Royal College of Obstetricians & Gynaecologists

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

Ipsos MORI

Third Annual Report

September 2013

Commissioned 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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A list of the National HMB Audit's Clinical Reference Group members, Project Board members and Clinical Advisors is provided in Appendix 1.

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

The National HMB Audit's project team consists of:

Royal College of Obstetricians and Gynaecologists

- Tahir Mahmood, Co-Chair of National HMB Audit project team
- Loveleen Bansi-Matharu, National HMB Audit Co-Lead
- Lisa Burke, Administrative Assistant
- Anita Dougall, Director of Clinical Quality
- Sara Johnson, Executive Director of Quality and Knowledge
- Benedetta La Corte, Project and Policy Lead
- 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
- Amit Kiran, Lecturer and National HMB Audit Co-Lead
- Sarah Smith, Lecturer

Ipsos MORI

- Chris Branson, Senior Research Executive
- Anna Carluccio, Research Director
- Sarah Colover, Executive Assistant
- Stefan Durkacz, Research Manager
- Katya Kostadintcheva, Research Manager
- Chris Marshall, Senior Research Executive
- Jonathan Nicholls, Director of Health Research
- Danny Slater, Research Executive

Abbreviations

BMI	body mass index
DBS	Demographics Batch Service
DOB	date of birth
EA	endometrial ablation
GP	general practitioner
HES	Hospital Episode Statistics
HMB	heavy menstrual bleeding
HQIP	Healthcare Quality Improvement Partnership
HRQoL	health-related quality of life
IQR	interquartile range
LHB	local health board (Wales)
LSHTM	London School of Hygiene & Tropical Medicine
MID	minimal important difference
NCAPOP	National Clinical Audit and Patient Outcomes Programme
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
ORCA	Office for Research and Clinical Audit (RCOG)
PDS	Personal Demographics Service
PEDW	Patient Episode Database for Wales
QoL	quality of life
RCOG	Royal College of Obstetricians and Gynaecologists
SHA	strategic health authority
UAE	uterine artery embolisation

Glossary of terms

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

Clinical Reference Group
The National HMB Audit's Clinical Reference Group comprises representatives of the key stakeholders in HMB care. Members 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 (EA)
A medical procedure that is used to remove (ablate) or destroy the endometrial lining of a woman's uterus.

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

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

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

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

Hysterectomy
The surgical removal of the uterus.

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

Intrauterine system
Hormonal contraceptive inserted into the uterus.

Myomectomy
The surgical removal of fibroids from the uterus.

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

Foreword

It is with pleasure that I introduce the *Third Annual Report* of the National Heavy Menstrual Bleeding Audit. This 4-year audit programme describes patient-reported outcomes in an outpatient setting in England and Wales. Heavy menstrual bleeding (HMB) is a relatively common condition that affects women's physical, emotional, social and material quality of life.

Last year, in the first part of the prospective audit, over 16 000 women completed a questionnaire when they attended an outpatient gynaecology clinic for HMB for the first time. Of those who met the inclusion criteria, three-quarters reported having HMB symptoms for more than one year before they were referred and, more worryingly, one-third indicated that they had not received any treatment in primary care.

In this third report, we describe patient-reported outcomes and experiences of women one year after their first visit to an outpatient gynaecology clinic. We also describe the treatment and care they received in secondary care. We are pleased to note that more than 8000 women have taken the time to respond to the follow-up questionnaire.

The majority of women who responded to this follow-up questionnaire stated that they were satisfied with the care they had received in secondary care. It is also reassuring to note that clinicians, by and large, appear to be following the National Institute for Health and Care Excellence (NICE) guidelines. The follow-up questionnaire also revealed that women experiencing less severe symptoms of shorter duration were mostly treated with oral medications while surgical interventions such as endometrial ablation and hysterectomy appeared to be more commonly used for women with more severe symptoms.

However, we need to focus on younger women, women of non-white ethnicity, women with severe pain and women with relatively poor health as these groups of women reported that they were less satisfied with the care they had received.

I commend this report to healthcare professionals as it demonstrates that we need to start developing care pathways that will improve access not only to first-line treatments in primary care but also to more specialised treatments in secondary care, especially for the more vulnerable women identified in this report.

Tahir Mahmood CBE, FRCOG
Co-Chair, National HMB Audit project team

Executive summary

Heavy menstrual bleeding (HMB) is a common condition affecting one-quarter of women of reproductive age.[1] It can have a profound effect on quality of life. Initial treatment is typically based on various types of medication and is managed within primary care. However, medical therapies are not always effective and approximately 30 000 women in England and Wales undergo surgical treatment for HMB each year.

The latest guidelines on HMB treatment were published by NICE in 2007[2] and by RCOG in 2008.[3] However, information on how the NHS has responded to these guidelines is lacking.

The National HMB Audit is a 4-year audit that began on 1 February 2010. It aims to describe the care received by women with HMB who were referred to NHS outpatient gynaecology clinics in England and Wales, and to assess their experience of care. The audit has two principal components: an organisational audit of acute NHS trusts in England and NHS local health boards in Wales, and a prospective audit of patient-reported outcomes for women with HMB.

This *Third Annual Report* describes the results of the second year of the prospective audit. It focuses on women who completed a one-year follow-up questionnaire on the treatments and care received in secondary care as well as reporting on their experience and outcomes, having attended NHS outpatient gynaecology clinics for the first time between 1 February 2011 and 31 January 2012.

Patient characteristics

Of the 15 325 women who attended an initial outpatient gynaecology clinic and met the inclusion criteria for this study, 8517 (55.6%) completed a follow-up questionnaire. The responders had similar characteristics to the non-responders except for their median age (45 years versus 42 years) and ethnicity (90.8% white versus 85.2% white). Women indicating they had one or two GP visits in the year prior to their first outpatient visit were most likely to return the follow-up questionnaire, whereas women reporting severe pain or fair/poor health or those who would feel 'terrible' if their symptoms remained the same over the next five years were least likely to return the questionnaire.

Treatment reported in secondary care

In the year following their first outpatient visit, 18.0% of women who responded to the follow-up questionnaire reported receiving no treatment (of this figure, almost half had no new symptoms), 57.2% stated they received one treatment and 24.8% indicated they received two or more treatments. Women reporting a shorter duration of symptoms, fewer GP visits and no prior treatment and who indicated they were in little or no pain at baseline appeared more likely to have received no treatment or oral medication/intrauterine system (IUS) in secondary care. Conversely, women reporting a longer duration of symptoms, a greater number of GP visits and severe pain at their first outpatient visit were more likely to report having had an endometrial ablation (EA) or hysterectomy performed in secondary care. Overall, three-quarters of women stated that their symptoms were better compared with a year ago. The proportion of women who reported being in severe/very severe pain at their first outpatient visit and who felt they had remained so over the course of one year was 13.2%.

The adapted UFS-QoL tool was used to assess severity of symptoms and health-related quality of life (HRQoL). On average, the severity score (ranging from 0 to 100, with higher severity scores indicating greater symptom severity) decreased on follow-up by nearly 37 units and

76.0% of women were identified as having 'meaningful improvement' (≥10 unit improvement). Older women and those of white ethnicity were more likely to show a meaningful improvement in their severity score. Similar findings were observed using the HRQoL.

Experience in secondary care

Almost three-quarters of women stated they had received the correct amount of information from the hospital on their HMB condition and treatment. The proportion of women who felt they had not received enough information was higher among those of younger age (31.7% of those under 35 compared with 16.0% of those aged over 50 years) and those of non-white ethnicity (26.1% compared with 18.3% women of white ethnicity). Women reporting severe/very severe pain in the follow-up questionnaire were also more likely to indicate they had not received enough information compared with those women who indicated they were not in pain.

With regard to communication with doctors in secondary care, about 60% of women reported that they definitely felt involved in the decisions for care and treatment and about 80% reported 'definitely' being treated with respect. Nearly three-quarters of all women who completed the follow-up questionnaire rated the overall level of care received as excellent or very good. Women of younger age, of non-white ethnicity, in fair/poor overall health and those who reported a greater number of new symptoms compared with a year ago were more likely to rate the overall care received as fair/poor.

Variation among providers

There appeared to be no significant variation by provider in the treatment received by the responders in secondary care. In particular, there was little evidence to suggest that the proportion of women stating they were treated for hysterectomy or EA, or those indicating they were in severe/very severe pain at follow-up, varied at provider level. The mean change in severity score and HRQoL score also showed only slight variation by provider.

Conclusion

The National HMB Audit's patient-reported outcome and experience component has shown that the majority of women referred to secondary care appear to have received at least one treatment in the first year after their first outpatient gynaecology visit, with IUS, oral medication and EA being the most commonly indicated treatments. Three-quarters of women who completed the follow-up questionnaire reported fewer symptoms at follow-up than at their first outpatient visit and over three-quarters had a meaningful improvement in their severity score. The majority of women rated their overall level of care as excellent or very good. Women who completed the follow-up questionnaire reported no significant variations in care outcomes and experiences at the NHS provider level.

1 Introduction

1.1 Heavy menstrual bleeding – background and guidelines

Heavy menstrual bleeding (HMB) is a condition that can have a profound effect on the quality of life of women of a reproductive age. HMB is defined by the National Institute for Health and Care Excellence (NICE) as 'excessive menstrual blood loss which interferes with a woman's physical, social, emotional and/or material quality of life'.[2] HMB is a common condition, affecting around one-quarter of women of reproductive age.[1] Initial treatment is typically based on various types of medication and managed within primary care. However, medical therapies are not always effective and approximately 30 000 women in England and Wales will undergo surgical treatment for HMB each year.

Clinical guidelines on the treatment of HMB were first published in 1995 and have been updated periodically. The latest guidelines were published by NICE in 2007[2] and by the Royal College of Obstetricians and Gynaecologists (RCOG) in 2008.[3] However, information on how the NHS has responded to these guidelines is lacking.

Recent evidence also suggests wide variations in practice in the treatment patterns of women with HMB in secondary care.[4–6] Wide variation in the ratio of hysterectomies to endometrial ablations (EAs) was also reported. While some of this variation may be explained by factors such as clinical judgement and women's preferences, it does indicate the need for further investigation.

The RCOG, in partnership with the London School of Hygiene & Tropical Medicine (LSHTM) and Ipsos MORI, has been conducting an HMB audit in England and Wales.

1.2 HMB audit – aims and objectives

Established in February 2010, the National HMB Audit's overall aims are to describe the care received by those women with HMB who were referred to NHS outpatient gynaecology clinics in England and Wales and to assess their patient outcomes and experience of care.

This 4-year audit has two principal components:

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

Specific audit objectives are to investigate:

- the severity of menstrual problems experienced by women referred to NHS outpatient gynaecology 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 an outpatient visit have had on women's health and quality of life.

This will enable the audit to provide comparative information for clinicians, to identify where improvements could potentially be made and to assess whether the care received by women with HMB is consistent with recommended practice.

1.3 Previous annual reports published

The first component of the National HMB Audit was completed in August 2010. Information was collected from hospitals to evaluate the organisation of hospital gynaecological services, current referral patterns and local protocols with reference to the management of HMB. The results of the organisational audit were published in the *First Annual Report*.[5]

The second component, the prospective audit, consists of two parts. In the first part, women were asked to complete a questionnaire (referred to as the 'baseline questionnaire') at their first visit to an NHS outpatient gynaecology clinic. Recruitment took place between 1 February 2011 and 31 January 2012. Consenting women aged between 18 and 60 years in England and Wales who had a new referral for HMB to an outpatient gynaecology clinic were asked to complete a questionnaire. Women who had visited an outpatient gynaecology clinic for HMB within the previous 12 months were excluded. The questionnaire included questions on the severity of the women's 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 asked to complete the questionnaires on their own. Therefore, women with insufficient English comprehension or a cognitive or visual impairment that precluded self-completion were excluded. Results of this phase of the prospective audit were published in the *Second Annual Report*[6] in July 2012.

1.4 Current and future annual reports

In the second part of the prospective audit, consenting women who had completed a baseline questionnaire were sent a follow-up questionnaire one year after their first outpatient visit. The follow-up questionnaire included questions on subsequent treatments and care received as well as the same questions on their quality of life as were used in the baseline questionnaire. Patient-reported outcomes and further questions on quality of life were also included in the follow-up questionnaire. This *Third Annual Report* summarises the results of the follow-up questionnaire and describes patient experiences, treatments received and the women's perceived quality of life one year after referral to secondary care.

In the *Fourth Annual Report*, the patient-reported information gathered using both the baseline and follow-up questionnaires will be linked to Hospital Episode Statistics (HES) data for England and to the Patient Episode Database for Wales (PEDW) to give an even richer description and history of patient care and outcomes. A case note review exercise will also be investigated, comparing patient-reported information with the clinical information available in the notes. The *Fourth Annual Report* will be published in 2014.

2 Summary of previous annual reports

2.1 *First Annual Report* findings

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

All NHS providers with outpatient gynaecology departments in England and Wales completed a questionnaire on organisational issues related to the availability of facilities, local treatment protocols and patterns of primary and secondary care. In brief, while 80% of hospitals reported having access to ultrasound, hysteroscopy and endometrial biopsy, only 38% of hospitals had a dedicated menstrual bleeding clinic, and only 30% of hospitals had a local written protocol regarding the care and management of women with HMB.

