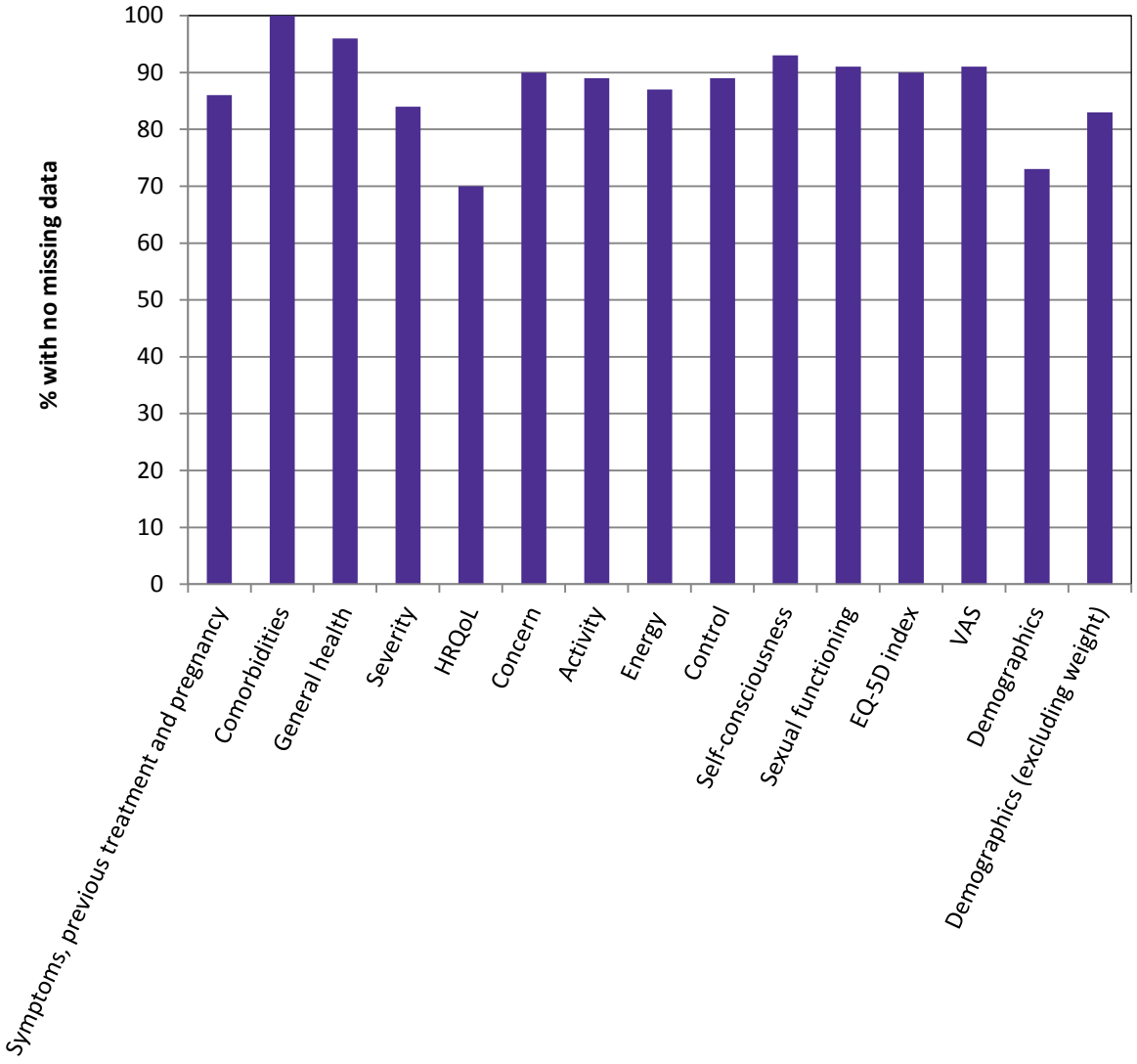

Figure 4.1 Proportion of women with no missing data, stratified by defined categories

Completeness was slightly lower in the demographics category. This was mainly due to the question on body weight not being completed by 20.6% of women.

Given the extremely low proportion of missing data, women who had not answered specific questions were not included in any analyses relating to the section being analysed.

5 Clinical symptoms among women referred for HMB to outpatient clinics

5.1 Patient characteristics

The baseline patient characteristics of the 15 812 women who met the inclusion criteria are shown in Table 5.1.

Table 5.1 Overview of patient characteristics

Patient characteristic	*n*	%*
Age in years		
<35	2381	15.1
35–39	2031	12.8
40–44	4199	26.6
45–49	4924	31.1
≥50	2277	14.4
Ethnicity		
Non-white	1790	12.2
White	12919	87.8
Missing/do not want to answer: 1103 (7.0%)		
Age at leaving full-time education		
≤16	5747	39.7
17–18	4126	28.5
≥19	4590	31.7
Missing/do not want to answer: 1349 (8.5%)		
BMI		
≤25 (underweight/normal)	4819	39.7
26–30 (overweight)	3866	31.8
>30 (obese)	3458	28.5
Missing: 3669 (23.2%)		
Parity		
Nulliparous	2625	17.1
Multiparous	12690	82.9
Missing/do not want to answer: 497 (3.1%)		
Future pregnancy consideration		
Yes	2054	13.4
No	12140	79.0
Not sure	1170	7.6
Missing/do not want to answer: 448 (2.8%)		
Operation on uterus/cervix		
Yes	3242	22.3
No	11306	77.7
Missing/do not know: 1264 (8.0%)		

* The percentages are calculated based on the total number of women who answered the relevant question

The median age of women completing the questionnaire was 44 years, and overall 87.8% of women were of white ethnicity. While the proportion of women of white ethnicity was generally constant across SHAs, there were substantially more women of non-white ethnicity in London (46.5%).

Figure 5.1 shows the association between parity, consideration of future pregnancy and age. As expected, the percentage of multiparous women increased with increasing age and, conversely, the percentage of women considering future pregnancy decreased with increasing age.

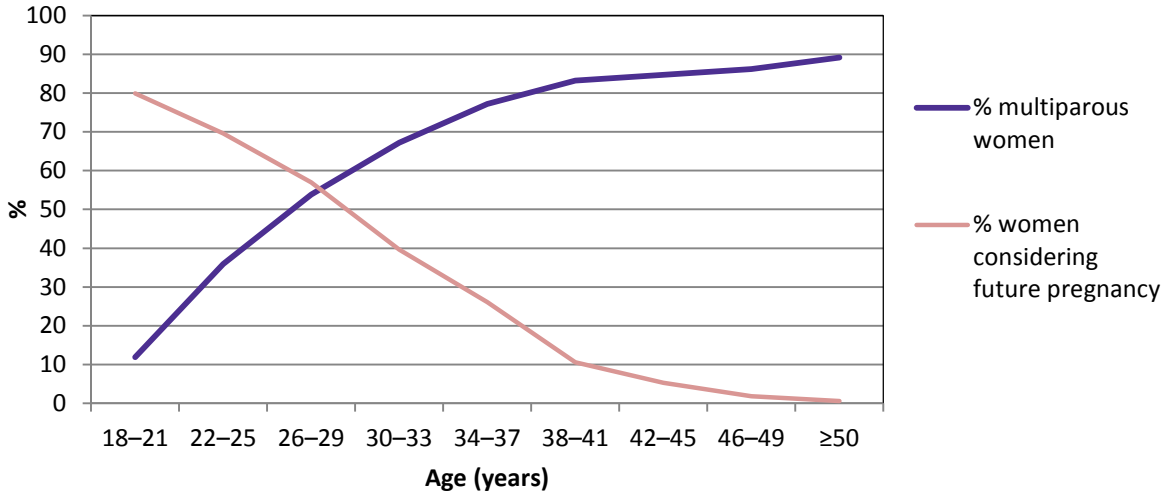

Figure 5.1 Proportion of multiparous women and those considering future pregnancy, stratified by age

5.2 Known HMB-related conditions and other comorbidities

The questionnaire asked about three known HMB-related conditions: uterine fibroids, polyps and/or endometriosis. The following groups were used to categorise women according to which known HMB-related conditions they had:

HMB only:	No known HMB-related conditions
Fibroids and/or polyps:	Uterine fibroids alone
	Polyps alone
	Uterine fibroids and polyps
Endometriosis with or without polyps:	Endometriosis alone
	Endometriosis and polyps
Fibroids and endometriosis with or without polyps:	Uterine fibroids and endometriosis
	Uterine fibroids, polyps and endometriosis

The associations between these groups and other patient characteristics are shown in Table 5.2.

Women with uterine fibroids or polyps alone (fibroids and/or polyps and fibroids and endometriosis with or without polyps groups) were more likely to be of older age and non-white ethnicity, while women with endometriosis were more likely to have at least one comorbidity.

Depression, high blood pressure and thyroid disorder were the most prevalent comorbidities, reported by 15.6%, 10.3% and 6.8% of women, respectively.

Table 5.2 Associations between known HMB-related conditions and other patient characteristics

Patient characteristic	Number of women with known HMB-related conditions, *n* (%)*			
	HMB only	Fibroids and/or polyps	Endometriosis with or without polyps	Fibroids and endometriosis with or without polyps
Total, *N*	8207	6352	856	397
Age in years				
<35	1707 (20.8)	399 (6.3)	251 (29.3)	24 (6.0)
35–39	1141 (13.9)	665 (10.5)	166 (19.4)	59 (14.9)
40–44	2170 (26.4)	1690 (26.6)	224 (26.2)	115 (29.0)
45–49	2246 (27.4)	2361 (37.2)	175 (20.4)	142 (35.8)
≥50	943 (11.5)	1237 (19.5)	40 (4.7)	57 (14.4)
Ethnicity				
Non-white	716 (9.4)	957 (16.3)	58 (7.2)	59 (15.9)
White	6926 (90.6)	4932 (83.8)	748 (92.8)	313 (84.1)
Missing: 7.0%				
Parity				
Nulliparous	1284 (16.1)	1036 (16.9)	211 (25.5)	94 (24.4)
Multiparous	6691 (83.9)	5090 (83.1)	618 (74.5)	291 (75.6)
Missing/do not want to answer: 3.1%				
Number of comorbidities				
0	5366 (65.4)	4345 (68.4)	542 (63.3)	237 (59.7)
1	2135 (26.0)	1496 (23.6)	238 (27.8)	125 (31.5)
≥2	706 (8.6)	511 (8.0)	76 (8.9)	35 (8.8)
Comorbidities				
Depression	1387 (16.9)	820 (12.9)	175 (20.4)	78 (19.7)
High blood pressure	779 (9.5)	738 (11.6)	67 (7.8)	46 (11.6)
Thyroid disorder	567 (6.9)	421 (6.6)	52 (6.1)	30 (7.6)
Lung disease	358 (4.4)	235 (3.7)	44 (5.1)	17 (4.3)
Diabetes	278 (3.4)	207 (3.3)	22 (2.6)	15 (3.8)
A bleeding disorder	136 (1.7)	74 (1.2)	13 (1.5)	12 (3.0)
Heart disease/adenomyosis/ cancer/kidney disease	216 (2.6)	140 (2.2)	40 (4.7)	29 (7.3)

* The percentages are calculated based on the total number of women who answered the relevant question

5.3 HMB symptoms

HMB-related conditions were also assessed according to duration of symptoms, symptom severity and satisfaction with the condition if symptoms remained the same over the next 5 years (Table 5.3).

Duration of symptoms

Over three-quarters of women with fibroids and/or endometriosis had had HMB-related symptoms for over 1 year. However, even among women without known HMB-related conditions, 71.1% had had HMB-related symptoms for over 1 year. No association was seen between age or ethnicity and duration of symptoms.