The HES database was used to analyse patterns of surgical treatment for women with HMB in England. Between April 2006 and December 2009, the age-standardised annual rate of surgery for HMB was 152 procedures/100 000 women. Surgical rates varied widely across strategic health authorities (SHAs). Regions ranged from 70 to 255 procedures/100 000 women.[6] Surgical rates also varied widely among primary care trusts, ranging from 14 to 392/100 000 women. Similarly, using PEDW, the annual rate of surgery ranged from 76 to 241 procedures/100 000 women across the local health boards (LHBs) in Wales between April 2006 and March 2010.[7] With more women undergoing EA, the rate of surgery has increased in recent years. However, the level of variation was similar to that observed previously.[4]

2.2 *Second Annual Report* findings

In the *Second Annual Report*, the project team presented results of the first phase of the prospective audit of patient-reported outcomes. The report focused on women with HMB symptoms who attended NHS outpatient gynaecology clinics for the first time between 1 February 2011 and 31 January 2012.

The average age of these women was 44 years and 88% were of white ethnicity. Nearly half reported having fibroids, endometriosis and/or uterine polyps together with their HMB condition. Three-quarters of women indicated they had their HMB symptoms for more than one year and 54% of women reported severe or very severe pain at their first outpatient visit. The majority of women (83%) indicated that they would feel unhappy or terrible if their symptoms persisted for the next five years.

With regard to their initial treatment in primary care, nearly one-third of women (31%) reported that they had received no treatment prior to referral. This percentage was higher among women of non-white ethnicity, those with HMB alone and those who had fewer GP visits.

In summary, women being referred to secondary care tended to report a prolonged duration of symptoms and typically indicated that their HMB caused severe levels of pain. There were no statistically significant differences among NHS providers in the type of medical care that women reported receiving in primary care, their clinical symptoms, or their quality of life scores. However, the wide variation in surgical practice seen in secondary care (as reported in the *First Annual Report*) does not seem to be explained by referral practice from primary care.

3 Patients and methods

3.1 Data collection

There were two phases of data collection in the prospective audit:

- Baseline questionnaires given to consenting women aged between 18 and 60 at the time of their first visit to an NHS outpatient gynaecology clinic, collected between February 2011 and January 2012. This information formed the basis of the *Second Annual Report*.
- Follow-up questionnaires mailed to the women's home address one year after the first outpatient visit (February 2012 to January 2013). The data collected during this phase is described in this report.

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

This *Third Annual Report* focuses on the second phase of data collection. In the follow-up questionnaire, which consists of 63 questions, women were asked to verify their date of birth and to complete questions on treatment received in the past year, cause of HMB, new symptoms and standard of care received in secondary care. Both the adapted UFS-QoL and the EQ-5D instruments were included in the follow-up questionnaire.

3.2 Verification of consent and patient details

Details of consent forms, confirming that women were aged between 18 and 60 years, that they were happy to be re-contacted a year after completing the baseline questionnaire and that they were willing for their survey data to be anonymously linked to other health data, were verified in a two-phase process. After the initial classification of forms, subsequent processes such as sending letters, checking data on consent forms and tracing against the Personal Demographics Service (PDS) (an electronic database of NHS patient demographic details) were conducted quarterly.

First, consent forms were classified as 'accepted', 'pending' or 'rejected'. Forms with no missing information, i.e. with full name, signature and either address or NHS number, were classified as accepted. Forms with an address or NHS number but without a signature or full name were classified as pending and forms without a full name and signature, or without both an address and NHS number were classified as rejected. The project team wrote to all women in the pending category in order to request the missing information. Women who returned the requested information were then reclassified as accepted.

The second phase of verification involved checking the patient details using the Demographic Batch Service (DBS) against the PDS; in this way, the project team was able to gather missing NHS numbers and verify women's addresses one year after completion of the baseline

questionnaire. Further information on the files requested from the DBS can be found in Appendix 2. Only women for whom the DBS trace had been successful were sent a follow-up questionnaire one year after their referral to an NHS outpatient gynaecology clinic.

3.3 Follow-up mailout and linkage to baseline questionnaire

Women consenting to be contacted a year after referral were sent the follow-up questionnaire, a covering letter and a pre-stamped, pre-addressed envelope in which to return the questionnaire. If questionnaires had not been returned within three weeks, a reminder letter was sent with a second copy of the follow-up questionnaire. The mailout was performed on a monthly basis around one year after the woman's first outpatient visit.

Each baseline questionnaire was labelled with a unique nine-digit identifier that was then printed on the follow-up questionnaire. Returned questionnaires were linked to baseline questionnaires using this unique identifier.

3.4 Statistical analyses

Patient responses for the responding women as a whole and for individual NHS providers are presented. Statistics are defined as the number and proportion of women falling into specific pre-defined categories, typically reflecting the response categories to particular questions. The chi-squared test at 5% significance level was used for comparing categorical responses.

Funnel plots have been used to formally assess variation across NHS providers, i.e. whether results at an individual NHS provider differ significantly from the national average. These results have not been adjusted – they will be adjusted for patient risk factors in the *Fourth Annual Report*. A funnel plot is a graphical method for comparing the performance of institutions using cross-sectional statistics.[8] This technique takes into account the number of responses from women referred to each institution, which is important because the extent to which the provider's result is expected to vary is related to the number of responses. The horizontal axis represents the number of women included in the analysis at each provider and the vertical axis measures the factor of interest.

The funnel plot is defined by three lines. The horizontal centre line represents the national average (all providers combined). The two funnel lines represent expected levels of random variation that are two standard deviations (inner funnel) or three deviations (outer funnel) away from the national average. These control limits are shown by dashed lines and represent the 95% (inner funnel) and 99.8% (outer funnel) control limits. If a result falls outside the control limits, it is considered to be different from the national average at a 5% or a 0.2% significance level, respectively. The funnel plots for outcomes measured in proportions were compiled using exact binomial limits.

4 Baseline patient characteristics of responders and non-responders

4.1 Proportion of questionnaires returned

Of the 15 325 women who were eligible for the study and who completed the baseline questionnaire, 8517 (55.6%) women returned the completed follow-up questionnaire to the project team. Returned follow-up questionnaires were linked to baseline questionnaires as described in Section 3.3.

4.2 Comparison of responders and non-responders

Baseline characteristics of those who did return a follow-up questionnaire were compared with those who did not (Appendix 3). Women of older age and white ethnicity were more likely to return a follow-up questionnaire than those of younger age or non-white ethnicity. While there was little difference in response rates with regard to parity or body mass index (BMI) category, women who did not answer these specific questions on the baseline questionnaire were less likely to return the follow-up questionnaire.

With regard to GP visits, women with one or two visits in the year prior to their first visit to an NHS outpatient gynaecology clinic were most likely to return the follow-up questionnaire. Women who indicated they were in severe pain, those who stated they had endometriosis or those who reported they were in fair/poor health were least likely to return the follow-up questionnaire, as were women who would feel 'terrible' if their symptoms remained the same over the next five years. Small differences of borderline significance were observed in terms of the duration of symptoms (responders reported having had symptoms for longer), stated prior treatment and the number of comorbidities (responders appeared to have a lower number of comorbidities).

There were only small differences noted between severity and HRQoL scores and response rates. The mean severity scores at baseline for those who did and did not return a follow-up questionnaire were 67.2 and 69.6, respectively. The mean HRQoL score for responders was 47.8 and for non-responders it was 36.7.

Patient response rates were also stratified by provider, giving an average provider response rate of 56.3% (standard deviation 8%) with variations shown in Figure 4.1. These variations were largely within the control limits; however, some providers had response rates outside of what would be expected by random fluctuation alone.

Further analysis of the responders was performed to identify whether differences existed in the baseline characteristics of those who returned a follow-up questionnaire prior to the reminder letter being sent (three weeks after the initial contact if the follow-up questionnaire had not been returned) and those who did so only after the reminder letter was sent (table available from authors). One-third of the women who responded were late responders. Women of younger age and white ethnicity were more likely to return a follow-up questionnaire earlier than those of older age or non-white ethnicity.

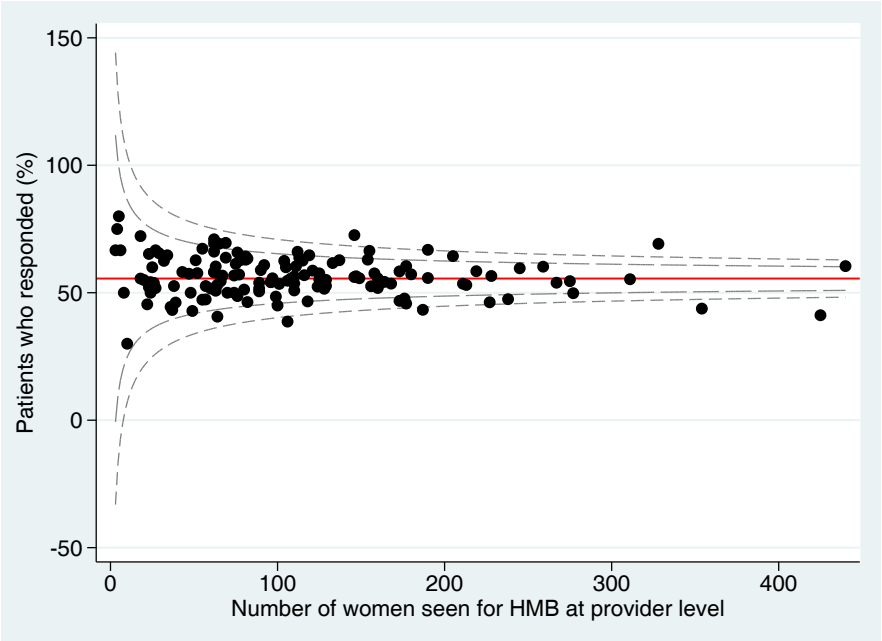

Figure 4.1 Responder proportions by provider

4.3 Summary

The response rate for questionnaires completed one year after each initial respondent's first visit to an NHS outpatient gynaecology clinic was 55.6%. Differences in characteristics between responders and non-responders were evident, particularly with regard to age and ethnicity. Women of non-white ethnicity were less likely to respond to the follow-up questionnaire than those of white ethnicity. However, it is important to recognise that 9.2% (740/8021) of the overall number of women who did return a follow-up questionnaire were of non-white ethnicity. Women were also less likely to return a questionnaire if they had indicated in the baseline questionnaire that they were in poor overall health. These women, possibly owing to the severity of their HMB-condition or other conditions, may have been too ill or not alive to complete and return the follow-up questionnaire.

5 Treatment and symptoms reported at follow-up

5.1 Treatment reported in secondary care

Of the 8517 women who returned the follow-up questionnaire one year after their first outpatient visit, 8183 women reported on the treatment they received in secondary care. As shown in Table 5.1, these women appear to have received various treatments in the year after their first outpatient visit and some women indicated they had received more than one treatment. Overall, 29.3% of women reported receiving oral medication (predominantly from their GP) and 33.3% of women stated they had received an IUS. Surgical treatment appeared to be common, with 23.1% reporting having EA, 13.8% a hysterectomy, 4.4% a myomectomy and 1.4% a uterine artery embolisation (UAE).

The majority of women stated they had received one treatment. Among those who indicated they only had one treatment ($n = 4683$), the most common treatments were IUS (29.4%), EA (22.9%) and oral medication (21.7%). Among women who reported receiving two treatments ($n = 1548$), the most commonly indicated combinations were oral medication and IUS (28.7%), oral medication and EA (13.4%) and IUS and EA (12.9%).

In further analyses, reported treatment in the year following the women's first outpatient visit was re-categorised according to what was likely (by clinical experience and protocol) to be the last treatment received by women; hence, women who reported receiving more than one treatment (24.8%) could only fall into one of the groups listed in Table 5.1. Women who did not know which treatment they had received and those who had not answered the question on treatment received were classed as 'unknown or missing'.

Surgical treatment accounted for 37.3% of the last likely treatment received, followed by 34.6% for oral medication or IUS. The association between the last likely treatment received by women and their baseline demographics and clinical characteristics is described in Table 5.2.

Women who reported receiving surgical treatment were more likely to be older, of white ethnicity, indicate a longer duration of symptoms, to have had three or more reported GP visits and to state that they were in severe or very severe pain. Women who reported they had received no treatment were more likely to report a shorter duration of symptoms, fewer GP visits, no previous treatment and to state they were in little or no pain at their first outpatient visit.

5.2 Symptoms and severity of pain at one year

The last likely treatment received was further analysed by the reported number of new symptoms and pain status one year after the women's first outpatient visit (Table 5.3). Women who indicated they had received surgical treatment were more likely to report their overall health as good or better, to have mild to no pain and to have one or no new symptoms. When asked how they would feel if their symptoms stayed the same for the next five years, women who indicated they had received surgical treatment were most likely to respond that they would be 'delighted/pleased/mostly satisfied'.

Table 5.1 Treatment reported in the year following first outpatient visit

	Women reporting treatment, % (*n* = 8183)
Treatments reported in the last year†	
No treatment	18.0 (1472)
Oral medication (including the pill)	29.3 (2396)
From hospital	12.8 (1044)
From GP/family planning clinic	20.4 (1673)
Intrauterine system (IUS)	33.3 (2729)
From hospital	27.9 (2284)
From GP/family planning clinic	6.8 (553)
EA	23.1 (1888)
Hysterectomy	13.8 (1128)
Myomectomy	4.4 (358)
UAE	1.4 (118)
Other treatment	10.9 (894)
Unknown or missing	3.9 (334)
Number of treatments received	
0	18.0 (1472)
1	57.2 (4683)
2	18.9 (1548)
≥3	5.9 (480)
Unknown or missing	3.9 (334)
Last 'likely' treatment received	
No treatment	18.0 (1472)
Oral medication (including the pill)	12.4 (1015)
IUS	22.2 (1819)
EA	19.3 (1582)
Hysterectomy	13.7 (1118)
Myomectomy	3.3 (273)
UAE	1.0 (80)
Other treatment	10.1 (824)
Unknown or missing	3.9 (334)

† Some women reported receiving more than one treatment

5.3 Cause of HMB as diagnosed in secondary care

Of the 8517 women who returned the follow-up questionnaire one year after their first outpatient visit, 8297 women reported the cause of HMB as diagnosed in secondary care. Some women stated they were diagnosed with more than one cause, as shown in Table 5.4. The most common reported cause of HMB was uterine fibroids (32.5%) followed by polyps of the lining of the womb (14.0%), endometriosis (9.0%) and hormonal imbalance (8.5%). No known cause of HMB (no obvious cause, other cause or don't know) was reported by almost half of the women (48.4%).

The majority of women reported one cause of HMB diagnosed ($n = 7365$), of which the most common was uterine fibroids (27.4%). Among women who reported two causes of HMB ($n = 837$), the most common combinations were uterine fibroids and polyps of the lining of the womb (27.8%), and uterine fibroids and endometriosis (17.9%).

Table 5.2 Treatment reported by baseline factors

Baseline demographics and clinical characteristics	Treatment reported in follow-up questionnaire			
	No treatment, % (*n* = 1472)	Oral medication/IUS, % (*n* = 2834)	EA/hysterectomy/myomectomy/UAE, % (*n* = 3053)	Other treatment, % (*n* = 824)
Age				
18–34	11.6 (170)	12.6 (358)	4.9 (149)	16.6 (137)
35–39	11.4 (168)	10.9 (310)	11.1 (338)	12.3 (101)
40–44	23.0 (339)	26.1 (739)	29.9 (914)	24.8 (204)
45–49	31.7 (467)	32.9 (933)	39.7 (1212)	28.8 (237)
≥50	22.3 (328)	17.5 (494)	14.4 (440)	17.5 (145)
Ethnicity				
White	89.6 (1235)	91.4 (2445)	92.4 (2659)	88.5 (694)
Non-white	10.4 (144)	8.6 (231)	7.6 (220)	11.5 (90)
Missing: 5.7% (465)				
Duration of symptoms				
<2 months	5.4 (77)	1.9 (52)	1.2 (36)	2.1 (17)
>2 months, <1 year	29.0 (416)	26.7 (741)	16.3 (489)	24.4 (195)
≥1 year	65.6 (942)	71.4 (1988)	82.5 (2475)	73.5 (588)
Unknown or missing: 2.0% (167)				
Number of GP visits				
None	10.7 (151)	6.2 (171)	3.9 (117)	5.5 (44)
1–2	56.4 (797)	53.9 (1494)	44.3 (1322)	53.6 (430)
3–4	22.2 (313)	28.3 (786)	34.5 (1029)	26.6 (213)
>4	10.7 (152)	11.6 (322)	17.3 (514)	14.3 (115)
Unknown or missing: 2.6% (213)				
Previous treatment[†]				
None	44.1 (640)	33.0 (921)	21.1 (636)	30.2 (246)
The pill (oral contraception)	20.8 (302)	26.7 (746)	28.5 (860)	29.4 (239)
Other medication (not the pill)	28.9 (420)	40.7 (1135)	46.3 (1395)	39.3 (320)
IUS	13.2 (191)	11.7 (327)	32.5 (981)	16.1 (131)
EA	4.5 (66)	1.8 (49)	6.9 (208)	3.8 (31)
Other treatment	8.4 (122)	8.9 (249)	11.1 (335)	13.3 (108)
Unknown or missing: 2.2% (181)				
Pain				
None	9.2 (129)	5.8 (160)	4.4 (130)	6.6 (52)
Very mild/mild	18.9 (266)	17.6 (485)	14.0 (413)	15.5 (122)
Moderate	30.1 (424)	28.0 (772)	25.6 (754)	24.4 (192)
Severe/very severe	41.9 (591)	48.5 (1336)	56.0 (1653)	53.5 (421)
Missing: 3.5% (283)				

[†] Some women reported receiving more than one treatment

Table 5.3 Treatment reported by symptoms and severity of pain at one year

	No treatment, % (*n*=1472)	Oral medication/IUS, % (*n*=2834)	EA/hysterectomy/myomectomy/UAE, % (*n*=3053)	Other treatment, % (*n*=824)
Overall health				
Excellent/very good	44.7 (648)	45.9 (1283)	49.3 (1481)	44.3 (362)
Good	37.1 (538)	37.2 (1040)	36.5 (1095)	34.2 (280)
Fair/poor	18.2 (263)	16.9 (471)	14.2 (427)	21.5 (176)
Missing: 1.5% (119)				
Pain				
None	11.8 (133)	12.8 (293)	16.2 (240)	10.1 (66)
Very mild/mild	31.1 (349)	38.2 (873)	37.3 (552)	30.8 (202)
Moderate	32.8 (369)	28.0 (639)	23.2 (343)	31.6 (207)
Severe/very severe	24.3 (273)	21.0 (481)	23.3 (344)	27.5 (181)
No period or missing: 32.2% (2638)				
Number of new symptoms reported				
0	45.8 (649)	35.4 (974)	44.8 (1312)	40.6 (326)
1	21.5 (304)	23.9 (658)	25.1 (734)	21.9 (176)
≥2	32.7 (464)	40.7 (1119)	30.1 (880)	37.5 (302)
Missing: 3.5% (285)				
Feeling if symptoms stayed the same for next 5 years				
Delighted/pleased/mostly satisfied	27.3 (365)	40.1 (1083)	47.2 (1160)	32.8 (256)
Equally satisfied/dissatisfied	16.5 (221)	11.5 (310)	5.2 (129)	11.3 (88)
Mostly dissatisfied	13.2 (177)	7.6 (205)	3.4 (84)	6.4 (50)
Unhappy	20.7 (277)	16.1 (436)	9.2 (226)	16.7 (130)
Terrible	22.2 (297)	24.7 (667)	35.0 (861)	32.9 (257)
Missing: 11.1% (904)				

Table 5.4 Causes of HMB as diagnosed in secondary care

Causes of HMB†	Women reporting causes of HMB, % (*n*=8297)
Hormonal imbalance	8.5 (707)
Polyps of the lining of the womb	14.0 (1159)
Endometriosis	9.0 (745)
Uterine fibroids	32.5 (2700)
No obvious cause	22.3 (1853)
Other cause	9.2 (761)
Don't know	16.9 (1403)
Missing: 2.6 (220)	
Number of causes diagnosed	
1	88.7 (7365)
2	10.1 (837)
≥3	1.2 (95)
Missing: 2.6 (220)	

† Some women reported more than one cause of HMB

5.4 Variation in treatment received across NHS providers

The reported treatment received by women in the year following their first outpatient visit, in particular the last likely treatment received, was analysed further. Funnel plots were used to assess the variations in the treatment received across NHS providers. The unadjusted plots, shown in Figure 5.1, represent the proportion of women by provider who had no treatment, oral medication/IUS, surgical treatment and other treatment. The overall averages, shown by the solid horizontal line in the plots, were 18.0%, 34.6%, 37.3% and 10.1%, respectively. There was some variation between providers but the results largely fell within the control limits of the plots.

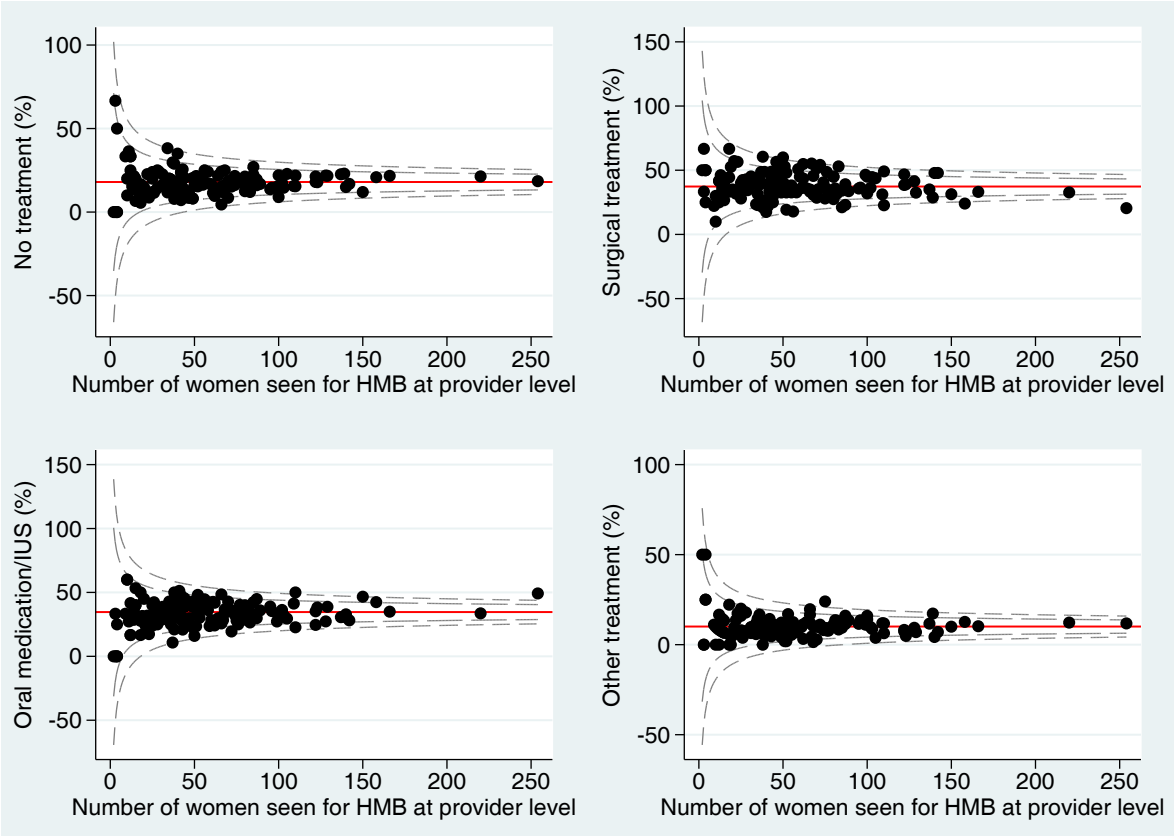

Figure 5.1 Variation in last likely treatment received in secondary care

5.5 Summary

Over 80% of women reported receiving at least one treatment in the year following their first outpatient visit, with 37.3% of women having surgical treatment as their last likely treatment received. Women who stated they had received surgical treatment were more likely to be older, of white ethnicity, have a longer duration of symptoms reported at baseline, three or more reported GP visits and to have felt they were in severe or very severe pain at baseline. At follow-up, these women were more likely to report their overall health as good or better, with mild to no pain and one or no new symptoms.

Women reported a number of causes for HMB as diagnosed in secondary care, with the most common known cause being uterine fibroids. 11.3% of women reported at least two causes. Funnel plots were used to assess the variations in the reported treatments received by women across NHS providers. The proportion of women receiving each treatment did vary by provider; however, the majority of this variation was within the expected limits of random variation.

6 Quality of life at one year

In the follow-up questionnaire, questions relating to disease-specific and general quality of life were the same as those used in the baseline questionnaire, allowing for direct comparisons between the respective scores at baseline and follow-up.

6.1 Severity score and health-related quality of life score

Of the 8517 women who returned the follow-up questionnaire one year after their first outpatient visit, 8367 women provided responses that allowed their severity scores to be calculated; 8139 of these women also provided severity scores at their first outpatient visit, which allowed the change in score over the year to be calculated. For the health-related quality of life (HRQoL) scores, 7967 women provided responses at follow-up, of which 7012 women had also provided responses at baseline.

The adapted UFS-QoL tool was used to assess severity scores and HRQoL scores. Both scores range from 0 to 100, with higher severity scores indicating greater symptom severity and higher HRQoL scores indicating better quality of life.

The median (interquartile range, IQR) severity score at first outpatient visit was 68.8 (53.1, 84.4) and at follow-up this was 21.9 (3.1, 50.0). Almost one-quarter of women had a severity score of 0 at follow-up, which is the best possible severity score, indicating no symptom severity. The mean change in severity score from baseline to follow-up dropped by 36.9 units, and 84.4% of women had lower severity scores at follow-up compared with their baseline severity score.

Table 6.1 shows the percentage of women with lower severity scores by symptoms and treatment at baseline and follow-up. Women who reported a shorter duration of symptoms and more severe pain at their first outpatient visit were less likely to show an improvement in severity scores than those who reported a longer duration of symptoms and no pain. Women who reported a worsening of symptoms and new symptoms in the year following their first outpatient visit were also less likely to show lower severity scores than those reporting improved symptoms and no new symptoms.