Table 5.3 Associations between known HMB-related conditions, duration of symptoms, symptom severity and feeling about health over the next 5 years

Patient characteristic	Number of women with known HMB-related conditions, *n* (%)*			
	HMB only	Fibroids and/or polyps	Endometriosis with or without polyps	Fibroids and endometriosis with or without polyps
Total, *N*	7418	5771	783	350
Duration of symptoms				
<2 months	248 (3.1)	111 (1.8)	11 (1.3)	6 (1.6)
2 months to 1 year	2031 (25.7)	1383 (22.3)	135 (16.2)	62 (16.0)
>1 year	5614 (71.1)	4713 (75.9)	687 (82.5)	320 (82.5)
Missing/do not know: 3.1%				
Severity of pain				
None	450 (5.8)	365 (6.0)	11 (1.3)	13 (3.5)
Very mild/mild	1266 (16.2)	918 (15.0)	61 (7.5)	31 (8.3)
Moderate	1926 (24.6)	1670 (27.4)	126 (15.4)	83 (22.2)
Severe/very severe	4178 (53.4)	3152 (51.6)	620 (75.8)	246 (66.0)
Missing: 4.4%				
Satisfaction if symptoms remained the same over next 5 years				
Delighted/pleased/satisfied	94 (1.2)	80 (1.3)	7 (0.8)	3 (0.8)
Equivocal	416 (5.3)	394 (6.4)	44 (5.3)	12 (3.1)
Dissatisfied	727 (9.2)	640 (10.3)	68 (8.1)	33 (8.6)
Unhappy	2285 (29.0)	1853 (29.9)	234 (28.0)	113 (29.5)
Terrible	4349 (55.3)	3227 (52.1)	484 (57.8)	222 (58.0)
Missing: 3.3%				

* The percentages are calculated based on the total number of women who answered the relevant question

Severity of pain

Severe or very severe pain was reported in 75.8% of women with endometriosis, 66.0% of those with fibroids and endometriosis, and 51.6% of those with fibroids and/or polyps. Even among those without known HMB-related conditions, 53.4% reported severe/very severe pain.

An increasing trend was evident in the association between severity and duration of symptoms: among those with duration of symptoms of less than 2 months, 30.1% reported experiencing severe or very severe pain, compared with 42.9% of those with duration more than 2 months but less than 1 year and 55.9% of those with duration over 1 year.

The percentage of women with severe or very severe pain decreased with increasing age, from 63.1% for those under 35 years to 37.2% for those over 50 years. While this was true regardless of which group of known HMB-related conditions the women had, the absolute difference was smallest in those with fibroids alone and endometriosis alone (Figure 5.2).

The proportion of women with severe or very severe pain increased with increasing number of comorbidities (49.8% of those with no comorbidities, 54.8% of those with one comorbidity and 58.7% of those with two or more comorbidities) and with increasing BMI (17.7% of those with a BMI less than or equal to 25, 18.0% of those with a BMI of between 26 and 30, and 23.2% of those with a BMI of more than 30).

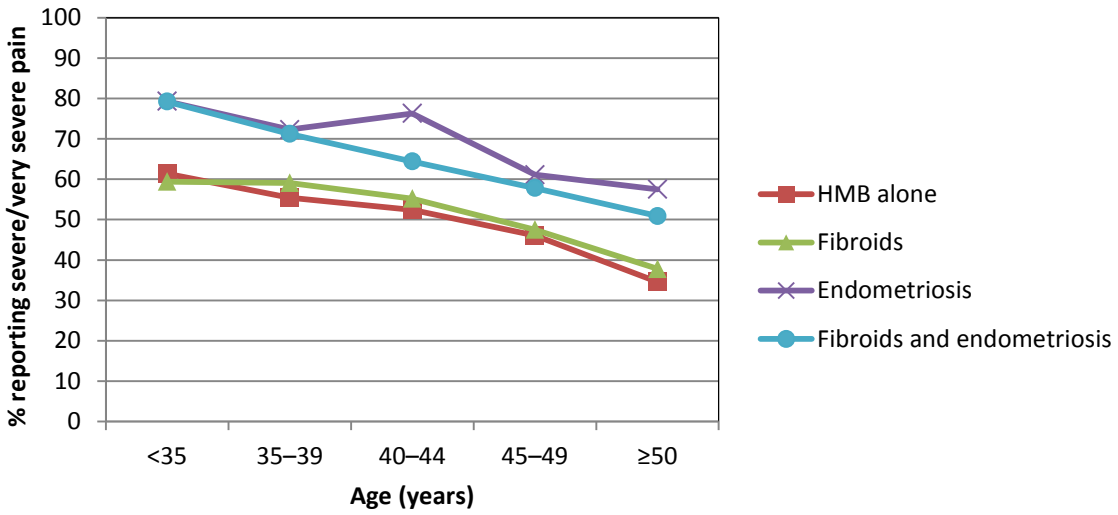

Figure 5.2 Proportion of women reporting severe or very severe pain, stratified by known HMB-related conditions and age

Satisfaction with condition if symptoms remained the same

We also asked how satisfied women would be if their HMB symptoms were to remain the same over the next 5 years. The women's level of satisfaction with their HMB symptoms was similar among all groups (including those with no known HMB-related conditions). Over 80% of women would feel unhappy or terrible if their symptoms persisted over the next 5 years. Women with higher levels of pain were more likely to feel unhappy or terrible if symptoms persisted over the next 5 years: 71.0% in those with no pain, 73.6% in those with very mild or mild pain, 76.2% in those with moderate pain and 90.7% in those with severe or very severe pain. Women with longer duration of symptoms were also more likely to feel unhappy or terrible if symptoms were to persist over the next 5 years (81.0% of those with symptom duration of less than 1 year versus 84.8% of those with duration over 1 year).

5.4 Variation in symptoms of women across NHS providers

Funnel plots were used to assess whether there was variation in symptoms across NHS providers.

In Figure 5.3, the proportion of women in whom the duration of symptoms was over 1 year was plotted against the number of women seen for HMB at each trust, adjusted for age and HMB-condition status. The national average (proportion of women across all trusts) was 74.0%. While it is evident that differences among trusts did exist in relation to duration of symptoms, almost all trusts had results that fell within the range that can be expected only based on random variation. Hence, there was little evidence to suggest that differences in practice exist at primary care level.

Figure 5.4 shows the proportion of women who were experiencing severe or very severe pain at their first outpatient visit. The national average was 54.2%. Again, while differences in the proportion of women experiencing severe or very severe pain among trusts did exist, there was little evidence of systematic variation among trusts.

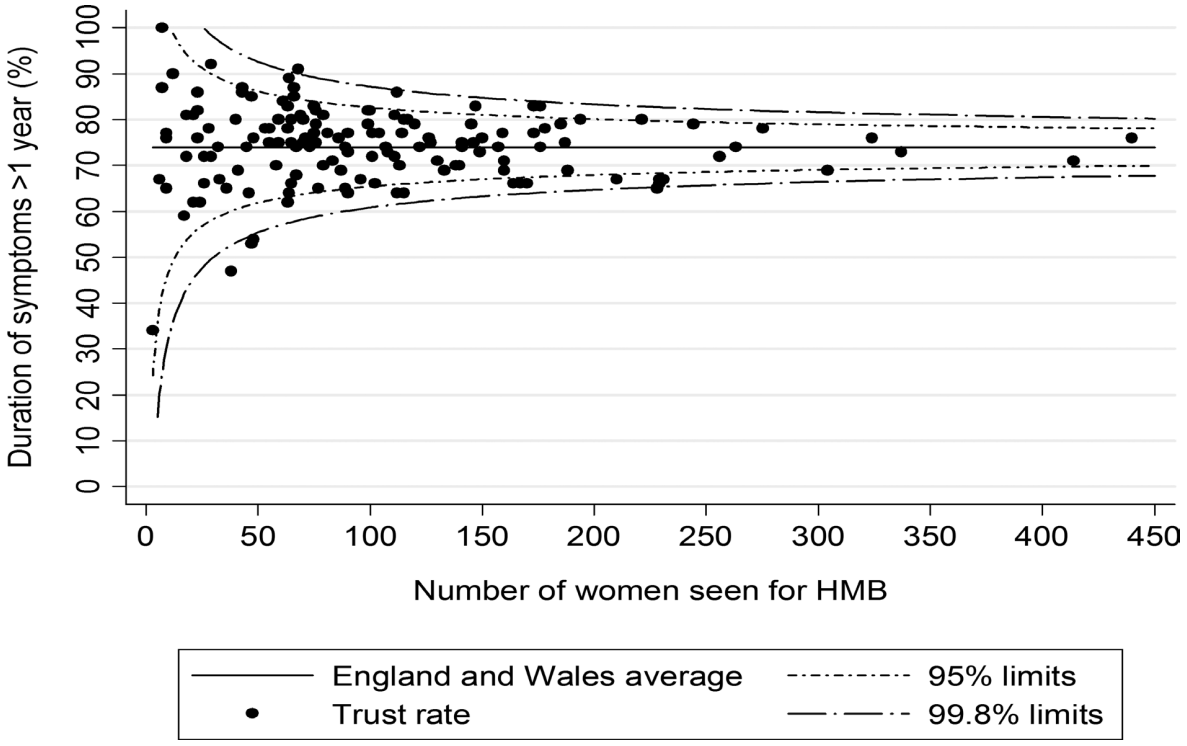

Figure 5.3 Proportion of women with duration of symptoms over 1 year; adjusted proportions by trust

Adjusted for age and known HMB-related conditions

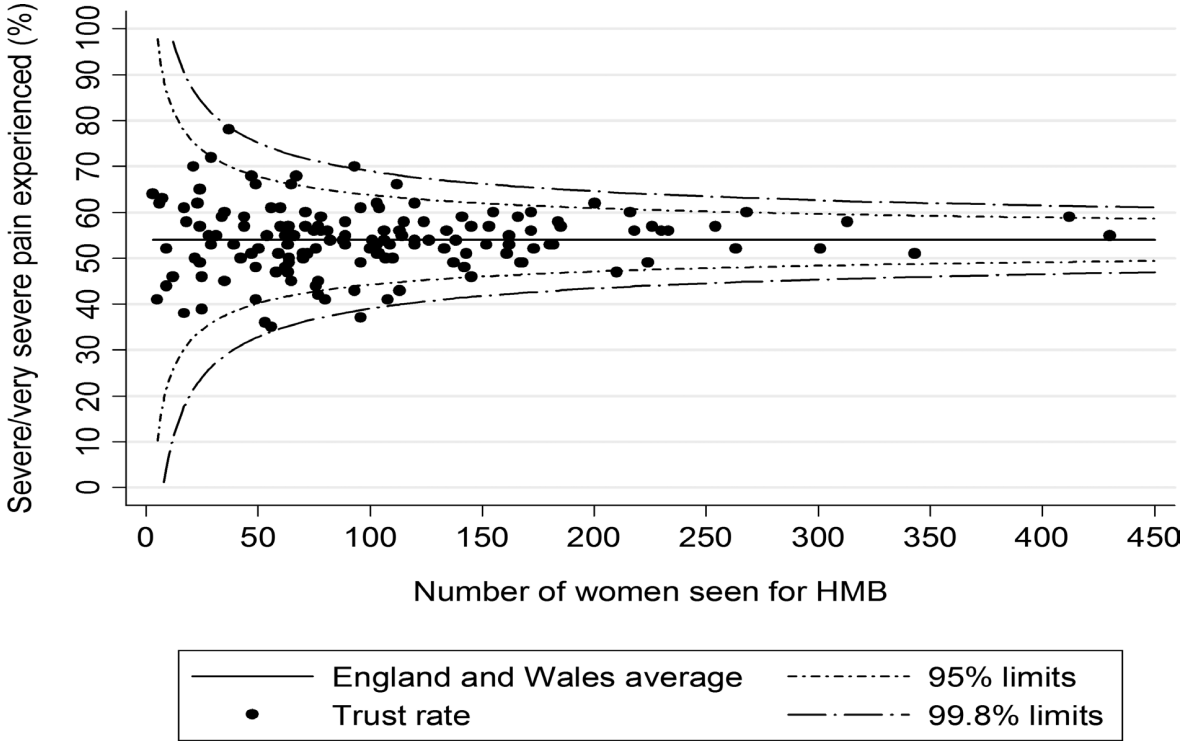

Figure 5.4 Proportion of women with severe or very severe pain; adjusted proportions by trust

Adjusted for age and known HMB-related conditions

6 Quality of life of women at the first outpatient visit

6.1 Health-related quality of life and severity

The adapted UFS-QoL tool[2] was used to assess severity and health-related quality of life (HRQoL) scores. Higher severity scores indicate greater symptom severity (maximum score = 100) and higher HRQoL scores indicate better quality of life.

The mean severity score among the 97.0% of women who completed this section of the questionnaire was 62.5 (standard deviation 21.2). One-quarter of women had a score below 50. Figure 6.1 shows the severity score stratified by various factors of interest. A strong association was seen between the severity score and pain experienced, with greater scores evident among those experiencing severe or very severe pain. Severity scores were also higher among those with longer duration of symptoms, those with a greater number of comorbidities and those with complex HMB-related conditions.