To assess whether women's changes in severity scores from baseline to follow-up was of significance, the minimal important difference (MID) was calculated. The mean change in score among those who indicated their symptoms were 'about the same' prior to referral to secondary care was subtracted from the mean change in severity score among women who reported their symptoms were 'a little better'. The result was the minimum change required for an improvement in quality of life.

MID = mean change (symptoms 'a little better') – mean change (symptoms 'about the same')
= (–19.6) – (–10.6)
= 10.0 unit improvement

Overall, 76.0% of women could be identified as having had a 'meaningful improvement' in their severity scores, i.e. an improvement in severity score of at least 10.0 units. Factors associated with this meaningful change in severity score were identified using multivariable logistic regression. Women with a higher baseline severity score, and who reported fewer GP visits, less severe baseline pain status and better overall health were associated with a meaningful improvement in severity scores. In addition, the proportion of women who achieved the MID on the severity scale (those who could then be considered as having the minimum change required for an 'improvement in quality of life') rose as age increased but it was lower among women of non-white ethnicity compared with those of white ethnicity.

Table 6.1 Women with lower severity scores stratified by symptoms and treatment

Factor	Women with lower severity score, % (*n*=8139)
Baseline	
Duration of symptoms	
<2 months	2.1 (147)
>2 months, <1 year	22.5 (1546)
≥1 year	75.4 (5192)
Unknown or missing: 2.2 (179)	
Number of GP visits	
None	5.6 (386)
1–2	50.2 (3438)
3–4	30.5 (2090)
>4	13.7 (933)
Unknown or missing: 2.6 (214)	
Pain	
None	5.7 (386)
Very mild/mild	16.5 (1117)
Moderate	27.1 (1837)
Severe/very severe	50.7 (3450)
Missing: 3.4 (281)	
Overall health	
Excellent/very good	41.7 (2900)
Good	40.9 (2843)
Fair/poor	17.4 (1212)
Missing: 0.9 (77)	
Follow-up	
Number of new symptoms	
0	42.8 (2912)
1	23.9 (1626)
≥2	33.3 (2259)
Missing: 3.3 (274)	
Change in symptoms	
Much better	69.5 (4687)
A little better	14.7 (993)
About the same	11.3 (761)
A little worse	2.6 (172)
Much worse	1.9 (130)
Missing: 3.8 (315)	
Last 'likely' treatment received	
No treatment	16.0 (1086)
Oral medication/IUS	34.7 (2350)
EA/hysterectomy/myomectomy/UAE	39.9 (2707)
Other treatment	9.4 (634)
Unknown or missing: 3.8 (314)	

Similar patterns were seen with regard to the HRQoL score. The median (IQR) HRQoL score at baseline and follow-up was 47.4 (35.7, 59.1) and 83.6 (42.2, 100.0), respectively, with almost one-third of women having the best possible HRQoL score of 100 at follow-up. The mean change from baseline to follow-up in HRQoL score was an improvement of 23.1 units. The MID

was 12.5 and 61.0% of women could be identified as having had meaningful improvement. Multivariable logistic regression showed that those women with a lower baseline HRQoL score, less severe baseline pain status and better overall health were associated with a meaningful improvement in HRQoL scores (table available from authors). Older women and those of white ethnicity were also more likely to show a meaningful improvement in HRQoL scores.

6.2 Variation across providers – severity and HRQoL score changes

The mean improvement in severity score from baseline to follow-up by provider is shown in the unadjusted funnel plot in Figure 6.1. While variations by providers were observed, they were largely within the control limits. Similarly, funnel plots using the mean change in HRQoL score also show little systematic difference among providers.

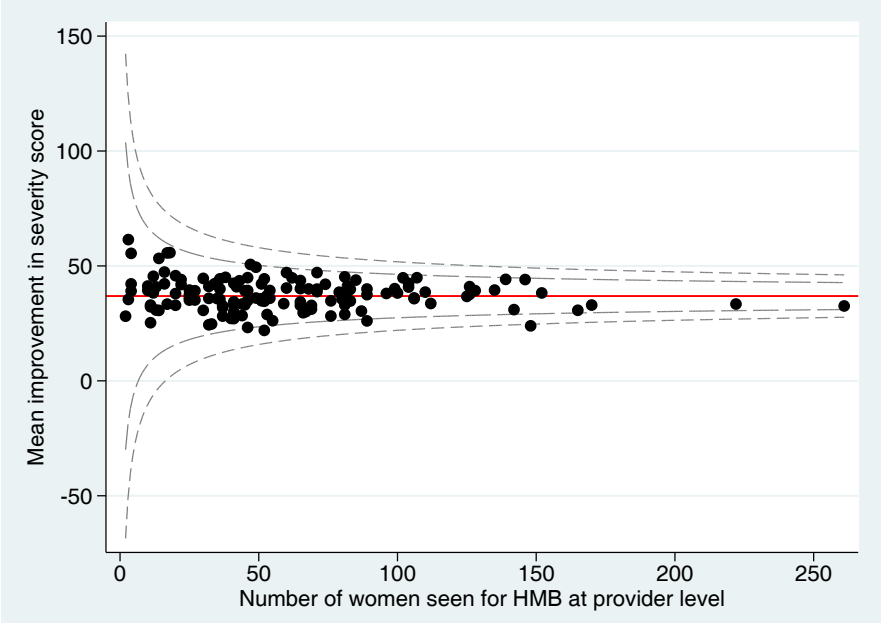

Figure 6.1 Mean improvement in severity score by provider

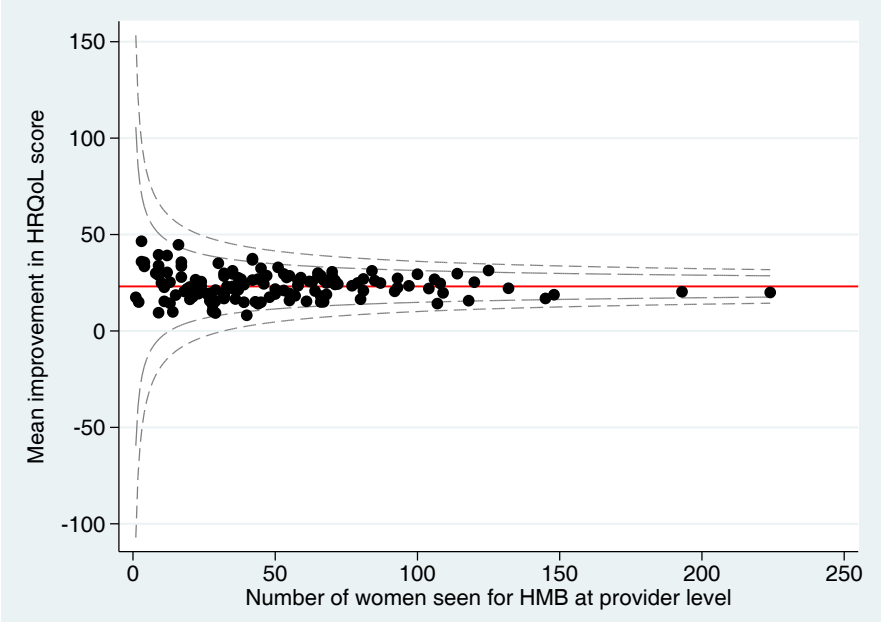

Figure 6.2 Mean change in HRQoL score by provider

6.3 Summary

The adapted UFS-QoL tool was used to assess severity and HRQoL scores. In the year following their first outpatient visit, 84.4% of women had a lower severity score and 76.0% of women were identified as having had a meaningful improvement (10.0 units or more) in this score. In addition, the proportion of women who achieved the MID on the severity scale rose as age increased but it was lower among women of non-white ethnicity.

Similar patterns were seen with regard to the HRQoL score, where 61.0% of women were identified as having had meaningful improvement (12.5 units or more). The proportion of women who achieved the MID on the HRQoL scale also rose as age increased but, again, it was lower among women of non-white ethnicity.

At the provider level, variations in the mean change in severity score and the mean change in HRQoL score were observed. However, these were largely contained in the control limits of the funnel plot, suggesting little systematic difference among providers.

7 Experience in secondary care

7.1 Information received and satisfaction with information received

Of the 8517 women who returned the follow-up questionnaire one year after their first outpatient visit, 8306 women answered the question on the amount of information received from the hospital regarding their HMB condition and treatment. Of this number, 73.4% indicated they had received the correct amount of information, 19.2% stated they had not received enough information, 0.3% felt they had received too much information and 7.1% reported they had received no information at all. The proportion of women who stated they had not received enough information was higher among those of younger age (31.7% of those under 35 years compared with 16.0% of those aged over 50 years) and those of non-white ethnicity (26.1% compared with 18.3% of white ethnicity). The proportion of women who reported they had not received enough information was lowest among those whose last likely treatment was either hysterectomy (12.9%) or EA (12.0%), while it was considerably higher among women who had received other treatments as their last likely treatment (the highest being 27.9% for oral medication). Women reporting severe/very severe pain were also more likely to feel they had not received enough information, compared with those women reporting no pain. Women of younger age and those who indicated they had not had an operative procedure in secondary care were also more likely to feel dissatisfied with the information received in secondary care.

7.2 Communication with doctors in secondary care

At follow-up, women were asked six questions based around communication with doctors in secondary care. These questions (Q14 to Q19) can be seen in Appendix 6. The overall proportion of women who answered either 'yes definitely', 'yes, to some extent' or 'no' to these questions can be seen in Figure 7.1. The proportions were very similar across the first four questions, with around 60% of women answering 'yes definitely' to being involved in decisions about care and treatment, receiving answers from doctors they could understand, having the doctor listen to what they had to say and feeling the doctor understood what they

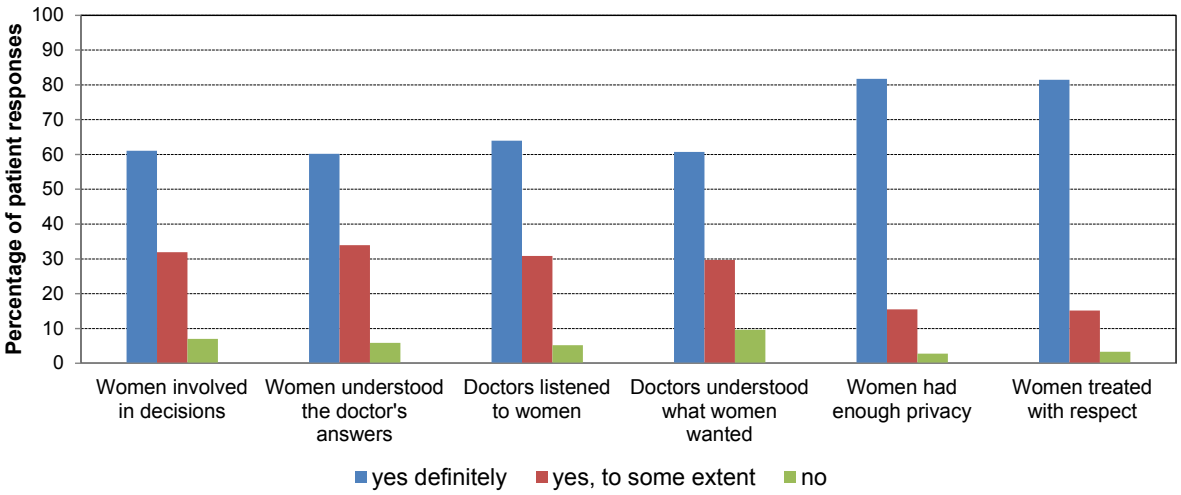

Figure 7.1 Communication with doctors in secondary care

wanted. When asked about being given enough privacy for the discussion and being treated with respect, about 80% of women answered 'yes definitely'. Women of younger age were more likely to answer 'no' to questions on involvement in decisions, receiving understandable answers to questions, being listened to and doctors understanding what was being said; a similar association was not seen between ethnicity and these questions.

Women who reported receiving oral medication, 'other' treatment or no treatment, and those indicating they were in severe/very severe pain at baseline or follow-up were also more likely to answer 'no' to questions based around communication with doctors in secondary care.

7.3 Overall rating of care received

In the follow-up questionnaire, women were asked about the overall level of care they received, for which 8333 women provided responses. 74.3% of women rated the overall level of care received as excellent or very good, 16.0% reported it as good and 9.7% reported it as fair/poor. The overall level of care by baseline demographics, baseline symptoms and treatment at follow-up is shown in Table 7.1.

Women who reported the overall care received in secondary care as fair/poor were more likely to be of younger age, of non-white ethnicity and to indicate they were in fair/poor overall health at their first outpatient visit. They were also more likely to report that their symptoms had worsened and that they had new symptoms.

The proportion of women who rated their overall care as fair/poor was plotted by provider, as shown in Figure 7.2. The national average was 10.1% and variations were observed at the provider level. However, the majority of the results were within the control limits of the funnel plot, suggesting little systematic difference.