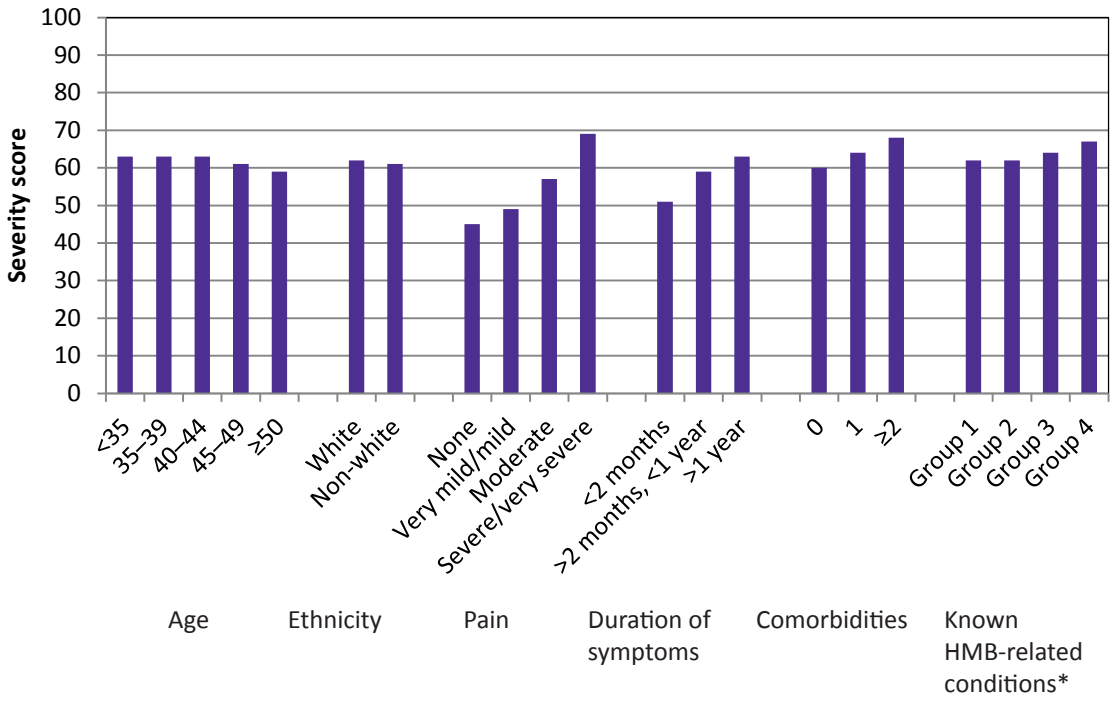

Figure 6.1 Mean adapted UFS-QoL severity scores stratified by factors of interest

* Group 1: HMB alone; Group 2: Fibroids and/or polyps; Group 3: Endometriosis with or without polyps; Group 4: Fibroids and endometriosis with or without polyps

Severity scores were lower among women of older age (mean score of 59 among those over 50 years compared with 63 among those under 35 years). This is consistent with the finding that women of older age reported lower levels of pain. When stratified by levels of pain reported, severity scores were similar across all age groups, ranging from around 45 among those in no pain to 69 among those in severe or very severe pain.

Similar patterns were seen with the HRQoL score (Figure 6.2), albeit, as expected, in the opposite direction.

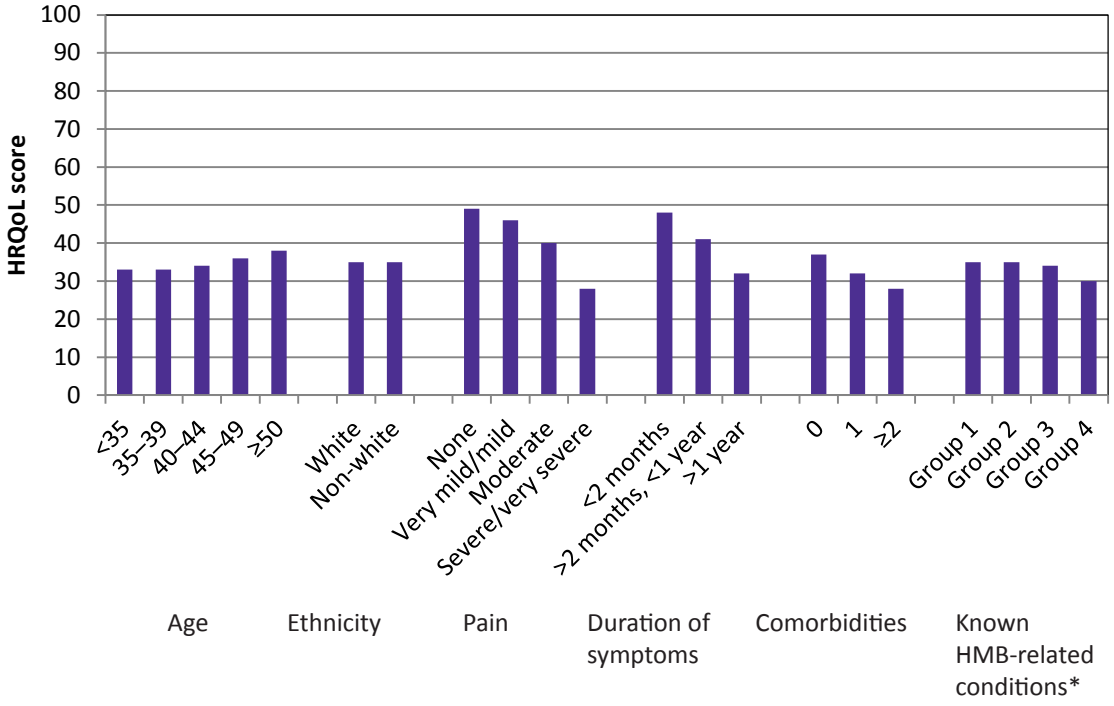

Figure 6.2 Mean adapted UFS-QoL HRQoL scores stratified by factors of interest

* Group 1: HMB alone; Group 2: Fibroids and/or polyps; Group 3: Endometriosis with or without polyps; Group 4: Fibroids and endometriosis with or without polyps

6.2 EQ-5D score

The EQ-5D score was also associated with the various factors outlined above. A low EQ-5D score is indicative of poorer quality of life. The mean EQ-5D score was 0.65 (standard deviation 0.33). In general, associations between the EQ-5D score and the various factors of interest were similar to that seen with the HRQoL scores in Figure 6.2. Figure 6.3 shows the EQ-5D scores decreasing with higher severity of pain, longer symptom duration and greater number of comorbidities. The EQ-5D score did, however, differ from the HRQoL score with regard to HMB-related conditions. Women with endometriosis (rather than those with complex HMB-related conditions such as fibroids and endometriosis together) had the lowest EQ-5D score, indicating the poorest quality of life. Associations between age and EQ-5D score and between ethnicity and EQ-5D score were also stronger than those seen using the adapted UFS-QoL score.

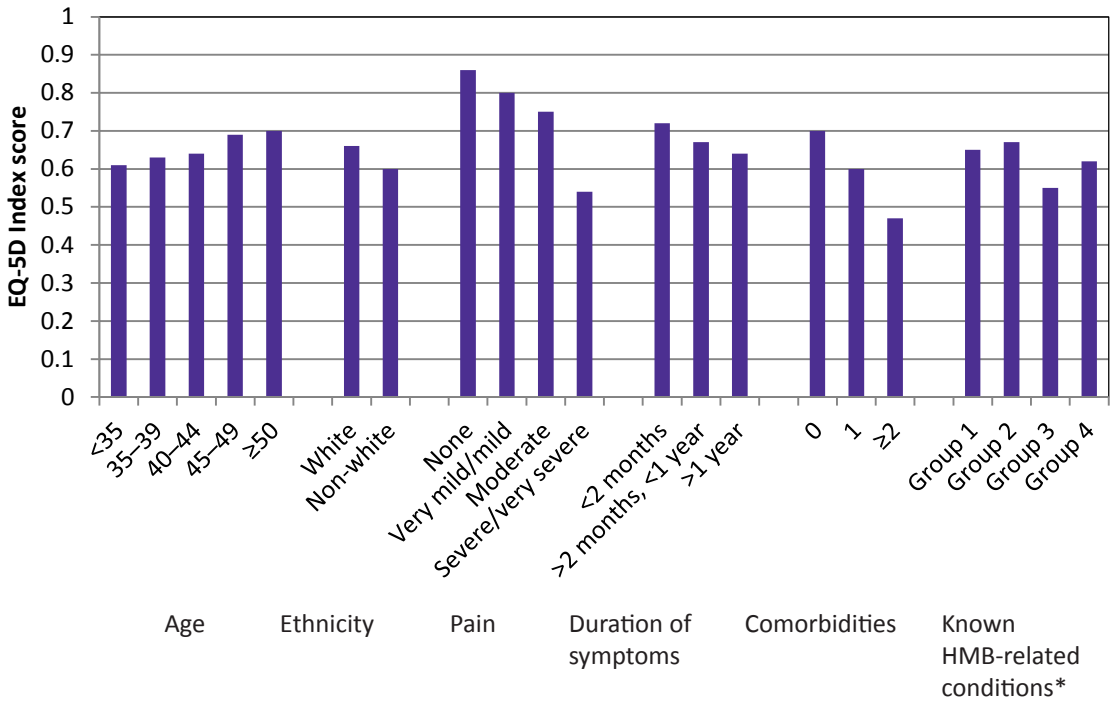

Figure 6.3 Mean EQ-5D scores stratified by factors of interest

* Group 1: HMB alone; Group 2: Fibroids and/or polyps; Group 3: Endometriosis with or without polyps; Group 4: Fibroids and endometriosis with or without polyps

6.3 Variation across trusts in adapted UFS-QoL and EQ-5D scores

Figures 6.4 and 6.5 show the adapted UFS-QoL severity and HRQoL scores at each trust. Severity scores at trust level were scattered closely around the national average severity score across England and Wales (62), suggesting that there were no systematic differences among trusts with regard to severity scores. Similarly, HRQoL scores were scattered closely around 35, which is the national average of HRQoL scores across all trusts.

The EQ-5D score at each trust is shown in Figure 6.6. The mean score was 0.65. While differences were evident among trusts, there was no evidence to suggest that these differences could not be explained by random variation.

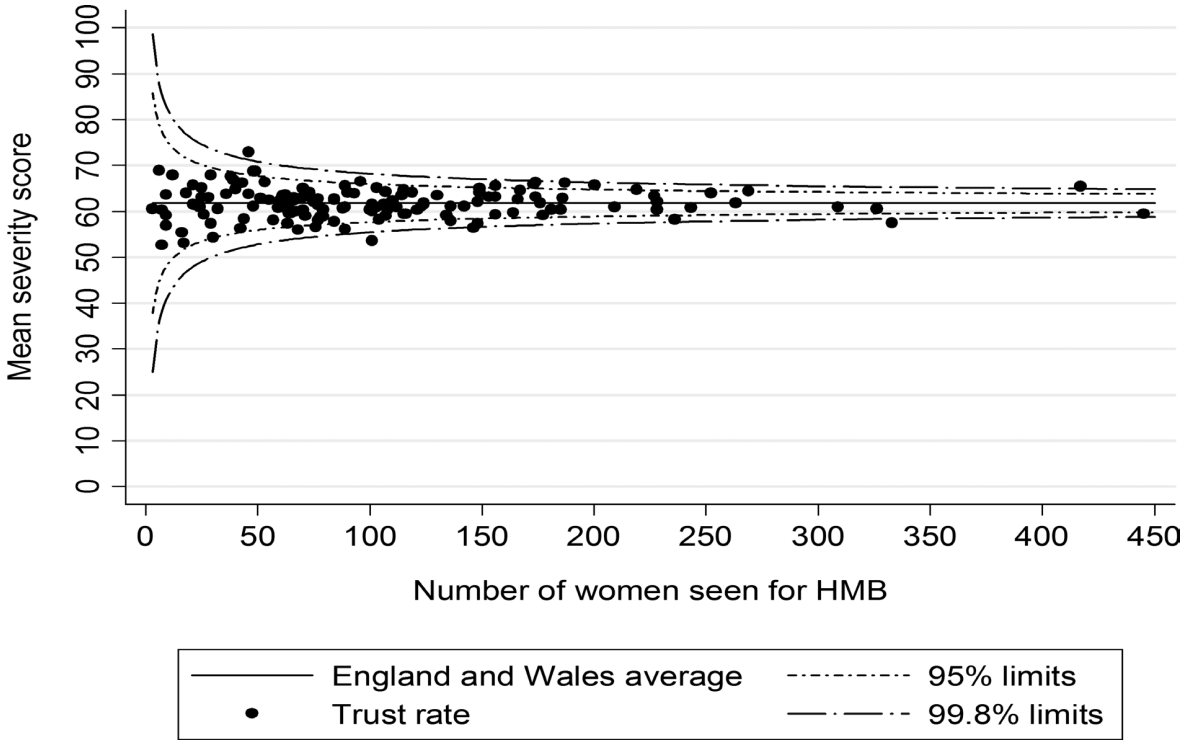

Figure 6.4 Unadjusted mean adapted UFS-QoL severity scores across trusts (*N* = 15 338; women with missing answers excluded)

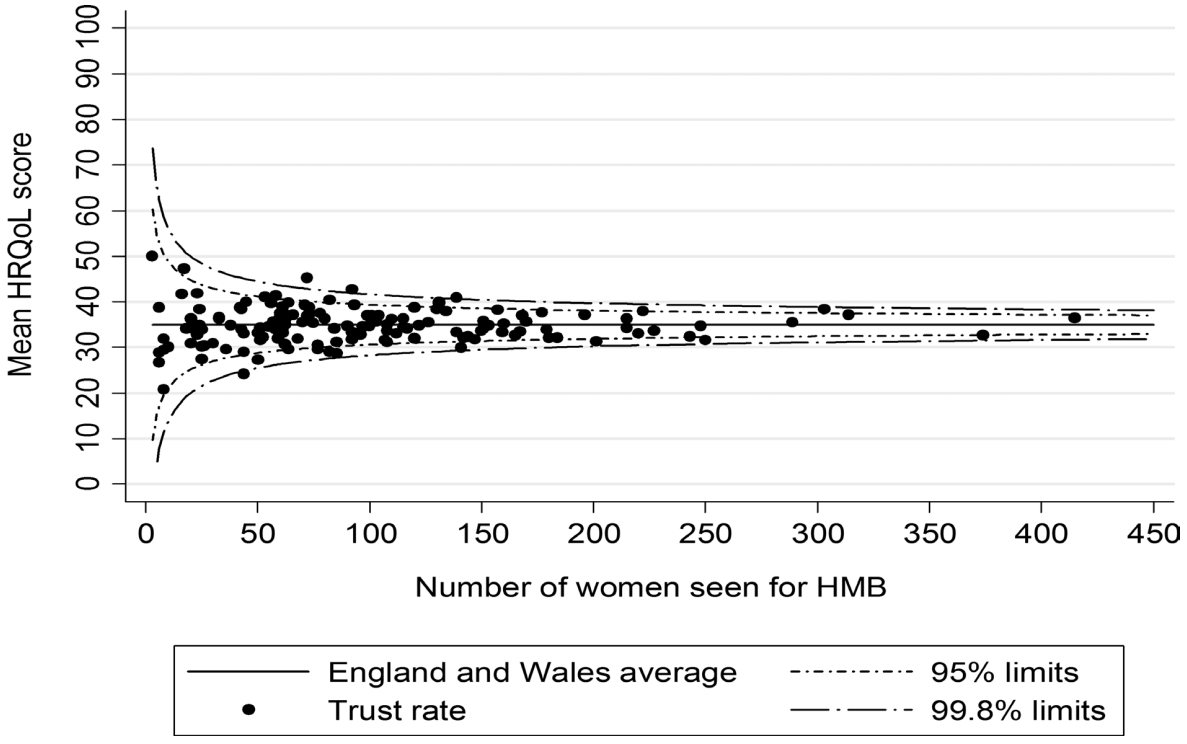

Figure 6.5 Unadjusted mean adapted UFS-QoL HRQoL scores across trusts (*N* = 14 394; women with missing answers excluded)

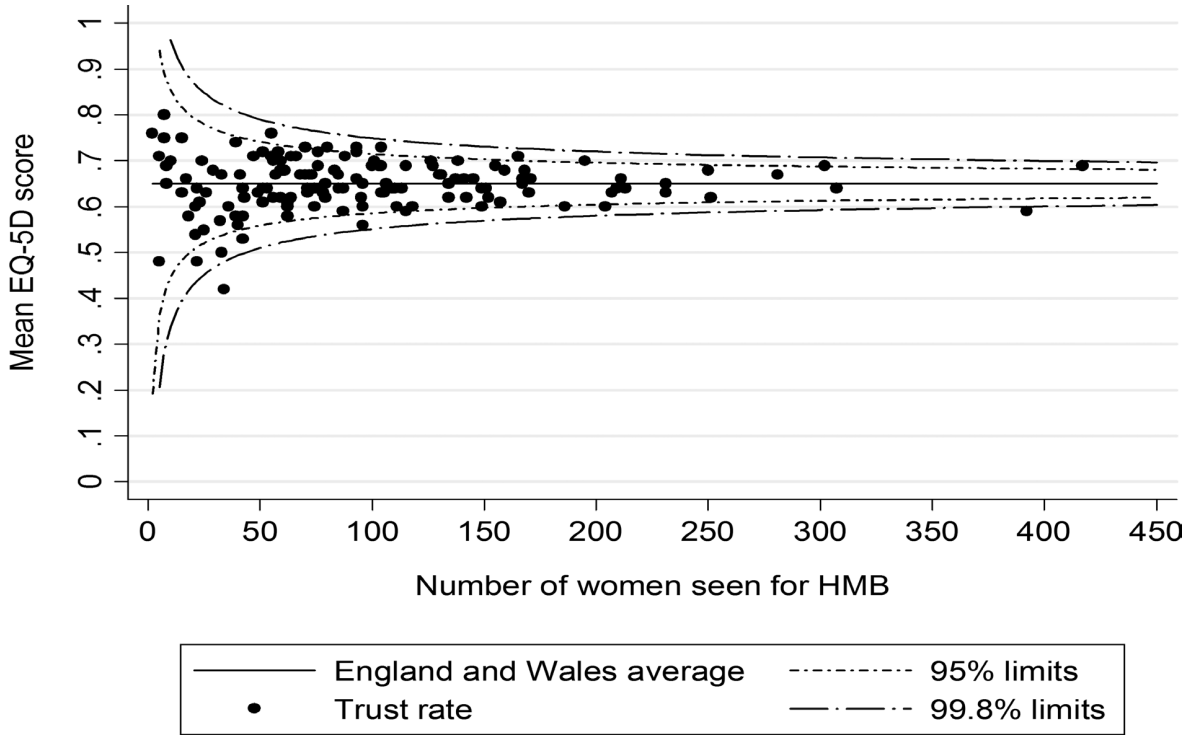

Figure 6.6 Unadjusted mean EQ-5D scores across trusts (*N* = 14 202; women with missing answers excluded)

7 Patterns of primary care treatment among women prior to referral

In this chapter, we focus on the care received prior to the first outpatient visit. This includes associations with the number of GP visits before referral and the number and type of previous treatments received. Funnel plots are used to assess differences among trust in relation to primary care.

7.1 GP visits prior to referral

Three-quarters of women had had one to four GP visits in the year before being referred to secondary care. Six percent of women had had no GP visits, and 16.4% had had more than four visits before secondary care referral. There was no association between number of GP visits and known HMB-related conditions, but associations did exist, as expected, with various other factors (Table 7.1).

The proportion of women with more than four GP visits increased with younger age (28.7% of those under 35 years compared with 11.7% of those over 50 years), longer duration of symptoms (18.8% of those with duration over 1 year compared with 5.8% of those with duration less than 2 months) and greater severity of pain (21.3% of those experiencing severe or very severe pain compared with around 10% of those in each of the lesser pain categories). Women with comorbidities were also more likely to have had more than four GP visits (22.4% of those with at least two comorbidities, 19.1% of those with one comorbidity and 14.7% of those with no comorbidities had more than four GP visits).

7.2 Previous treatment

Thirty-one percent of women had received no previous treatment before their referral to secondary care. The proportion of women who had received no previous treatment increased with older age, from 24.3% of those under 35 years to 36.6% of those over 50 years (Table 7.2). Women with longer duration of symptoms, higher numbers of GP visits, non-HMB-related comorbidities, higher levels of pain and known HMB-related conditions were less likely to have received no previous treatment.

Six hundred and fifteen women (4.0%) had had neither any GP visits in the year prior to referral nor any previous treatment prior to referral to secondary care. Almost one-third of these women (30.1%) were experiencing severe or very severe pain at their first outpatient visit and 59.3% of these 615 women had had their HMB symptoms for over 1 year. A significant proportion of these women with no GP visits or prior treatment were seen in London (21.6%) and the North West (18.9%).

Among the 10 567 women who had received previous treatment, 64.9% had received one treatment, 25.7% had received two treatments and the remaining 9.4% had received three or more treatments. The most frequent combinations of treatments received, stratified by known HMB-related conditions, are shown in Table 7.3. Women with HMB only and those with HMB and fibroids and/or polyps were more likely to have received no previous treatment than those with more complex HMB-related conditions (such as endometriosis with or without polyps or fibroids and endometriosis with or without polyps). Medication

Table 7.1 Associations between number of GP visits and various other factors

Patient characteristic	Number of women, *n* (row %)		
	No GP visits	1–4 GP visits	>4 GP visits
All patients	992 (6.5)	11756 (77.1)	2505 (16.4)
Age in years			
<35	151 (6.7)	1462 (64.6)	650 (28.7)
35–39	118 (6.0)	1474 (75.3)	365 (18.7)
40–44	236 (5.8)	3184 (78.7)	624 (15.4)
45–49	317 (6.6)	3858 (80.7)	608 (12.7)
≥50	170 (7.7)	1778 (80.6)	258 (11.7)
Ethnicity			
Non-white	167 (9.7)	1153 (67.2)	396 (23.1)
White	745 (6.0)	9841 (78.7)	1913 (15.3)
Missing/do not want to answer: 6.8%			
Known HMB-related conditions			
HMB only	560 (7.1)	5952 (75.4)	1378 (17.5)
Fibroids	356 (5.8)	4897 (79.6)	899 (14.6)
Endometriosis	57 (6.9)	601 (73.2)	163 (19.9)
Fibroids and endometriosis	19 (4.9)	306 (78.5)	65 (16.7)
Duration of symptoms			
<2 months	67 (18.4)	277 (75.9)	21 (5.8)
2 months to 1 year	200 (5.7)	2969 (83.9)	371 (10.5)
>1 year	623 (5.7)	8263 (75.5)	2060 (18.8)
Missing/do not know: 3.1%			
Severity of pain			
None	89 (10.8)	646 (78.7)	86 (10.5)
Very mild/mild	226 (10.2)	1766 (80.0)	215 (9.7)
Moderate	267 (7.2)	3036 (81.9)	406 (11.0)
Severe/very severe	365 (4.6)	5839 (74.1)	1678 (21.3)
Missing: 4.4%			
Health			
Excellent/very good	379 (6.7)	4648 (81.9)	646 (11.4)
Good	391 (6.2)	4903 (78.1)	984 (15.7)
Fair/poor	208 (6.8)	2044 (66.5)	822 (26.7)
Missing: 1.6%			
Number of comorbidities			
0	701 (6.9)	7946 (78.4)	1485 (14.7)
1	215 (5.6)	2892 (75.3)	733 (19.1)
≥2	76 (5.9)	918 (71.7)	287 (22.4)

Women with missing data on the number of GP visits are excluded

(excluding the pill) was most frequently received among women without known HMB-related conditions and those with fibroids, while the pill was most frequently received among those with endometriosis.

An association was evident between age and type of previous treatment: the percentage of women receiving other medication (*not* the pill) aged under 35, 35–99, 40–44, 45–49 and over 50 years was 14.5%, 19.6%, 22.0%, 25.5% and 27.7%, respectively, while younger women were more likely to receive the pill and the pill with other medication (Figure 7.1). This finding is important as it highlights that women's treatment choices are very much dependent on whether or not they are considering having children in the future – in Chapter 5, Figure 5.1 showed that women of younger age were more likely to consider future pregnancy.