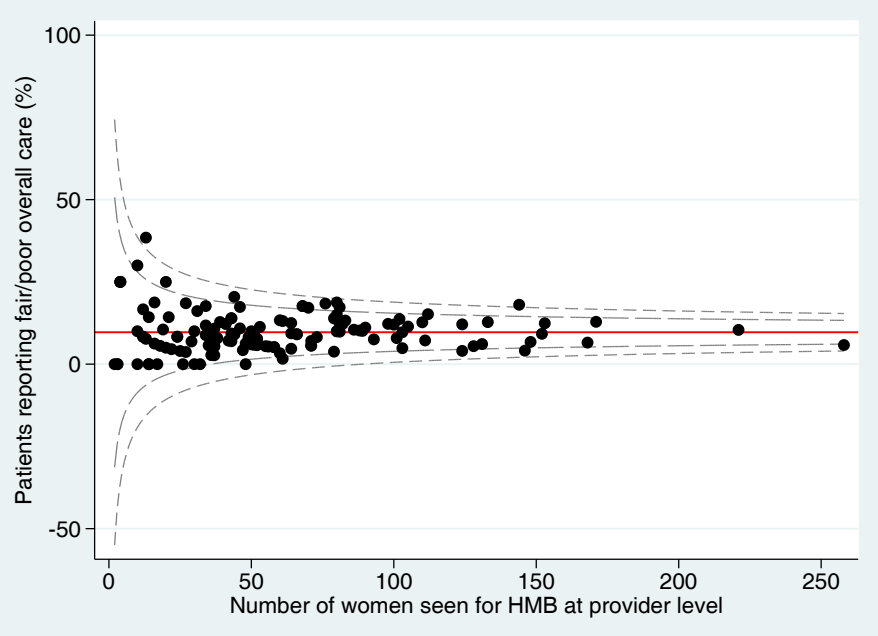

Figure 7.2 Proportion of women rating overall care as fair/poor

7.4 Summary

Almost three-quarters of women reported receiving the correct amount of information from the hospital with regard to their HMB condition and treatment. The proportion of women who indicated they had not received enough information was higher among those of younger

Table 7.1 Association between patient demographics, symptoms and treatment and the overall level of care received

	Excellent/very good, % (*n*=6193)	Good, %, (*n*=1332)	Fair/poor, % (*n*=808)
Baseline			
Age			
18–34	8.2 (506)	14.0 (187)	17.8 (144)
35–39	10.6 (654)	13.4 (178)	13.5 (109)
40–44	27.0 (1672)	24.6 (327)	27.0 (218)
45–49	35.7 (2210)	34.3 (457)	28.7 (232)
≥50	18.6 (1151)	13.7 (183)	13.0 (105)
Ethnicity			
White	92.2 (5408)	85.5 (1057)	88.6 (668)
Non-white	7.8 (459)	14.5 (179)	11.4 (86)
Missing: 5.7% (476)			
Overall health			
Excellent/very good	44.4 (2718)	33.6 (441)	31.3 (251)
Good	39.9 (2441)	44.3 (582)	43.0 (344)
Fair/poor	15.7 (964)	22.1 (290)	25.7 (206)
Missing: 1.2% (96)			
Feeling if symptoms stayed the same for next 5 years			
Delighted/pleased/mostly satisfied	1.2 (74)	1.2 (15)	1.4 (11)
Equally satisfied/dissatisfied	5.6 (341)	6.7 (87)	6.7 (53)
Mostly dissatisfied	10.0 (605)	11.1 (144)	9.2 (73)
Unhappy	29.8 (1804)	32.2 (417)	24.5 (195)
Terrible	53.3 (3225)	48.8 (631)	58.2 (463)
Missing: 2.3% (195)			
Follow-up			
Symptoms compared to a year ago			
Much/a little better	84.5 (5035)	65.1 (842)	54.6 (430)
Same	10.5 (623)	22.9 (296)	28.7 (226)
A little/much worse	5.0 (298)	12.1 (156)	16.7 (131)
Missing: 3.6% (296)			
Number of new symptoms			
0	43.9 (2638)	33.9 (438)	33.0 (261)
1	23.9 (1436)	23.8 (308)	20.1 (159)
≥2	32.2 (1937)	42.3 (546)	46.9 (371)
Missing: 2.9% (239)			
Last 'likely' treatment received			
No treatment	16.1 (963)	22.4 (283)	23.4 (182)
Oral medication/IUS	34.2 (2041)	36.7 (465)	34.5 (268)
EA/hysterectomy/myomectomy/UAE	40.5 (2419)	28.4 (360)	28.7 (223)
Other treatment	9.3 (554)	12.5 (158)	13.4 (104)
Unknown or missing: 3.8% (313)			

age and those of non-white ethnicity. Approximately 60% of women reported 'definitely' being involved in decisions about care and treatment, receiving answers from doctors they could understand, having the doctor listen to what they had to say and feeling the doctor understood what they wanted. About 80% reported 'always' being treated with respect.

Women who felt they had not received enough information were more likely to report having had oral medication, 'other' treatment or no treatment, and were more likely to report having been in severe/very severe pain at baseline.

When asked about the overall level of care received, three-quarters of women rated this as excellent or very good. However, women of younger age, of non-white ethnicity and who indicated they were in fair/poor overall health at their first outpatient visit were more likely to rate the overall care received as fair/poor. The proportion of women who rated their overall care as fair/poor was plotted by provider. While variations at the provider level were observed, the results were largely contained within the control limits of the funnel plot.

8 Discussion

The patient-reported outcomes component of the National HMB Audit has shown that over 80% of women referred to secondary care appear to have received at least one treatment in the year following their first visit to an NHS outpatient gynaecology clinic. Non-surgical treatment appeared to be more likely for younger women, and for those reporting symptoms that were less severe and/or of a shorter duration. In the first year after the outpatient visit, symptoms and quality of life appeared to improve significantly for the majority of women, including for those who indicated they did not receive any treatment. Patient experience in secondary care was rated very good or excellent by three-quarters of the women, with the majority feeling they had received sufficient information, were treated with dignity and respect, and were involved in the decisions about their care. While regional differences in the quality of life scores as well as reported symptoms and treatment did exist, there was little evidence of systematic variation among providers.

The overall response rate to the one-year questionnaire was 55.6%. The response rates for postal questionnaires in other recent national surveys were: 38% (GP Patient Survey[9]); 54% (National Maternity Survey[10]); and 64–85% (PROMs Programme For Elective Surgery[11]). In line with the National HMB Audit, the evidence on surveys of hospital patients in the UK suggests that women of older age and of white ethnicity are more likely to return a follow-up questionnaire whereas younger women, those of non-white ethnicity and those who have indicated poorer health status and/or lower quality of life are less likely to return the follow-up questionnaire.[12] Response rates also appear to depend on the nature of the condition and the length of time between initial and follow-up questionnaires.[11,13] It is important to note that the population of the National HMB Audit is younger than that of the PROMs Programme, and a higher proportion of the women in the National HMB Audit reported comorbidities (notably depression); women in the audit also appear to have a relatively low overall quality of life, at least lower than in patients undergoing surgery for groin hernia or varicose veins.[6]

While there are differences in the response rates by ethnicity, it is important to note that 9.2% of the responders were of non-white ethnicity, which is broadly representative of the demography of the UK.[14,15] The proportion of women of non-white ethnicity who reported having no treatment in the year following their outpatient gynaecology clinic visit was higher (21%) than that for women of white ethnicity (18%), and the overall levels of improvement in QoL scores were significantly lower. It is possible that these differences in the choice of treatment according to ethnicity was influenced by whether women were considering a future pregnancy, as completed family, severity of symptoms and older age are strong predictors for surgical treatment.[16]

While there are a number of studies that report outcomes and subsequent treatments after surgery for HMB,[17–19] this is the only national study reporting on first treatments received in secondary care. In this audit, 18% of women indicated they had received no treatment, 29% reported being treated with oral medication and, more importantly, one-third of women stated they had received an IUS in the year after their first visit to an outpatient gynaecology clinic.

Just over 23% of women reported having an EA and nearly 14% a hysterectomy. The overall patterns of treatment observed in this study are in line with a general idea that the majority of women would prefer a treatment that does not eliminate their periods.[20] It is of interest to note that nearly 1 in 5 women indicated they did not receive any treatment. It is possible that these women had mainly wanted reassurance that there were no serious underlying conditions.[16,21]

It is reassuring that, by and large, NICE guidelines (with regard to managing symptoms with the recommended order of management options) appear to be being followed in practice,

as about one-third of women indicated they had an IUS followed by EA, and only a small proportion stated they had received multiple medications as their first line of treatment. The reported pattern of care also reflects that younger women appeared to be more likely to be treated with oral medication and, conversely, older women appeared more likely to be treated with an IUS. The overall QoL and symptom severity improved for women with severe symptoms when treated with either IUS, EA or hysterectomy, which is in line with other studies.[17]

The National HMB Audit's *First Annual Report* described regional differences in the rates of EA and hysterectomy for HMB. However, in this study, the variation between providers in EA/hysterectomy rates is less prominent.

With regard to the reports of treatments received, causes of HMB diagnosed in secondary care and pain experienced in secondary care, variations were observed at the NHS provider level. However, they were largely within the acceptable range defined by the control limits of the funnel plots. Factors such as clinical judgement and women's preferences may explain some of the variation.

Informed choice can only be supported in clinical practice if NHS staff can provide women with full information[22] to empower them to opt for the right treatment.[23,24] Although about three-quarters of the responders reported being satisfied with their care and the level of information provided, nearly 10% of women stated they were dissatisfied with the care they received and just over 25% felt they did not receive enough information or any information about their HMB. Furthermore, one-third of younger women (under 35), one-quarter of women of non-white ethnicity, one-third of women indicating they were in severe/very severe pain, and one-third reporting they were in poor health appear not to have received adequate information. A lack of information could have a direct impact on the quality of care and type of treatment asked for by the patient, such as hysterectomy in preference to EA even though EA is less invasive.[25] We need to explore newer ways of providing women with information about their disease, condition and treatment options, especially the young and those of non-white ethnicity.

The *Fourth Annual Report* will link the prospective National HMB Audit database with data from HES and PEDW to give a more detailed understanding of patient care and outcomes, including further investigations into the implicit factors contributing to variations in processes observed at the provider level. A case note review exercise will also be carried out comparing the information that women reported about their treatments with the clinical information available in the notes. This, along with a second organisational audit, will provide further information on the compliance with national guidelines and confirm potential areas for improvement.

Appendix 1

Clinical Reference Group, Project Board and Clinical Advisors

Clinical Reference Group

Angela Hyde (Chair)	RCOG Women's Network
Loveleen Bansi-Matharu	RCOG
Anna Carluccio	RCOG
Patrick Chien FRCOG	Ninewells Hospital, Dundee
David Cromwell	London School of Hygiene & Tropical Medicine
Hilary Denyer	Endometriosis UK, Patient Representative
Anita Dougall	RCOG
Stefan Durkacz	Ipsos MORI
Jonathan Frappell FRCOG	Derriford Hospital, Plymouth
Ipek Gurol-Urganci	London School of Hygiene & Tropical Medicine
Debby Holloway	Royal College of Nursing
Sara Johnson	RCOG
Amit Kiran	London School of Hygiene & Tropical Medicine
Mary Ann Lumsden FRCOG	University of Glasgow
Tahir Mahmood FRCOG	RCOG, National HMB Audit project team Co-Chair
Michael Maresh FRCOG	St Mary's Hospital, Manchester
Jan van der Meulen	London School of Hygiene & Tropical Medicine, National HMB Audit project team Co-Chair
Jonathan Nicholls	Ipsos MORI
Judy Shakespeare	Royal College of General Practitioners
Allan Templeton FRCOG	RCOG

Project Board

Robert Shaw FRCOG (Chair)	Emeritus Professor of Obstetrics and Gynaecology, University of Nottingham and Chair, National Collaborating Centre, Women's and Children's Health
Loveleen Bansi-Matharu	RCOG
Anna Carluccio	RCOG
Anita Dougall	RCOG
Stefan Durkacz	Ipsos MORI
Ipek Gurol-Urganci	London School of Hygiene & Tropical Medicine
Angela Hyde	RCOG, Chair of Clinical Reference Group
Sara Johnson	RCOG
Amit Kiran	London School of Hygiene & Tropical Medicine
Tahir Mahmood FRCOG	RCOG, National HMB Audit project team Co-Chair
Samantha McIntyre	Health Quality Improvement Partnership representative

Jan van der Meulen	London School of Hygiene & Tropical Medicine, National HMB Audit project team Co-Chair
Jonathan Nicholls	Ipsos MORI
Yvonne Silove	Health Quality Improvement Partnership representative
Allan Templeton FRCOG	RCOG

Clinical Advisors

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

DBS tracing

DBS traces involve submitting request files to the NHS spine, and receiving output files the following day (since the traces are performed automatically overnight). If the data provided in these files matches a record on the NHS spine, then the personal details of this individual are returned in the output file (including NHS number and contact details, but not including any clinical data).