Table 7.2 Associations between previous treatment and various other factors

Patient characteristic	Number of women, *n* (row %)	
	No previous treatment	Some previous treatment
All patients	4770 (31.1)	10567 (68.9)
Age in years		
<35	556 (24.3)	1734 (75.7)
35–39	572 (29.1)	1391 (70.9)
40–44	1266 (31.1)	2808 (68.9)
45–49	1564 (32.6)	3227 (67.4)
≥50	812 (36.6)	1407 (63.4)
Ethnicity		
Non-white	542 (32.4)	1132 (67.6)
White	3879 (30.7)	8738 (69.3)
Missing/do not want to answer: 7.0%		
Known HMB-related conditions		
HMB only	2532 (32.0)	5383 (68.0)
Fibroids	1998 (32.2)	4201 (67.8)
Endometriosis	166 (19.9)	667 (80.1)
Fibroids and endometriosis	74 (19.0)	316 (81.0)
Duration of symptoms		
<2 months	183 (51.1)	175 (48.9)
2 months to 1 year	1578 (45.3)	1902 (54.7)
>1 year	2838 (25.6)	8260 (74.4)
Missing/do not know: 3.1%		
Number of GP visits in the previous year		
0	615 (63.9)	348 (36.1)
1–2	2901 (41.2)	4142 (58.8)
3–4	850 (19.2)	3571 (80.8)
>4	290 (12.0)	2133 (88.0)
Missing: 3.5%		
Severity of pain		
None	357 (44.0)	455 (56.0)
Very mild/mild	848 (38.5)	1355 (61.5)
Moderate	1317 (35.5)	2398 (64.5)
Severe/very severe	2075 (26.0)	5897 (74.0)
Missing: 4.4%		
Number of comorbidities		
0	3330 (32.7)	6846 (67.3)
1	1112 (28.6)	2769 (71.4)
≥2	328 (25.6)	952 (74.4)

Women with missing data on previous treatment are excluded

Associations were also evident between severity of symptoms and type of previous treatment. Women experiencing higher levels of pain were more likely to have received the pill (11.7% of those in severe or very severe pain compared with 6.2% of those in no pain), although little difference was seen in relation to other medication and severity of symptoms (around 22% received other medication regardless of symptom severity). Conversely, duration of symptoms was not associated with receiving the pill (around 10% of women received the pill, regardless of duration of symptoms) or with receiving other medication (around 22% received other medication, regardless of duration of symptoms). Women with longer duration of symptoms were, however, more likely to receive the pill and other medication (1.7% of those with

Table 7.3 Frequency of previous treatments received, stratified by known HMB-related conditions

Previous treatment		Number of women with known HMB-related conditions, *n* (%)			
		HMB only	Fibroids and/or polyps	Endometriosis with or without polyps	Fibroids and endometriosis with or without polyps
All patients	15337	7915	6199	833	390
None	4770	2532 (32.0)	1998 (32.2)	166 (19.9)	74 (19.0)
Other medication (not the pill)	3449	1751 (22.1)	1519 (24.5)	113 (13.6)	66 (16.9)
The pill	1621	978 (12.4)	490 (7.9)	118 (14.2)	35 (9.0)
The pill and other medication	986	581 (7.3)	315 (5.1)	63 (7.6)	27 (6.9)
Intrauterine system (IUS)	889	403 (5.1)	420 (6.8)	37 (4.4)	26 (6.7)
Other treatment	720	323 (4.1)	335 (5.4)	40 (4.8)	22 (5.6)
The pill and IUS	495	271 (3.4)	178 (2.9)	30 (3.6)	16 (4.1)
Other medication and IUS	479	219 (2.8)	222 (3.6)	24 (2.9)	14 (3.6)
The pill, other medication and IUS	433	242 (3.1)	143 (2.3)	34 (4.1)	14 (3.6)
Other	1498	615 (7.8)	579 (9.3)	208 (25.0)	96 (24.6)

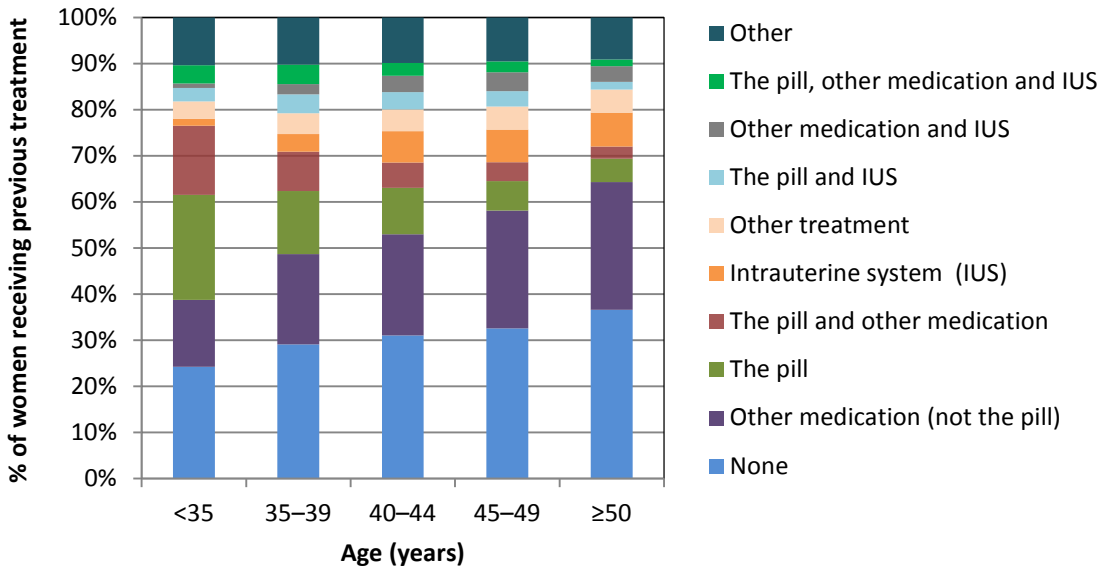

Figure 7.1 Type of previous treatment received, stratified by age

duration of less than 2 months, 3.7% of those with duration more than 2 months but less than 1 year and 7.5% of those with duration more than 1 year).

7.3 NHS providers and variations in primary care

The proportion of women who had had no GP visits prior to referral to secondary care, stratified by SHA is shown in Figure 7.2. Overall, 6.5% of women had not had a GP visit in the year prior to their first outpatient appointment. However, this proportion ranged from

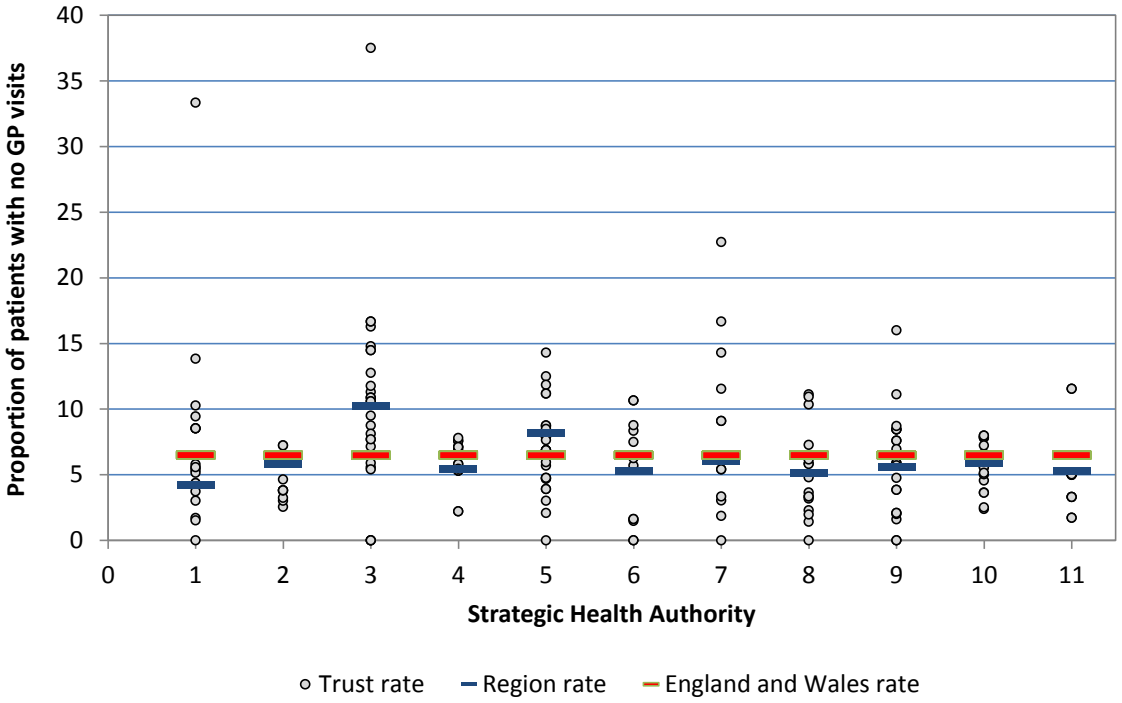

Figure 7.2 Proportion of women with no prior GP visits, at trust, SHA and national level

SHA codes: 1 = East Midlands; 2 = East England; 3 = London; 4 = North East; 5 = North West; 6 = South Central; 7 = South East; 8 = South West; 9 = West Midlands; 10 = Yorkshire; 11 = Wales

4.2% to 10.2% among SHAs. The London SHA had the highest average proportion of women who had had no prior GP visits, although this proportion ranged from 0% to 37.5% within trusts in London.

Figure 7.3 shows the proportion of women at each trust who had had no GP visits in the year before their first outpatient appointment, adjusted for potential confounding factors. This proportion was considerably higher than the national average (6.5%) for some trusts and, in particular, two trusts were identified at which this proportion fell outside the 99.8% control limits. This suggests that the difference between the proportion at these two trusts and the national average is unlikely to be explained by chance alone.

In Figure 7.4, the proportion of women who had had no previous treatment is shown for each trust. The overall proportion was 31.1%. While differences between trusts were apparent, the proportions were generally within the control limits. However, three trusts were identified as having higher rates than expected. Two of these trusts were the same trusts as those which had a higher than expected proportion of women who had had no prior GP visits, as shown in Figure 7.3.

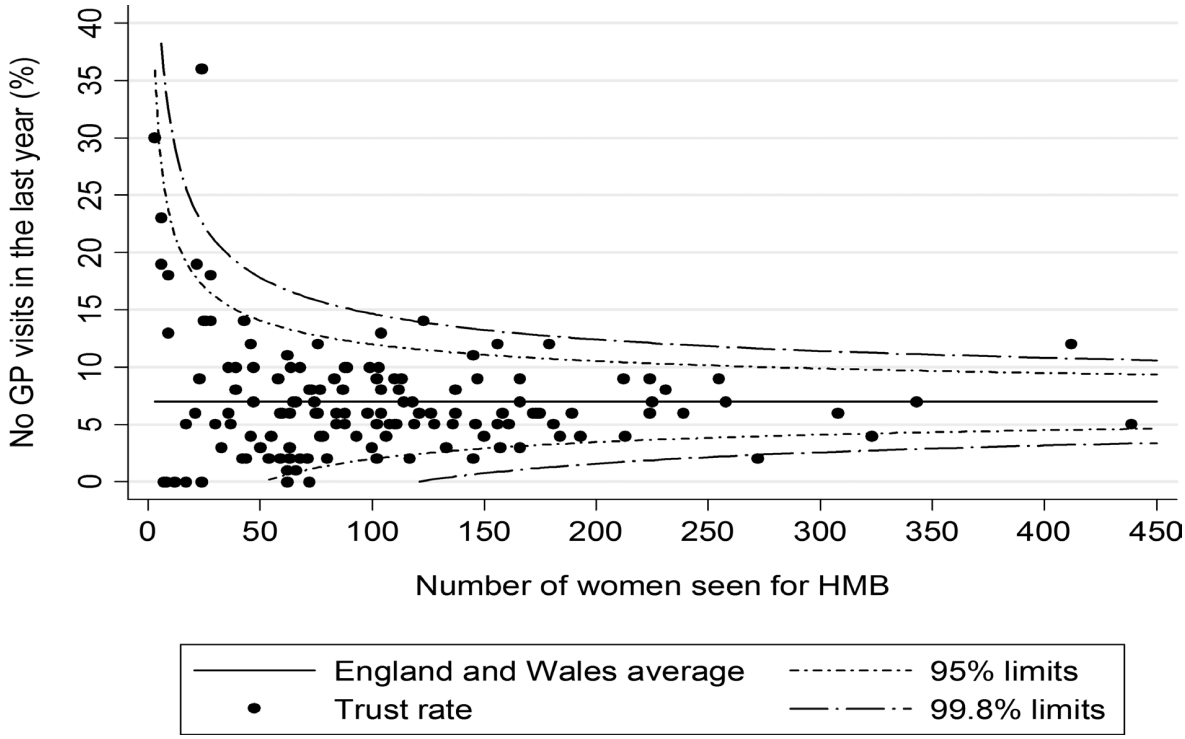

Figure 7.3 Proportion of women with no prior GP visits;* adjusted proportions by trust

* *N* = 15 253; women with missing/'do not know' answers excluded
Adjusted for age, ethnicity, known HMB-related conditions, pain and HRQoL score

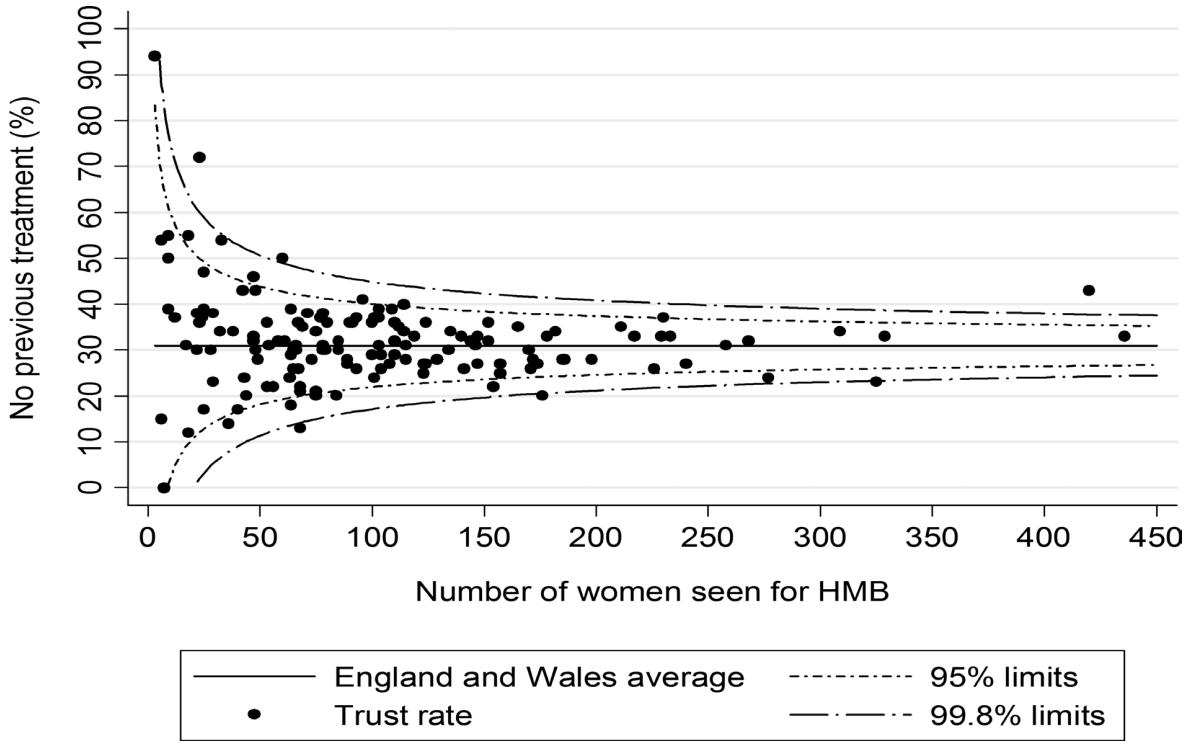

Figure 7.4 Proportion of women with no previous treatment;* adjusted rates by trust

* *N* = 15 337; women with missing/'do not know' answers excluded
Adjusted for age, ethnicity, known HMB-related conditions, pain and HRQoL score

8 Review of the prospective audit

The HMB audit is a unique national clinical audit as it includes women at the time of their first referral to an outpatient clinic. Rather than including women who undergo a specific *procedure*, this audit assesses the care received by women from the time that they attend an outpatient clinic with a specific *problem*. Data on the care they receive in the year following their visit and how this treatment affects their quality of life will be obtained by collecting data from the patients themselves. Women must be enrolled when they visit the outpatient clinic so that they can be given a questionnaire. This poses challenges because of the short time during which the woman is available in clinic.

Given the difficult methodology, the project team undertook a qualitative telephone survey of participating NHS hospitals to examine how the audit could be continued in the long term.

8.1 Methodology of the qualitative survey

Between June and August 2011 (around half-way through the data collection), the project team conducted a qualitative survey of the 199 hospitals participating in the audit. Each hospital was initially contacted by telephone. Up to four attempts were made to contact either the clinical lead or the local audit coordinator (LAC). If contact was not made after three attempts, an email detailing the purpose of the call was sent to both the clinical lead and the LAC at the relevant hospital. During the telephone conversation, hospital staff were asked for their views on:

- the recruitment procedures and recruitment rates
- the motivation of staff and patients to participate
- difficulties with the audit methodology.

8.2 Results of the qualitative survey

Of the 199 hospitals taking part in the audit, telephone contact was made with 174 hospitals (88%).

In many cases, the sustainability of the audit was hospital-specific. While some hospitals were in a position to follow the advice given at the start of the audit, this was not the case with all of them. However, several themes emerged repeatedly across hospitals, and these are discussed briefly below.

Issues with audit estimates of hospital denominator

In some instances, it was felt that the estimate for the hospital denominator did not accurately represent the number of women seen for HMB for the first time at their clinic. Several reasons were given for this:

a. many HMB patients were now being dealt with in primary care, resulting in a drop in the number of referrals

b. a number of independent sector treatment centres have opened nationwide, and a significant number of patients are being referred to these rather than to hospitals

c. some estimates provided by hospitals to HES were at trust-level rather than unit-level; this resulted in an overestimation of the denominator for all units belonging to a single trust.

Issues related to staff and patient motivation

d. Shortage of staff was quoted as the main staff-related reason affecting recruitment. This resulted in referral letters not being screened and therefore eligible women not being identified in advance. In these cases, the responsibility for handing out the questionnaire fell on the clinic nursing staff and eligible patients may have been missed.

e. A further and significant issue with staff was the motivation of the consultants. Generally, if the consultant was interested in the audit, the team working in the clinic were fully motivated in recruiting eligible women. In such cases, the audit was brought up in regular internal meetings and staff were fully aware of the procedures involved. Conversely, if the consultants showed little interest in the audit, the team did not see it as a priority either and this resulted in low recruitment rates. Furthermore, many clinics employed part-time or temporary staff and thus not everyone was aware that the audit was ongoing.

f. Patient motivation was also mentioned as an issue that influenced recruitment rates. A minority of patients were not able to fill in the questionnaire because they did not have sufficient skills in the English language to understand the questions fully. This posed a major problem for some hospitals located in inner-city areas.

g. A further issue raised by some hospitals was that there was insufficient time to complete the questionnaire before the appointment.

Health service issues

h. One final issue that affected the ability of hospitals to enrol women was the operation of the 'choose and book' system. Hospitals were unable to screen referral letters if appointments were booked through 'choose and book', and they consequently missed eligible patients because women could not be identified in advance. In some situations, these women were identified at the time of appointment but this very much depended on who the initial contact at the hospital was with.

8.3 Suggestions by project team in response to issues

In response to issues surrounding hospital denominators, we asked clinical leads and/or LACs to provide us with up-to-date data on the number of new HMB referrals. In situations where cultural and language barriers were prevalent, clinicians were asked to estimate the proportion of patients who were not able to fill in the questionnaire because of these barriers. Denominators were then reduced by this percentage where appropriate. Denominators were revised for 60 hospitals.

In instances where staff shortage was an issue, although not ideal, it was suggested that the doctors who saw women for HMB handed them the questionnaire at the end of their appointment and asked them to complete it before they left the clinic.

To improve staff motivation, we reminded both clinical leads and LACs that the audit was one of those included in the Quality Accounts and that the trust's chief executive would be asked to report recruitment rates in the annual Quality Accounts to the Department of Health.

Our telephone discussions often led to clinical leads and/or LACs offering to put the audit on the agenda in forthcoming internal meetings.

8.4 Lessons learnt

The overall view of the audit was generally positive, which suggests that the approach is feasible and realistic if there is sufficient local clinical support. However, in order to recruit all eligible women, a designated member of the audit team at each unit is needed. Staff shortages across the NHS have resulted in existing staff already being overworked and hence ensuring recruitment into the audit was often not seen as a priority. This would inevitably increase the amount of funding needed for such audits and, as such, the balance between high recruitment and affordable funding must be made.

A few hospitals mentioned that women felt that the eight-page questionnaire was too long. While their remarks are not consistent with the results of the questionnaire pilot, it is important to keep future questionnaires as short as possible to maximise patient motivation.

8.5 Further engagement with hospitals

There was an active effort to keep hospitals engaged during the audit. An online portal system was set up that allowed clinical leads and LACs to keep up to date with the number of cases submitted each month. A monthly newsletter in which the top recruiters were identified and key events of the previous month were summarised was sent to each unit. Letters were sent to the medical director, clinical director, clinical lead and/or the LAC at each unit at key points during the audit:

- June 2011 – letter sent to clinical directors, clinical leads and LACs regarding lower recruitment rates than anticipated and reminding units to recruit all eligible women
- August 2011 – letter sent to medical directors to inform them of the recruitment status of the unit (very good, below expected, not yet recruiting); a request was made to hospitals with low recruitment rates to improve such rates
- November 2011 – letter sent to clinical leads and LACs, highlighting that it was the last quarter of the audit and requesting them to continue improving recruitment rates
- December 2011 – letter sent to clinical leads and LACs to encourage active recruitment in the last month of the audit.

In addition to these letters, the project team was in contact with staff from the units throughout the audit, both by email and by telephone.

8.6 Summary

This qualititative telephone survey has provided important insights into the logistical challenges of an outpatient-based audit. The lessons learnt from this survey provide guidance on the sustainability of future outpatient-based national audits. In particular, engagement with the clinicians and the working arrangement put in place by the LAC within the individual unit are key to the success of such audits.

9 Discussion

The results of the patient-reported outcomes component of the audit in women who visit a gynaecological outpatient clinic for HMB have shown that the majority of women referred to secondary care have had their symptoms for a prolonged duration and are experiencing either severe or very severe pain. Overall, almost one-third of women had received no initial treatment before their first outpatient appointment. While regional differences in symptoms, primary care treatment and quality of life did exist, there was little evidence of systematic variation among trusts.

Other studies have reported differences in management at primary care level and wide variation in referral rates from primary care to secondary care.[16,17] In the First Annual Report[2] (published in 2011), we reported considerable regional variations in rates of hysterectomy and endometrial ablation. It is therefore surprising that we found little variation in the care received by women with HMB in primary care. Although this finding does warrant further investigation, it does suggest that differences in referral practice contribute little to the wide variation seen in surgical practice.

Current guidelines recommend that medical treatment be offered initially in primary care and hence it is surprising that about 30% of women had received no previous treatment. Also of concern is the high proportion of women with known comorbidities. Over 15% of women had been told by their doctor that they had depression. This figure is likely to be an underestimate as women may not yet have been diagnosed, but it is still slightly higher than the national average proportion of women with depression (12%).[18] This is likely to contribute to the relatively low quality of life scores for women completing the questionnaire. The average EQ-5D scores were considerably lower than those seen in preoperative groin hernia or varicose veins patients.[19]

Around half of all women who completed the questionnaire had known fibroids or endometriosis (with or without polyps). Again, this is an underestimate as it is likely that these conditions had not yet been diagnosed in some women. Hence, while it is clear that women seen at outpatients for the first time for HMB are in considerable pain and have a relatively low quality of life score, these women may be even more unwell than the results in this report have shown.

As discussed in Chapter 8, the methodology of this audit is difficult. The biggest challenge for the project team has been identifying the number of women with HMB; that is, setting the denominator of the case ascertainment estimate for each trust. A considerable number of trusts did not agree with the estimates calculated using HES data, and were also unable to provide us with more accurate in-house data.

Our qualititative telephone survey showed that most trusts feel that they lack the resources to adequately support national clinical audits. Communication between the Department of Health and trusts with regard to the importance of national clinical audits is needed as the Department considers the costs of participation in national audits to be included in the tariffs that trusts receive for the care and treatments they provide. The project team consistently reminded staff at trusts that they needed to include the HMB Audit in their Quality Accounts returns but the impact of these reminders seemed to be small.

The NICE guidelines define HMB as ‘excessive menstrual blood loss which interferes with the woman’s physical, emotional, social, and material quality of life’. In this report, we have shown that HMB does indeed have a significantly negative impact on women’s quality of life. Women at their first outpatient visit have poor disease-specific and general quality of life scores. It will be of interest to see how these scores are affected after referral into secondary care.

A follow-up questionnaire is being sent to all women who completed the baseline questionnaire 1 year after their first outpatient visit. In this questionnaire, we include questions on treatment received in the past year and further symptoms experienced. Results from the follow-up questionnaire will enable us to investigate to what extent the care that women receive in secondary care meets national guidelines. In addition, it may also contribute to a better understanding of the factors contributing to the wide variation in surgical treatment for HMB as reported in the First Annual Report. We look forward to reporting these results in the Third Annual Report.