Ipsos MORI included four request files in each batch of DBS traces. Each file provides different data fields in order to utilise the different methods DBS has of achieving a match. With the exception of trace 4, a match requires all data entries provided in the request file to exactly match all corresponding data entries on the NHS spine:

- Trace 1: NHS number and date of birth (DOB) only (full match required): the preferred method of tracing, but requires present and correct NHS number and correct DOB.
- Trace 2: forename, surname, gender and DOB (full match required): the most useful trace if no NHS number is provided (or if the NHS number is incorrect); if multiple matches occur (i.e. multiple individuals with the same name and DOB), then this will show in the output file, but no data will be returned.
- Trace 3: forename, surname, gender, DOB and postcode (full match required): the main use of this trace is for distinguishing between 'multiple' matches in trace 2; it is of limited use by itself, however, since the quality of postcode data (e.g. formatting issues that are not simple to correct) means that this trace tends to have a much lower success rate.
- Trace 4: NHS number, forename, surname, gender and DOB (requires full match of NHS number, plus two out of three elements in the DOB to match (i.e. two from day, month and year), plus the initial of the forename and the first three letters of the surname): useful if the NHS number is provided but there is a single error in the DOB.

A small percentage of records return no successful traces (about 2–3%). In these cases the relevant field data is checked against the consent form scan, the fields corrected as appropriate if errors are found, and a second batch of traces is run (i.e. traces 1–4 again).

The output files from DBS are collated, such that there is then one set of trace data for each successful trace linked into the follow-up (Q2) sample. Trace data is cross-checked to ensure that multiple successes are consistent (i.e. the data from trace 1 is the same as the data from trace 2, etc.), and that returned dates of birth, if different (i.e. if trace 4 data is being used) are checked to ensure that the respondent remains eligible (i.e. women aged between 18 and 60 years). Returned data for trace 2 is also checked where the returned postcode is different: in two cases the record of a different individual was returned when a DOB was incorrect and the names were common.

Appendix 3

Baseline characteristics of responders and non-responders

Table A3.1 Baseline characteristics of responders and non-responders

	Non-responders†, % (*n*=6808)	Responders†, % (*n*=8517)	*P* value
Age (years)			
All, median (IQR)	42 (36, 47)	45 (40, 48)	<0.001
18–34	21.0 (1427)	10.0 (856)	
35–39	15.0 (1020)	11.2 (951)	
40–44	26.4 (1799)	26.7 (2272)	<0.001
45–49	27.0 (1835)	34.7 (2959)	
≥50	10.7 (727)	17.4 (1479)	
BMI (kg/m²)			
All, median (IQR)	26.6 (23.3, 31.0)	26.3 (23.3, 30.7)	0.056
<25	38.8 (1927)	40.2 (2754)	
25–29.9	31.2 (1553)	32.0 (2186)	0.036
≥30	30.0 (1489)	27.8 (1903)	
Missing	*27.1 (1839)*	*19.7 (1674)*	
Ethnicity			
White	85.2 (5333)	90.8 (7281)	<0.001
Non-white	14.8 (929)	9.2 (740)	
Missing	*8.3 (546)*	*5.8 (496)*	
Age at leaving full-time education (years)			
≤16	41.3 (2531)	38.8 (3073)	
17–18	27.1 (1664)	29.8 (2362)	0.001
≥19	31.6 (1935)	31.4 (2494)	
Missing	*10.0 (678)*	*6.9 (588)*	
Parity			
Nulliparous	16.9 (1113)	17.1 (1417)	0.781
Multiparous	83.1 (5465)	82.9 (6873)	
Did not want to answer/missing	*3.4 (230)*	*2.7 (227)*	
Duration of symptoms			
≤2 months	2.6 (167)	2.3 (195)	
>2months and <1 year	24.4 (1595)	23.0 (1911)	0.077
≥1 year	73.1 (4780)	74.7 (6218)	
Don't know/missing	*3.9 (266)*	*2.3 (193)*	
GP visits in the last year			
0	6.8 (445)	6.1 (509)	
1–2	43.3 (2819)	50.8 (4212)	<0.001
3–4	30.6 (1992)	29.3 (2425)	
>4	19.3 (1253)	13.8 (1143)	
Don't know/missing	*4.5 (331)*	*2.7 (228)*	

Table A3.1 (*cont.*) Baseline characteristics of responders and non-responders

	Non-responders†, % (*n* = 6808)	Responders†, % (*n* = 8517)	*P* value
Prior treatment			
None	31.4 (2061)	30.7 (2553)	
The pill	45.1 (2957)	44.4 (3690)	
Other medication	17.1 (1121)	18.3 (1519)	0.051
IUS	5.2 (342)	5.8 (484)	
EA	1.0 (67)	0.8 (63)	
Other treatment	0.2 (10)	0.1 (10)	
Don't know/missing	*3.8 (277)*	*2.3 (198)*	
Pain experienced			
None	4.9 (318)	6.0 (490)	
Very mild/mild	13.2 (848)	16.5 (1355)	<0.001
Moderate	23.2 (1498)	26.9 (2211)	
Severe/very severe	58.7 (3784)	50.7 (4164)	
Don't know/missing	*5.3 (360)*	*3.5 (297)*	
HMB group			
HMB alone	56.3 (3834)	48.2 (4108)	
Fibroids and/or polyps	35.3 (2587)	44.2 (3765)	
Endometriosis with or without polyps	6.0 (436)	4.9 (420)	<0.001
Fibroids and endometriosis with or without polyps	2.4 (173)	2.6 (224)	
Number of comorbidities			
0	65.5 (4461)	67.0 (5704)	
1	25.6 (1745)	25.0 (2133)	0.080
≥2	8.9 (602)	8.0 (680)	
Overall health			
Excellent/very good	32.6 (2178)	41.5 (3490)	
Good	43.2 (2883)	40.9 (3441)	<0.001
Fair/poor	24.2 (1611)	17.7 (1487)	
Missing	*2.0 (136)*	*1.2 (99)*	
Feeling if symptoms stayed the same for next 5 years			
Delighted/pleased/mostly satisfied	1.2 (77)	1.2 (101)	
Equally satisfied/dissatisfied	5.3 (343)	5.9 (492)	
Mostly dissatisfied	8.9 (579)	10.2 (846)	0.002
Unhappy	28.6 (1860)	29.7 (2471)	
Terrible	56.1 (3654)	53.0 (4405)	
Missing	*4.3 (295)*	*2.4 (202)*	

† Age and BMI also show median (IQR)

Appendix 4

Case ascertainment for the National HMB Audit in England and Wales

The National HMB Audit requires provider-level estimates of the number of women with HMB who attend an NHS outpatient gynaecology clinic for the first time in England and Wales. This number is necessary as it provides the 'denominator' for the case-ascertainment estimates. The full description of the eligibility and inclusion criteria is provided in Box 1. There are three possible sources of information for these estimates:

- The most relevant data sources are Hospital Episodes Statistics (HES) and Patient Episode Database for Wales (PEDW) outpatient data. These datasets provide *first outpatient gynaecology visits* at the provider level. However, due to the limitations of diagnostic coding, the number of women specifically with HMB who attended these clinics cannot be determined.
- HES/PEDW inpatient data provides *the number of surgical procedures (EA and hysterectomy) for women who have HMB* as primary diagnosis. However, we need to know what proportion of women have surgery after their initial outpatient visit to be able to calculate the provider-level estimates for first outpatient visits.
- NHS providers can give their own estimates of the denominator.

This document describes the process in which the project team used these multiple sources of data and literature to estimate the final denominator data used to assess case ascertainment.

Box 1 Eligibility and inclusion criteria for the audit

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 in the National HMB Audit. Women who had visited a gynaecological outpatient clinic for HMB within the previous 12 months and women with insufficient English comprehension or a cognitive or visual impairment that precluded self-completion of the questionnaire were excluded. Data collection at NHS outpatient gynaecology clinics started on 1 February 2011 and ended on 31 January 2012 (hereafter known as 'the audit period').

Unit of analysis

Provider codes are given as five-digit codes in HES. Ideally, these provider codes should match one-to-one with hospital units. However, for a significant number of trusts, the data contained only one provider code although the NHS trust contained multiple participating units. PEDW data was provided at the health board level. Therefore, all data was aggregated to the trust level (three-digit codes) for comparisons across providers. These units represented:

- three primary care trusts (England)
- 134 NHS trusts (England)
- five local health boards (Wales).

Data sources

1) **Outpatient HES/PEDW data**
The number of first outpatient gynaecology attendances is available from HES/PEDW at the provider level for the audit period. The proportion of women with HMB among women referred to NHS outpatient gynaecology clinics for any condition was estimated by using multiple data sources, including clinicians' expert opinion, literature and routine data (Annex 1). The feedback from the units to our preliminary denominator estimates in the first year of the audit suggested that HES/PEDW outpatient data tended to overestimate the actual number of women with HMB who have attended their outpatient gynaecology clinics; therefore, the conservative assumption of 10% was used for further analysis. Provider-level HES/PEDW counts of women who fulfilled the inclusion criteria were multiplied by this proportion to generate 'outpatient data-based' denominators. Using HES/PEDW outpatient data for the audit, the project team would expect to have 74 000 women with HMB referred to NHS outpatient gynaecology clinics.

2) **Inpatient HES/PEDW data**
HES/PEDW inpatient data provides the number of surgical procedures (EA and hysterectomy) for women who have HMB as primary diagnosis. During the audit period, there were 4800 hysterectomies and 12 500 EAs in participating units. In the previous year, the number of hysterectomies was higher, at 5300.

   To calculate the national and provider-level denominators, it is necessary to know what proportion of women have surgery after their initial outpatient visit. Prior to the National HMB Audit follow-up questionnaire, which asked women to recount the treatments they received in the first year after their initial visit, these outpatient-to-inpatient conversion rates were not available to the project team. The only estimate was from the Somerset Morbidity Project from the 1990s, which reported that 42.6% (95% CI 37.6–48.3%) of women who were referred for HMB had a surgical procedure. However, this proportion is likely to be unrepresentative of the current practice as the patterns for surgery for HMB have significantly decreased over the last decade (Cromwell et al., 2009).

   Among the 8517 women who responded to the follow-up questionnaire, 1128 (11.2%) reported that they had a hysterectomy and 1888 (22.1%) had an EA. Using these conversion rates, the National HMB Audit denominator would be expected to be in the range of 36 000 (using the hysterectomy rate) to 56 000 (using the EA rate).
   For the estimation of provider-level estimates, it is possible to calculate a conversion rate for each provider for both hysterectomy and EA. However, for some providers the number of women who have responded to the questionnaire is too low to have an accurate estimate of the conversion rates, giving the distribution of provider-level conversion rates more extreme (and implausible) values. For providers with fewer than 20 responses, a median hysterectomy rate (13.4%) and EA rate (21.5%) were assumed. Conversion rates for the upper end of the distribution were truncated at the 75th percentile (8.8% for hysterectomy and 15.6% for EA), and the conversion rates for the lower end of the distribution were truncated at the 25th percentile (18.2% for hysterectomy and 28.6% for EA).

3) **Providers' own estimates**
Forty primary care trusts provided their own estimates, calculated using their hospital records.

Overall decision rule for provider-level estimates

- If the providers gave a revised estimator using their local information systems, and it has been agreed with the National HMB Audit project team, this revised denominator was used.
- For the remaining units, the final denominator was assumed to be the median of the seven possible data points: two inpatient and one outpatient estimates each for the audit period (2011/12) and previous year (2010/11), and the denominator reported in the *Second Annual Report*. The 'old' denominator was estimated using outpatient data from 2009/10 and the organisational survey responses.
- If there was an inconsistency between 'old' and new estimates (i.e. more than 25% difference), data from each trust was examined in detail and the most plausible estimate was chosen by the National HMB Audit project team.

Conclusion

Using multiple data sources, the National HMB Audit's overall denominator (the number of women who attended an outpatient gynaecology clinic for the first time in England and Wales) was estimated to be 49 515. Between February 2011 and January 2012, 15 812 women completed the outpatient questionnaire. The case ascertainment for the audit was thus 31.9%.

Annex 1: Data sources to estimate the proportion of women with HMB among women referred to gynaecology clinics

Literature

Bradlow et al. (1992) reported that 12% of all outpatient gynaecology referrals are for menstrual problems. This finding has been frequently cited in the literature on HMB.

Organisational survey

In the survey, clinical directors were asked to provide an estimate of first outpatient gynaecology visits and first outpatient HMB visits in their units. Some units reported trust-level values or left the question blank. For the 201 units registered in the National HMB Audit, the sum of the reported values of first outpatient gynaecology visits was 859 385 (54/201 values missing) and first HMB visits was 129 588 (87/201 values missing). In the 111 units that provided both values, the median ratio of HMB visits in all outpatient gynaecology clinics was 20% (IQR 13–30%).

Primary care attendances and referrals for HMB

The calculations described below duplicate the methods used in *Heavy Menstrual Bleeding Costing Report: Implementing the NICE Guideline* (NICE, 2007). Using national data from IMS Disease Analyzer, the NICE costing report authors found that 3.0% of women presenting to general practices in England had an HMB diagnostic code. Two small studies using practice-level data for women aged 30–49 found incidence rates of 2.6% (range 1.7–3.1%; Grant et al., 2000) and 5% (Vessey et al., 1992). Using data for the female GP-registered population in 2011 (Health and Social Care Information Centre, 2012) and the age-specific incidence rates from the NICE costing report, it is expected that about 440 000 women aged 20–59 present to primary care with HMB in England and Wales. Using Somerset Morbidity Project estimates (incidence rates of 2.6% for ages 30–49 and assuming 1.7% for other age groups), the number of women presenting to services would be about 320 000.