Appendix 1

Clinical Reference Group, Project Board and Clinical Advisors

Members of the Clinical Reference Group

Angela Hyde (Chair)	RCOG Consumers' Forum
Loveleen Bansi-Matharu	Project team
Patrick Chien FRCOG	Ninewells Hospital, Dundee
David Cromwell	London School of Hygiene & Tropical Medicine
Hilary Denyer	Endometriosis UK, Patient Representative
Jonathan Frappell FRCOG	Derriford Hospital, Plymouth
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Debby Holloway	Royal College of Nursing
Sara Johnson	Project team
Mary Ann Lumsden FRCOG	University of Glasgow
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Michael Maresh FRCOG	St Mary's Hospital, Manchester
Heather Mellows FRCOG	Department of Health
Jonathan Nicholls	Project team
Judy Shakespeare	Royal College of General Practitioners
Allan Templeton FRCOG	Project team
Jan van der Meulen	Project team Co-Chair

Members of the Project Board

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Loveleen Bansi-Matharu	Project team
Stefan Durkacz	Project team
Ipek Gurol-Urganci	London School of Hygiene & Tropical Medicine
Angela Hyde	Chair of Clinical Reference Group
Sara Johnson	Project team
Tahir Mahmood FRCOG	Project team Co-Chair
Samantha McIntyre	Health Quality Improvement Partnership representative
Jonathan Nicholls	Project team
Yvonne Silove	Health Quality Improvement Partnership representative
Allan Templeton FRCOG	Project team
Jan van der Meulen	Project team Co-Chair

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John Calvert FRCOG	Morriston Hospital, Swansea
T Justin Clark MRCOG	Birmingham Women's Hospital
Kevin Cooper MRCOG	Aberdeen Maternity Hospital

Sean Duffy FRCOG	St James's University Hospital, Leeds
Leroy Edozien FRCOG	St Mary's Hospital, Manchester
Jenny Higham FRCOG	Imperial College London
Elizabeth Owen FRCOG	West Middlesex University Hospital
Jane Preston FRCOG	James Paget Hospital, Norwich
Margaret Rees FRCOG	University of Oxford

Appendix 2

Overall levels of case ascertainment

Table Estimated case ascertainment for the 148 trusts over the audit period

Code	Trust	Actual cases	Expected cases	Case ascertainment
7A3	Abertawe Bro Morgannwg University Health Board	225	828	27%
RCF	Airedale NHS Trust	82	168	49%
7A6	Aneurin Bevan Health Board	168	720	23%
RTK	Ashford and St Peter's Hospitals NHS Trust	7	615	1%
RF4	Barking, Havering and Redbridge University Hospitals NHS Trust	66	299	22%
RVL	Barnet and Chase Farm Hospitals NHS Trust	47	286	16%
RFF	Barnsley Hospital NHS Foundation Trust	116	360	32%
RNJ	Barts and The London NHS Trust	48	240	20%
RDD	Basildon and Thurrock University Hospitals NHS Foundation Trust	42	799	5%
RN5	Basingstoke and North Hampshire NHS Foundation Trust	71	270	26%
RC1	Bedford Hospital NHS Trust	60	396	15%
7A1	Betsi Cadwaladr University Health Board	448	888	50%
RLU	Birmingham Women's NHS Foundation Trust	63	996	6%
RXL	Blackpool Fylde and Wyre Hospitals NHS Foundation Trust	132	380	35%
5NY	Bradford and Airedale	56	96	58%
RAE	Bradford Teaching Hospitals NHS Foundation Trust	46	144	32%
RXH	Brighton and Sussex University Hospitals NHS Trust	100	814	12%
RXQ	Buckinghamshire Hospitals NHS Trust	75	342	22%
RJF	Burton Hospitals NHS Foundation Trust	65	264	25%
RWY	Calderdale and Huddersfield NHS Foundation Trust	126	360	35%
RGT	Cambridge University Hospitals NHS Foundation Trust	66	435	15%
RW3	Central Manchester University Hospitals NHS Foundation Trust	30	576	5%
RQM	Chelsea and Westminster Hospital NHS Foundation Trust	12	352	3%
RFS	Chesterfield Royal Hospital NHS Foundation Trust	111	404	27%
RLN	City Hospitals Sunderland NHS Foundation Trust	192	487	39%
RDE	Colchester Hospital University NHS Foundation Trust	24	681	4%
RJR	Countess of Chester Hospital NHS Foundation Trust	61	456	13%
RXP	County Durham and Darlington NHS Foundation Trust	68	672	10%
7A5	Cwm Taf Health Board	158	684	23%
RN7	Dartford and Gravesham NHS Trust	33	468	7%
RTG	Derby Hospitals NHS Foundation Trust	159	600	27%
RP5	Doncaster & Bassetlaw Hospitals NHS Foundation Trust	262	449	58%
RBD	Dorset County Hospital NHS Foundation Trust	60	211	28%
5QM	Dorset Primary Care Trust	9	23	39%
RC3	Ealing Hospital NHS Trust	99	300	33%
RWH	East and North Hertfordshire NHS Trust	47	423	11%
RJN	East Cheshire NHS Trust	137	168	82%
RXR	East Lancashire Hospitals NHS Trust	242	381	64%
RXC	East Sussex Hospitals NHS Trust	315	562	56%
RVR	Epsom and St Helier University Hospitals NHS Trust	77	653	12%
RDU	Frimley Park NHS Foundation Trust	28	173	16%
RR7	Gateshead Health NHS Foundation Trust	88	195	45%
RLT	George Eliot Hospital NHS Trust	9	252	4%
RN3	Great Western Hospitals NHS Foundation Trust	146	480	30%

Code	Trust	Actual cases	Expected cases	Case ascertainment
RJ1	Guy's and St Thomas' NHS Foundation Trust	359	540	66%
RR1	Heart of England NHS Foundation Trust	170	612	28%
RD7	Heatherwood and Wexham Park Hospitals Trust	50	524	10%
RLQ	Hereford Hospitals NHS Trust	25	379	7%
RQQ	Hinchingbrooke Healthcare NHS Trust	78	204	38%
RQX	Homerton University Hospital NHS Foundation Trust	40	96	42%
RWA	Hull & East Yorkshire Hospitals NHS Trust	118	600	20%
7A2	Hywel Dda Health Board	120	540	22%
RYJ	Imperial College Healthcare NHS Trust	150	1080	14%
RGQ	Ipswich Hospital NHS Trust	190	572	33%
5QT	Isle of Wight Primary Care Trust	92	204	45%
RGP	James Paget University Hospitals NHS Foundation Trust	173	315	55%
RJZ	King's College Hospital NHS Foundation Trust	101	564	18%
RAX	Kingston Hospital NHS Trust	142	179	79%
RXN	Lancashire Teaching Hospitals NHS Trust	91	432	21%
RR8	Leeds Teaching Hospitals NHS Trust	67	714	9%
REP	Liverpool Women's NHS Foundation Trust	435	960	45%
RC9	Luton and Dunstable Hospital NHS Foundation Trust	162	264	61%
RWF	Maidstone and Tunbridge Wells NHS Trust	115	700	16%
RJ6	Mayday Healthcare NHS Trust	23	257	9%
RPA	Medway NHS Foundation Trust	57	734	8%
RBT	Mid Cheshire Hospitals NHS Foundation Trust	22	448	5%
RQ8	Mid Essex Hospital Services NHS Trust	218	584	37%
RJD	Mid Staffordshire General Hospitals NHS Trust	80	336	24%
RXF	Mid Yorkshire Hospitals NHS Trust	276	492	56%
RD8	Milton Keynes Hospital NHS Foundation Trust	149	596	25%
RNH	Newham University Hospital NHS Trust	37	396	9%
RM1	Norfolk and Norwich University Hospital NHS Trust	330	660	50%
RVJ	North Bristol NHS Trust	64	481	13%
RNL	North Cumbria Acute Hospitals NHS Trust	84	216	39%
RAP	North Middlesex University Hospital NHS Trust	6	688	1%
RVW	North Tees and Hartlepool NHS Trust	236	469	50%
RV8	North West London Hospitals NHS Trust	110	540	20%
RNS	Northampton General Hospital NHS Trust	105	432	24%
RBZ	Northern Devon Healthcare NHS Trust	44	159	28%
RJL	Northern Lincolnshire & Goole Hospitals NHS Foundation Trust	130	524	25%
RTF	Northumbria Healthcare NHS Foundation Trust	232	730	32%
RX1	Nottingham University Hospitals NHS Trust	108	231	47%
RTH	Oxford Radcliffe Hospitals NHS Trust	63	825	8%
RW6	Pennine Acute Hospitals NHS Trust	75	696	11%
RGN	Peterborough and Stamford Hospitals NHS Foundation Trust	127	420	30%
RK9	Plymouth Hospitals NHS Trust	71	586	12%
RD3	Poole General Hospital NHS Foundation Trust	67	276	24%
RHU	Portsmouth Hospitals NHS Trust	115	300	38%
RPC	Queen Victoria Hospital NHS Foundation Trust	26	64	41%
RHW	Royal Berkshire Foundation Trust	72	268	27%
REF	Royal Cornwall Hospitals NHS Trust	30	489	6%
RH8	Royal Devon & Exeter NHS Foundation Trust	178	696	26%
RAL	Royal Free Hampstead NHS Trust	77	707	11%
RA2	Royal Surrey County Hospital NHS Trust	7	324	2%
RD1	Royal United Hospital Bath NHS Trust	55	533	10%
RNZ	Salisbury Hospital NHS Foundation Trust	18	397	5%

Code	Trust	Actual cases	Expected cases	Case ascertainment
RXK	Sandwell & West Birmingham Hospitals NHS Trust	168	264	64%
RCC	Scarborough & North East Yorkshire Healthcare NHS Trust	140	246	57%
RHQ	Sheffield Teaching Hospitals NHS Trust	206	564	37%
RK5	Sherwood Forest Hospitals NHS Trust	96	428	22%
RXW	Shrewsbury & Telford Hospital NHS Trust	179	793	23%
RA9	South Devon Healthcare NHS Foundation Trust	112	500	22%
RYQ	South London Healthcare NHS Trust	0	110	0%
RTR	South Tees Hospitals NHS Trust	281	647	43%
RE9	South Tyneside NHS Foundation Trust	79	180	44%
RJC	South Warwickshire General Hospitals NHS Trust	18	318	6%
RHM	Southampton University Hospitals NHS Trust	25	73	34%
RAJ	Southend University Hospital NHS Foundation Trust	126	456	28%
RVY	Southport & Ormskirk Hospital NHS Trust	91	357	25%
RJ7	St George's Healthcare NHS Trust	104	116	90%
RBN	St Helens & Knowsley Hospitals NHS Trust	105	398	26%
RWJ	Stockport NHS Foundation Trust	110	240	46%
RMP	Tameside Hospital NHS Foundation Trust	81	416	19%
RBA	Taunton and Somerset NHS Foundation Trust	150	288	52%
RNA	The Dudley Group of Hospitals NHS Foundation Trust	51	319	16%
RAS	The Hillingdon Hospital NHS Trust	114	144	79%
RJ2	The Lewisham Hospital NHS Trust	24	142	17%
RTD	The Newcastle upon Tyne Hospitals NHS Foundation Trust	248	657	38%
RQW	The Princess Alexandra Hospital NHS Trust	3	261	1%
RCX	The Queen Elizabeth Hospital King's Lynn NHS Trust	36	288	13%
RFR	The Rotherham NHS Foundation Trust	90	390	23%
RMC	The Royal Bolton Hospital NHS Foundation Trust	231	492	47%
RDZ	The Royal Bournemouth and Christchurch NHS Foundation Trust	104	192	54%
RL4	The Royal Wolverhampton Hospitals NHS Trust	64	216	30%
RKE	The Whittington Hospital NHS Trust	108	336	32%
RM4	Trafford Healthcare NHS Trust	0	202	0%
RWD	United Lincolnshire Hospitals NHS Trust	190	432	44%
RRV	University College London Hospitals NHS Foundation Trust	71	180	39%
RJE	University Hospital of North Staffordshire NHS Trust	65	417	16%
RA7	University Hospitals Bristol NHS Foundation Trust	68	180	38%
RKB	University Hospitals Coventry and Warwickshire NHS Trust	182	609	30%
RWE	University Hospitals of Leicester NHS Trust	173	443	39%
RTX	University Hospitals of Morecambe Bay NHS Trust	79	560	14%
RM2	University Hospitals of South Manchester NHS Foundation Trust	120	348	34%
RBK	Walsall Hospitals NHS Trust	26	302	9%
RWW	Warrington and Halton Hospitals NHS Foundation Trust	185	360	51%
RWG	West Hertfordshire Hospitals NHS Trust	51	276	18%
RFW	West Middlesex University Hospital NHS Trust	108	374	29%
RYR	Western Sussex Hospitals NHS Trust	154	540	29%
RA3	Weston Area Health NHS Trust	39	190	21%
RGC	Whipps Cross University Hospital NHS Trust	118	534	22%
RN1	Winchester and Eastleigh Healthcare NHS Trust	86	400	22%
RBL	Wirral University Teaching Hospital NHS Foundation Trust	183	204	90%
RWP	Worcestershire Acute Hospitals NHS Trust	150	480	31%
5PL	Worcestershire Primary Care Trust	9	48	19%
RRF	Wrightington, Wigan and Leigh NHS Foundation Trust	65	549	12%
RA4	Yeovil District Hospital NHS Foundation Trust	82	195	42%
RCB	York Teaching Hospital NHS Foundation Trust	18	411	4%

Appendix 3

Patient questionnaire

Royal College of Obstetricians and Gynaecologists

Setting standards to improve women's health

FOR OFFICE USE ONLY
Place patient sticker here, with NHS number

If you do not have a patient sticker, fill in the patient's NHS number below.

Date of clinic visit ☐☐/☐☐/☐☐☐☐

HMB: A National Audit

Dear Patient,

We are carrying out a survey to help improve health care for women with heavy menstrual bleeding (HMB). Some people might call this "heavy periods". Sometimes this type of survey is called an "audit". The best way for us to improve services is to ask women with heavy menstrual bleeding to tell us about their experience. Everyone who comes to a hospital outpatient clinic for heavy menstrual bleeding for the first time in the last 12 months will be offered a questionnaire.

We would be really grateful if you could complete this questionnaire while you are in the clinic today, and hand it back to a member of staff before you leave.

If you are not here for heavy menstrual bleeding, or if you have been seen in a hospital for heavy menstrual bleeding in the last 12 months, please just give the blank questionnaire back to a member of staff.

The enclosed patient information sheet describes in more detail why we are undertaking this survey and how we will use your answers to this questionnaire. Taking part is voluntary. You may find some of the questions sensitive. If you agree to take part, please complete and sign the consent form on the next page.

When you have completed the consent form and questionnaire, tear off the consent form. Please put the questionnaire in the envelope provided. The questionnaire (placed in the envelope and sealed) and the consent form (not in the envelope) should both be handed to a member of staff before you leave the hospital.

Thank you very much for your help.

The National HMB Audit Team

Royal College of Obstetricians and Gynaecologists
London School of Hygiene & Tropical Medicine
Ipsos MORI

In partnership with:

London School of Hygiene & Tropical Medicine

Ipsos MORI

Funding provided by:

HQIP
Healthcare Quality Improvement Partnership

12345678910

Barcode placement only.

08-027840-02

Consent Form

Complete, tear off and return with your questionnaire

Please read the information, tick the relevant box and sign below.

I have read and understood the enclosed Patient Information Sheet.

I understand that patients who complete this questionnaire will not be identified by name in any published reports or papers.

I understand that I am free to withdraw from taking part at any time, without giving a reason.

I understand that all information I provide will be kept confidentially.

I agree to receive a second questionnaire by post in 12 months.

I agree that my personal details will be held and used by the National HMB Audit. These details will be used to send out the second questionnaire and to link the questionnaire to information that is routinely collected in other NHS databases (such as the hospital episode statistics databases).

I understand that the National HMB Audit will not release my personal details, unless required by law. In such an exceptional event, I will be told if any disclosure will take place.

☐ **I AGREE** to take part in the National HMB Audit.

If you have agreed to take part in this Audit please write your name and address in CAPITAL LETTERS below so that we can send you a second questionnaire in 12 months' time.

Title

First Name

Surname

Address

Postcode

Date of birth / / (dd/mm/yyyy)

Signature _____

Name (in capital letters) _____

Today's date / / (dd/mm/yyyy)

12345678910

The first few questions are about your symptoms, any treatment that you may have had and factors that may have influenced your treatment. Please indicate your answer by ticking (✓) the box or writing in the space provided.

Q1. How long have you had symptoms of heavy menstrual bleeding?

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

Q2. In the last year, how many times have you seen your GP about heavy menstrual bleeding?

- ☐ None
- ☐ 1-2 times
- ☐ 3-4 times
- ☐ 5-6 times
- ☐ More than 6 times
- ☐ Don't know

Q3. What previous treatment have you had for heavy menstrual bleeding?

Please tick (✓) as many boxes as you need to.

- ☐ 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

Q4. Have you had any operations on the uterus (womb) or cervix? Please do not include endometrial ablation.

- ☐ Yes
- ☐ No
- ☐ Don't know

Q5. During the last 3 months, how much pain did you experience during your periods?

- ☐ No pain
- ☐ Very mild pain
- ☐ Mild pain
- ☐ Moderate pain
- ☐ Severe pain
- ☐ Very severe pain

Q6. How many times have you been pregnant?

☐☐ pregnancies

☐ I do not want to answer this question

Q7. How many babies have you had?

☐ babies

☐ I do not want to answer this question

12345678910

Q8. Do you think you might want to become pregnant in the future?

☐ Yes ☐ No ☐ Not sure

☐ I do not want to answer this question

Q9. Have you been told by a doctor that you have any of the following?

Please tick (✓) as many boxes as you need to.

☐ 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)

Q10. Overall, how would you say your health is?

Excellent	Very good	Good	Fair	Poor
☐	☐	☐	☐	☐

Q11. If you were to spend the next 5 years with your heavy menstrual bleeding symptoms the way they are now, how would you feel about that?

Delighted	Pleased	Mostly satisfied	Mixed – about equally satisfied and dissatisfied	Mostly dissatisfied	Unhappy	Terrible
☐	☐	☐	☐	☐	☐	☐

Listed below are symptoms experienced by women who have heavy menstrual bleeding (heavy periods). Please consider each symptom as it relates to your heavy menstrual bleeding or menstrual cycle. Each question asks how much distress you have experienced from each symptom during the previous 3 months.

There are no right or wrong answers. Please be sure to answer every question by ticking (✓) the most appropriate box. If a question does not apply to you, please mark "not at all" as a response.

During the previous 3 months, how distressed were you by…	Not at all	A little bit	Some-what	A great deal	A very great deal
Q12. Heavy bleeding during your menstrual period	☐	☐	☐	☐	☐
Q13. Passing blood clots during your menstrual period	☐	☐	☐	☐	☐
Q14. Fluctuation in the duration of your menstrual period compared to your previous cycles	☐	☐	☐	☐	☐
Q15. Fluctuation in the length of your monthly cycle compared to your previous cycles	☐	☐	☐	☐	☐
Q16. Feeling tightness or pressure in your pelvic area	☐	☐	☐	☐	☐
Q17. Frequent urination during the daytime hours	☐	☐	☐	☐	☐
Q18. Frequent nighttime urination	☐	☐	☐	☐	☐
Q19. Feeling fatigued	☐	☐	☐	☐	☐

The following questions ask about your feelings and experiences regarding the impact of heavy menstrual bleeding symptoms (heavy periods) on your life. Please consider each question as it relates to your experiences with heavy menstrual bleeding during the previous 3 months.

There are no right or wrong answers. Please be sure to answer every question by ticking (✓) the most appropriate box. If the question does not apply to you, please tick "none of the time" as your option.

During the previous 3 months, how often have your symptoms related to heavy menstrual bleeding…	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Q20. Made you feel anxious about the unpredictable onset or duration of your periods?	☐	☐	☐	☐	☐
Q21. Made you anxious about travelling?	☐	☐	☐	☐	☐
Q22. Interfered with your physical activities?	☐	☐	☐	☐	☐
Q23. Caused you to feel tired or worn out?	☐	☐	☐	☐	☐
Q24. Made you decrease the amount of time you spent on exercise or other physical activities?	☐	☐	☐	☐	☐
Q25. Made you feel as if you are not in control of your life?	☐	☐	☐	☐	☐
Q26. Made you concerned about staining underclothes?	☐	☐	☐	☐	☐
Q27. Made you feel less productive?	☐	☐	☐	☐	☐
Q28. Caused you to feel drowsy or sleepy during the day?	☐	☐	☐	☐	☐
Q29. Made you feel self-conscious of weight gain?	☐	☐	☐	☐	☐
Q30. Made you feel that it was difficult to carry out your usual activities?	☐	☐	☐	☐	☐
Q31. Interfered with your social activities?	☐	☐	☐	☐	☐
Q32. Made you feel conscious about the size and appearance of your stomach?	☐	☐	☐	☐	☐
Q33. Made you concerned about staining bed linen?	☐	☐	☐	☐	☐
Q34. Made you feel sad, discouraged, or hopeless?	☐	☐	☐	☐	☐
Q35. Made you feel down hearted and low?	☐	☐	☐	☐	☐
Q36. Made you feel exhausted?	☐	☐	☐	☐	☐
Q37. Caused you to be concerned or worried about your health?	☐	☐	☐	☐	☐
Q38. Caused you to plan activities more carefully?	☐	☐	☐	☐	☐
Q39. Made you feel inconvenienced about always carrying extra pads, tampons, and clothing to avoid accidents?	☐	☐	☐	☐	☐
Q40. Caused you embarrassment?	☐	☐	☐	☐	☐
Q41. Made you feel uncertain about your future?	☐	☐	☐	☐	☐
Q42. Made you feel irritable?	☐	☐	☐	☐	☐
Q43. Made you concerned about staining outer clothes?	☐	☐	☐	☐	☐

During the previous 3 months, how often have your symptoms related to heavy menstrual bleeding…	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Q44. Affected the size of clothing you wear during your periods?	☐	☐	☐	☐	☐
Q45. Made you feel that you are not in control of your health?	☐	☐	☐	☐	☐
Q46. Made you feel weak as if energy was drained from your body?	☐	☐	☐	☐	☐
Q47. Diminished your sexual desire?	☐	☐	☐	☐	☐
Q48. Caused you to avoid sexual relations?	☐	☐	☐	☐	☐

The following questions are about your health overall. By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Q49. Mobility

- I have no problems in walking about ☐
- I have some problems in walking about ☐
- I am confined to bed ☐

Q50. Self-Care

- I have no problems with self-care ☐
- I have some problems washing or dressing myself ☐
- I am unable to wash or dress myself ☐

Q51. Usual Activities *(for example work, study, housework, family or leisure activities)*

- I have no problems with performing my usual activities ☐
- I have some problems with performing my usual activities ☐
- I am unable to perform my usual activities ☐

Q52. Pain/ Discomfort

- I have no pain or discomfort ☐
- I have moderate pain or discomfort ☐
- I have extreme pain or discomfort ☐

Q53. Anxiety/ Depression

- I am not anxious or depressed ☐
- I am moderately anxious or depressed ☐
- I am extremely anxious or depressed ☐

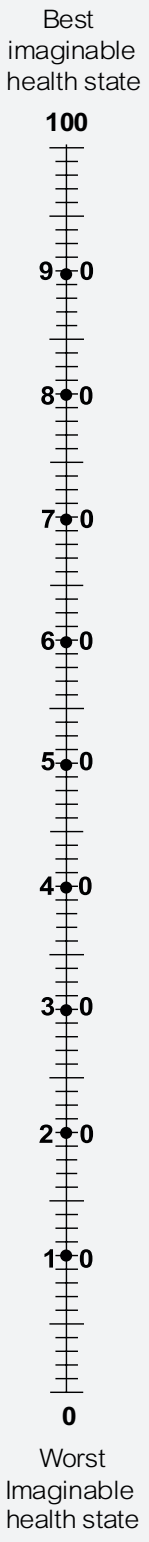
Q54. To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the black box below to whichever point on the scale indicates how good or bad your health state is today.

Please also write the number that represents your health today in the white boxes provided.

My health today (write number between 0 and 100 here)

Your own health state today



Q55. What is your current body weight?

☐☐☐ kg or ☐☐ stones ☐☐ pounds

Q56. What is your height?

☐☐☐ cm or ☐☐ feet ☐☐ inches

Q57. How old were you when you left full-time education (for example school, college or university)?

- ☐ 16 or under
- ☐ 17 to 18
- ☐ 19 or over
- ☐ I do not want to answer this question

Q58. What is your ethnic group?

Choose ONE section from A to E, then tick (✓) the appropriate box to indicate your ethnic group

A White

- ☐ British
- ☐ Irish
- ☐ Any Other White background

B Mixed

- ☐ White and Black Caribbean
- ☐ White and Black African
- ☐ White and Asian
- ☐ Any Other Mixed background

C Asian or Asian British

- ☐ Indian
- ☐ Pakistani
- ☐ Bangladeshi
- ☐ Any Other Asian background

D Black or Black British

- ☐ Caribbean
- ☐ African
- ☐ Any Other Black background

E Chinese or Other Ethnic Group

- ☐ Chinese
- ☐ Any Other

- ☐ I do not want to answer this question

Thank you for completing this questionnaire.

Please check that you have given us your correct name and address so that we can send you a second questionnaire and then give this questionnaire back to a member of staff.

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