The NICE costing report used the rate of referral of 37.8% from the Somerset Morbidity Project (95% CI 34–40%). (Grant et al., 2000). Using the two estimates for the number of women presenting to services and the referral rate of 37.8%, the number of referrals for HMB in England and Wales would be 120 000–160 000. In 2011, there were 1 000 000 outpatient gynaecology 'first attendances' for women aged 20–59 in England and Wales. Using the estimated number of referrals, the ratio of HMB referrals in all first gynaecology outpatient visits would be between 12% and 16%.

Expert opinion

The project team conducted a poll to elicit the expert opinion of 15 clinicians advising the National HMB Audit. The clinicians were asked for their best estimate of the proportion of women with HMB among women attending NHS outpatient gynaecology clinics for the first time. We received seven responses ranging from 10% to 15%.

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Appendix 5

Overall levels of case ascertainment

Table A5.1 Estimated case ascertainment for 142 providers

Code	Trust	Actual cases	Expected cases	Case ascertainment
7A3	Abertawe Bro Morgannwg University Health Board	225	828	27.2%
RCF	Airedale NHS Trust	82	168	48.8%
7A6	Aneurin Bevan Health Board	168	332	50.6%
RTK	Ashford and St Peter's Hospitals NHS Trust	7	276	2.5%
RF4	Barking, Havering and Redbridge University Hospitals NHS Trust	66	299	22.1%
RVL	Barnet and Chase Farm Hospitals NHS Trust	47	193	24.4%
RFF	Barnsley Hospital NHS Foundation Trust	116	278	41.7%
R1H	Barts Health NHS Trust	203	626	32.4%
RDD	Basildon and Thurrock University Hospitals NHS Foundation Trust	42	549	7.7%
RC1	Bedford Hospital NHS Trust	60	255	23.5%
7A1	Betsi Cadwaladr University Health Board	448	888	50.5%
RLU	Birmingham Women's NHS Foundation Trust	63	655	9.6%
RXL	Blackpool Fylde and Wyre Hospitals NHS Foundation Trust	132	380	34.7%
5NY	Bradford and Airedale	56	96	58.3%
RAE	Bradford Teaching Hospitals NHS Foundation Trust	46	144	31.9%
RXH	Brighton and Sussex University Hospitals NHS Trust	100	407	24.6%
RXQ	Buckinghamshire Hospitals NHS Trust	75	342	21.9%
RJF	Burton Hospitals NHS Foundation Trust	65	210	31.0%
RWY	Calderdale and Huddersfield NHS Foundation Trust	126	360	35.0%
RGT	Cambridge University Hospitals NHS Foundation Trust	66	180	36.7%
RW3	Central Manchester University Hospitals NHS Foundation Trust	30	441	6.8%
RQM	Chelsea and Westminster Hospital NHS Foundation Trust	12	314	3.8%
RFS	Chesterfield Royal Hospital NHS Foundation Trust	111	404	27.5%
RLN	City Hospitals Sunderland NHS Foundation Trust	192	487	39.4%
RDE	Colchester Hospital University NHS Foundation Trust	24	380	6.3%
RJR	Countess of Chester Hospital NHS Foundation Trust	61	351	17.4%
RXP	County Durham and Darlington NHS Foundation Trust	68	497	13.7%
RJ6	Croydon Health Services NHS Trust	23	112	20.5%
7A5	Cwm Taf Health Board	158	478	33.1%
RN7	Dartford and Gravesham NHS Trust	33	371	8.9%
RTG	Derby Hospitals NHS Foundation Trust	159	600	26.5%
RP5	Doncaster and Bassetlaw Hospitals NHS Foundation Trust	262	449	58.4%
RBD	Dorset County Hospital NHS Foundation Trust	60	211	28.4%
5QM	Dorset Primary Care Trust	9	23	39.1%
RC3	Ealing Hospital NHS Trust	99	159	62.3%
RWH	East and North Hertfordshire NHS Trust	47	403	11.7%
RJN	East Cheshire NHS Trust	137	168	81.5%
RXR	East Lancashire Hospitals NHS Trust	242	381	63.5%

Code	Trust	Actual cases	Expected cases	Case ascertainment
RXC	East Sussex Hospitals NHS Trust	315	449	70.2%
RVR	Epsom and St Helier University Hospitals NHS Trust	77	338	22.8%
RDU	Frimley Park NHS Foundation Trust	28	173	16.2%
RR7	Gateshead Health NHS Foundation Trust	88	195	45.1%
RLT	George Eliot Hospital NHS Trust	9	185	4.9%
RN3	Great Western Hospitals NHS Foundation Trust	146	413	35.4%
RJ1	Guy's and St Thomas' NHS Foundation Trust	359	450	79.8%
RN5	Hampshire Hospitals NHS Foundation Trust	157	525	29.9%
RR1	Heart of England NHS Foundation Trust	170	612	27.8%
RD7	Heatherwood and Wexham Park Hospitals NHS Foundation Trust	50	315	15.9%
RLQ	Hereford Hospitals NHS Trust	25	209	12.0%
RQQ	Hinchingbrooke Healthcare NHS Trust	78	185	42.2%
RQX	Homerton University Hospital NHS Foundation Trust	40	96	41.7%
RWA	Hull and East Yorkshire Hospitals NHS Trust	118	600	19.7%
7A2	Hywel Dda Local Health Board	120	418	28.7%
RYJ	Imperial College Healthcare NHS Trust	150	472	31.8%
RGQ	Ipswich Hospital NHS Trust	190	387	49.1%
R1F	Isle of Wight NHS Trust	92	184	50.0%
RGP	James Paget University Hospitals NHS Foundation Trust	173	315	54.9%
RJZ	King's College Hospital NHS Foundation Trust	101	416	24.3%
RAX	Kingston Hospital NHS Trust	142	179	79.3%
RXN	Lancashire Teaching Hospitals NHS Trust	91	432	21.1%
RR8	Leeds Teaching Hospitals NHS Trust	67	714	9.4%
REP	Liverpool Women's NHS Foundation Trust	435	720	60.4%
RC9	Luton and Dunstable Hospital NHS Foundation Trust	162	264	61.4%
RWF	Maidstone and Tunbridge Wells NHS Trust	115	332	34.6%
RPA	Medway NHS Foundation Trust	57	433	13.2%
RBT	Mid Cheshire Hospitals NHS Foundation Trust	22	343	6.4%
RQ8	Mid Essex Hospital Services NHS Trust	218	527	41.4%
RJD	Mid Staffordshire NHS Foundation Trust	80	336	23.8%
RXF	Mid Yorkshire Hospitals NHS Trust	276	492	56.1%
RD8	Milton Keynes Hospital NHS Foundation Trust	149	301	49.5%
RM1	Norfolk and Norwich University Hospital NHS Trust	330	576	57.3%
RVJ	North Bristol NHS Trust	64	477	13.4%
RNL	North Cumbria Acute Hospitals NHS Trust	84	216	38.9%
RAP	North Middlesex University Hospital NHS Trust	6	295	2.0%
RVW	North Tees and Hartlepool NHS Trust	236	469	50.3%
RV8	North West London Hospitals NHS Trust	110	229	48.0%
RNS	Northampton General Hospital NHS Trust	105	315	33.3%
RBZ	Northern Devon Healthcare NHS Trust	44	159	27.7%
RJL	Northern Lincolnshire and Goole Hospitals NHS Foundation Trust	130	405	32.1%
RTF	Northumbria Healthcare NHS Foundation Trust	232	703	33.0%
RX1	Nottingham University Hospitals NHS Trust	108	231	46.8%
RTH	Oxford Radcliffe Hospitals NHS Trust	63	634	9.9%
RW6	Pennine Acute Hospitals NHS Trust	75	696	10.8%

Code	Trust	Actual cases	Expected cases	Case ascertainment
RGN	Peterborough and Stamford Hospitals NHS Foundation Trust	127	420	30.2%
RK9	Plymouth Hospitals NHS Trust	71	542	13.1%
RD3	Poole General Hospital NHS Foundation Trust	67	276	24.3%
RHU	Portsmouth Hospitals NHS Trust	115	240	47.9%
RPC	Queen Victoria Hospital NHS Foundation Trust	26	64	40.6%
RHW	Royal Berkshire Foundation Trust	72	268	26.9%
REF	Royal Cornwall Hospitals NHS Trust	30	443	6.8%
RH8	Royal Devon and Exeter NHS Foundation Trust	178	571	31.2%
RAL	Royal Free Hampstead NHS Trust	77	288	26.7%
RA2	Royal Surrey County Hospital NHS Trust	7	261	2.7%
RD1	Royal United Hospital Bath NHS Trust	55	261	21.1%
RNZ	Salisbury Hospital NHS Foundation Trust	18	240	7.5%
RXK	Sandwell and West Birmingham Hospitals NHS Trust	168	264	63.6%
RHQ	Sheffield Teaching Hospitals NHS Trust	206	551	37.4%
RK5	Sherwood Forest Hospitals NHS Trust	96	428	22.4%
RXW	Shrewsbury and Telford Hospital NHS Trust	179	566	31.6%
RA9	South Devon Healthcare NHS Foundation Trust	112	418	26.8%
RTR	South Tees Hospitals NHS Trust	281	609	46.1%
RE9	South Tyneside NHS Foundation Trust	79	180	43.9%
RJC	South Warwickshire General Hospitals NHS Trust	18	139	12.9%
RHM	Southampton University Hospitals NHS Trust	25	73	34.2%
RAJ	Southend University Hospital NHS Foundation Trust	126	355	35.5%
RVY	Southport and Ormskirk Hospital NHS Trust	91	256	35.5%
RJ7	St George's Healthcare NHS Trust	104	116	89.7%
RBN	St Helens and Knowsley Teaching Hospitals NHS Trust	105	398	26.4%
RWJ	Stockport NHS Foundation Trust	110	240	45.8%
RMP	Tameside Hospital NHS Foundation Trust	81	416	19.5%
RBA	Taunton and Somerset NHS Foundation Trust	150	288	52.1%
RNA	The Dudley Group of Hospitals NHS Foundation Trust	51	318	16.0%
RAS	The Hillingdon Hospital NHS Trust	114	144	79.2%
RJ2	The Lewisham Hospital NHS Trust	24	142	16.9%
RTD	The Newcastle upon Tyne Hospitals NHS Foundation Trust	248	364	68.1%
RQW	The Princess Alexandra Hospital NHS Trust	3	261	1.1%
RCX	The Queen Elizabeth Hospital King's Lynn NHS Trust	36	288	12.5%
RFR	The Rotherham NHS Foundation Trust	90	390	23.1%
RMC	The Royal Bolton Hospital NHS Foundation Trust	231	387	59.7%
RDZ	The Royal Bournemouth and Christchurch NHS Foundation Trust	104	192	54.2%
RL4	The Royal Wolverhampton Hospitals NHS Trust	64	216	29.6%
RKE	The Whittington Hospital NHS Trust	108	267	40.4%
RWD	United Lincolnshire Hospitals NHS Trust	190	432	44.0%
RRV	University College London Hospitals NHS Foundation Trust	71	180	39.4%
RJE	University Hospital of North Staffordshire NHS Trust	65	417	15.6%
RA7	University Hospitals Bristol NHS Foundation Trust	68	180	37.8%
RKB	University Hospitals Coventry and Warwickshire NHS Trust	182	437	41.6%
RWE	University Hospitals of Leicester NHS Trust	173	443	39.1%

Code	Trust	Actual cases	Expected cases	Case ascertainment
RTX	University Hospitals of Morecambe Bay NHS Trust	79	450	17.6%
RM2	University Hospitals of South Manchester NHS Foundation Trust	120	245	49.0%
RBK	Walsall Hospitals NHS Trust	26	302	8.6%
RWW	Warrington and Halton Hospitals NHS Foundation Trust	185	271	68.3%
RWG	West Hertfordshire Hospitals NHS Trust	51	276	18.5%
RFW	West Middlesex University Hospital NHS Trust	108	204	52.9%
RYR	Western Sussex Hospitals NHS Trust	154	540	28.5%
RA3	Weston Area Health NHS Trust	39	179	21.8%
RBL	Wirral University Teaching Hospital NHS Foundation Trust	183	204	89.7%
RWP	Worcestershire Acute Hospitals NHS Trust	150	480	31.3%
5PL	Worcestershire Primary Care Trust	9	37	24.3%
RRF	Wrightington, Wigan and Leigh NHS Foundation Trust	65	231	28.1%
RA4	Yeovil District Hospital NHS Foundation Trust	82	195	42.1%
RCB	York Teaching Hospital NHS Foundation Trust	158	562	28.1%

Appendix 6

Patient questionnaire at follow-up

Royal College of Obstetricians and Gynaecologists

Bringing to life the best in women's health care

123456

The National HMB Audit in the NHS

Please fill in the questionnaire and send it back to us using the enclosed pre-paid envelope. In this questionnaire we refer to the symptoms you had a year ago as your "heavy menstrual bleeding symptoms". Some women will have the same symptoms that they had a year ago, whilst others may not have any symptoms now. Some women might even have different symptoms now compared with a year ago.

Whatever your situation, the information you provide on the questionnaires is valuable and we would very much like you to complete the questionnaire, even if your symptoms have gone away.

Thank you very much for your help.

Q.1 Please record the date on which you are completing this questionnaire (day, month and year)

☐☐/☐☐/☐☐☐☐

Q.2 Please confirm your date of birth (day, month and year)

☐☐/☐☐/☐☐☐☐

First we would like you to think about your diagnosis and any treatment you have had in the last year.

Please indicate your answers by ticking (✓) the box.

Q.3 In the last year what treatment(s) if any, did you have for heavy menstrual bleeding? Please tick all that apply.

- ☐ No treatment
- ☐ Oral medication (including the pill)
  - ☐ From hospital
  - ☐ From GP or Family Planning Clinic
- ☐ Intrauterine system (for example Mirena)
  - ☐ From hospital
  - ☐ From GP or Family Planning Clinic
- ☐ Endometrial ablation (treatment to remove the lining of uterus or womb)
- ☐ Hysterectomy
- ☐ Myomectomy (for fibroids)
- ☐ Uterine artery embolisation
- ☐ Other treatment
- ☐ I don't know what treatment I had

Q.4 What did the hospital doctor(s) say was causing your heavy menstrual bleeding? Please tick all that apply.

- ☐ Hormonal imbalance
- ☐ Polyps of the lining of the womb
- ☐ No obvious cause
- ☐ Other cause
- ☐ Endometriosis
- ☐ Uterine fibroids
- ☐ Don't know

Q.5 In the last year how many times have you seen your GP about heavy menstrual bleeding?

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

Q.6 In the last year, have you been pregnant?

- ☐ Yes
- ☐ No
- ☐ Not sure
- ☐ I do not want to answer this question

The next few questions are about your heavy menstrual bleeding symptoms and your health generally.

Q.7 Overall, how would you say your health is?

Excellent	Very good	Good	Fair	Poor
☐	☐	☐	☐	☐

Q.8 Overall, how are your heavy menstrual bleeding symptoms now compared with 1 year ago?

Much better	A little better	About the same	A little worse	Much worse
☐	☐	☐	☐	☐

Q.9 Do you have any new symptoms now that you didn't have 1 year ago? Please tick all that apply.

- ☐ I do not have any new symptoms
- ☐ Breast tenderness
- ☐ Mood changes
- ☐ Irregular bleeding
- ☐ Light periods
- ☐ Pelvic pain
- ☐ Bladder problems
- ☐ Wound problems
- ☐ Hot flushes
- ☐ Other

Q.10 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
☐	☐	☐	☐	☐	☐

☐ I haven't had a period in the last 3 months

Q.11 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
☐	☐	☐	☐	☐	☐	☐

Next we would like you to think overall about your experience at the hospital during the last year.

Q.12 How much information about your heavy menstrual bleeding or treatment was given to you at the hospital?

☐ Not enough ☐ The right amount ☐ Too much

☐ I did not receive any information from the hospital

Q.13 How satisfied or dissatisfied were you with the information you received from the hospital?

☐ Very satisfied ☐ Somewhat satisfied ☐ Somewhat dissatisfied ☐ Very Dissatisfied

☐ I did not receive any information from the hospital

Q.14 Were you involved as much as you wanted to be in decisions about your care and treatment?

☐ Yes definitely ☐ Yes, to some extent ☐ No

Q.15 If you had important questions to ask the hospital doctor(s), did you get answers that you could understand?

☐ Yes definitely ☐ Yes, to some extent ☐ No

Q.16 Did the hospital doctor(s) listen to what you had to say?

☐ Yes definitely ☐ Yes, to some extent ☐ No

Q.17 Did you feel that the hospital doctor(s) understood what you wanted?

☐ Yes definitely ☐ Yes, to some extent ☐ No

Q.18 Were you given enough privacy when discussing your condition or treatment?

☐ Yes definitely ☐ Yes, to some extent ☐ No

Q.19 Did you feel that you were treated with respect and dignity while you were in the hospital?

☐ Yes always ☐ Yes, sometimes ☐ No

Q.20 Overall, how would you rate the care you received from the hospital?

Excellent	Very good	Good	Fair	Poor
☐	☐	☐	☐	☐

Please answer the next set of questions even if your symptoms have gone away. If you do not have symptoms of heavy menstrual bleeding any more, please tick "not at all".

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
Q.21 Heavy bleeding during your menstrual period	☐	☐	☐	☐	☐
Q.22. Passing blood clots during your menstrual period	☐	☐	☐	☐	☐
Q.23 Fluctuation in the duration of your menstrual period compared to your previous cycles	☐	☐	☐	☐	☐
Q.24 Fluctuation in the length of your monthly cycle compared to your previous cycles	☐	☐	☐	☐	☐
Q.25 Feeling tightness or pressure in your pelvic area	☐	☐	☐	☐	☐
Q.26 Frequent urination during the daytime hours	☐	☐	☐	☐	☐
Q.27 Frequent nighttime urination	☐	☐	☐	☐	☐
Q.28 Feeling fatigued	☐	☐	☐	☐	☐

Please answer the next set of questions even if your symptoms have gone away. If you do not have symptoms of heavy menstrual bleeding any more, please tick "none of the time".

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
Q.29 Made you feel anxious about the unpredictable onset or duration of your periods?	☐	☐	☐	☐	☐
Q.30 Made you anxious about travelling?	☐	☐	☐	☐	☐
Q.31 Interfered with your physical activities?	☐	☐	☐	☐	☐
Q.32 Caused you to feel tired or worn out?	☐	☐	☐	☐	☐
Q.33 Made you decrease the amount of time you spent on exercise or other physical activities?	☐	☐	☐	☐	☐
Q.34 Made you feel as if you are not in control of your life?	☐	☐	☐	☐	☐
Q.35 Made you concerned about staining underclothes?	☐	☐	☐	☐	☐
Q.36 Made you feel less productive?	☐	☐	☐	☐	☐
Q.37 Caused you to feel drowsy or sleepy during the day?	☐	☐	☐	☐	☐
Q.38 Made you feel self-conscious of weight gain?	☐	☐	☐	☐	☐
Q.39 Made you feel that it was difficult to carry out your usual activities?	☐	☐	☐	☐	☐
Q.40 Interfered with your social activities?	☐	☐	☐	☐	☐
Q.41 Made you feel conscious about the size and appearance of your stomach?	☐	☐	☐	☐	☐

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
Q.42 Made you concerned about staining bed linen?	☐	☐	☐	☐	☐
Q.43 Made you feel sad, discouraged, or hopeless?	☐	☐	☐	☐	☐
Q.44 Made you feel down hearted and low?	☐	☐	☐	☐	☐
Q.45 Made you feel exhausted?	☐	☐	☐	☐	☐
Q.46 Caused you to be concerned or worried about your health?	☐	☐	☐	☐	☐
Q.47 Caused you to plan activities more carefully?	☐	☐	☐	☐	☐
Q.48 Made you feel inconvenienced about always carrying extra pads, tampons, and clothing to avoid accidents?	☐	☐	☐	☐	☐
Q.49 Caused you embarrassment?	☐	☐	☐	☐	☐
Q.50 Made you feel uncertain about your future?	☐	☐	☐	☐	☐
Q.51 Made you feel irritable?	☐	☐	☐	☐	☐
Q.52 Made you concerned about staining outer clothes?	☐	☐	☐	☐	☐
Q.53 Affected the size of clothing you wear during your periods?	☐	☐	☐	☐	☐
Q.54 Made you feel that you are not in control of your health?	☐	☐	☐	☐	☐
Q.55 Made you feel weak as if energy was drained from your body?	☐	☐	☐	☐	☐
Q.56 Diminished your sexual desire?	☐	☐	☐	☐	☐
Q.57 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.

Q.58 Mobility

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

Q.59 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 ☐

Q.60 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 ☐

Q.61 Pain/ Discomfort

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

Q.62 Anxiety/ Depression

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

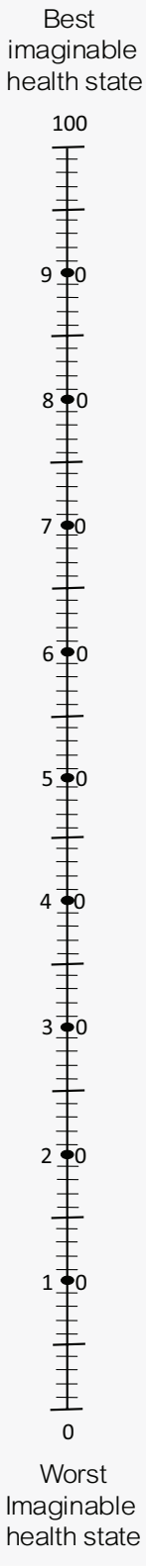
Q.63 To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

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



Thank you for completing this questionnaire.

Addendum to the report

National HMB Audit: report on patterns of care among women of non-white ethnicity with HMB

(As outlined in the response of the National HMB Audit project team to issues raised at the Contract Review meeting with the Healthcare Quality Improvement Partnership, 14 June 2012).

Background

It has been suggested that women of non-white ethnicity face additional barriers to care for HMB. A criticism of the National HMB Audit has been that it could not investigate this issue fully as it only provided questionnaires in English. It is important to note that 12% of the women who participated in the audit were of non-white ethnicity. In this report, women of non-white ethnicity are compared with those of white ethnicity to investigate whether women of non-white ethnicity received different patterns of care and had different QoL scores at their first outpatient visit for HMB than those of white ethnicity.

Methods

Results from the baseline questionnaires completed by women with HMB at their first visit to an NHS outpatient gynaecology clinic between 1 February 2011 and 31 January 2012 are analysed in this report. This questionnaire included questions on the severity of the women's 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.

Differences in primary care and HMB-related characteristics were compared among women of white, Asian, black and other ethnicities using chi-squared and Mann–Whitney U tests. Logistic regression was used to analyse whether differences seen in univariate analyses remained significant after adjusting for known confounders such as age. Two instruments were used to measure quality of life: the adapted UFS-QoL score (a condition-specific QoL instrument adapted from the UFS-QoL and consisting of 37 questions) and the EQ-5D generic QoL instrument (used to measure general health-related quality of life). Kruskal–Wallis tests were used to identify whether differences in QoL scores existed among women of different ethnicities.

Results

A total of 16 439 women completed the baseline questionnaire and 15 812 of these questionnaires met the inclusion criteria. The vast majority of these women ($n = 14\,709$, 93.0%) had completed the question on ethnicity and were therefore eligible for analyses.

Table Add.1 shows the patient characteristics of the 14 709 women included in the analyses, stratified by ethnicity.

The vast majority of women were of white ethnicity (87.8%); 4.4% of women were of Asian ethnicity, 5.6% of women were of black ethnicity and 2.2% of women were of other ethnicities. Women of white ethnicity were more likely to be older than those of non-white ethnicity. BMI scores were higher among women of white and black ethnicities compared with those of Asian ethnicity or other ethnicities. However, a large proportion of women did not complete the questions on weight and height and therefore did not have a BMI score recorded; this proportion was particularly high for women of black and Asian ethnicities.

Table Add.1 Personal characteristics stratified by ethnicity

	White, $n=12\,919$ (87.8%)	Asian, $n=652$ (4.4%)	Black, $n=817$ (5.6%)	Other, $n=321$ (2.2%)	*P* value
Age (years), n (%)					
18–34	1891 (14.6)	145 (22.2)	127 (15.5)	62 (19.3)	
35–39	1606 (12.4)	100 (15.3)	141 (17.3)	50 (15.6)	
40–44	3393 (26.3)	175 (26.8)	232 (28.4)	90 (28.0)	<0.001
45–49	4073 (31.5)	162 (24.9)	246 (30.1)	90 (28.0)	
≥50	1956 (15.1)	70 (10.7)	71 (8.7)	29 (9.0)	
BMI score					
<25	4162 (32.2)	190 (29.1)	184 (22.5)	127 (39.6)	
25–29.9	3319 (25.7)	155 (23.8)	185 (22.6)	84 (26.2)	<0.001
≥30	2977 (23.0)	133 (20.4)	197 (24.1)	48 (15.0)	
Missing	*2461 (19.1)*	*174 (26.7)*	*251 (30.7)*	*62 (19.3)*	
Age (years) at leaving full-time education, n (%)					
≤16	5390 (41.7)	95 (14.6)	83 (10.2)	48 (15.0)	
17–18	3640 (28.20	130 (19.9)	163 (20.0)	83 (25.9)	<0.001
≥19	3449 (26.7)	325 (49.9)	480 (58.8)	160 (49.8)	
Missing	*440 (3.4)*	*102 (15.6)*	*91 (11.1)*	*30 (9.4)*	
Previous operation on uterus, n (%)					
Yes	2685 (20.8)	94 (14.4)	174 (21.3)	72 (22.4)	
No	9259 (71.7)	490 (75.2)	565 (69.2)	223 (69.5)	<0.001
Don't know/missing	*975 (7.6)*	*68 (10.4)*	*78 (9.6)*	*26 (8.1)*	
Number of pregnancies, n (%)					
0	1571 (12.2)	89 (13.7)	126 (15.4)	56 (17.5)	
1	1574 (12.2)	55 (8.4)	130 (15.9)	47 (14.6)	
2	3553 (27.5)	140 (21.5)	145 (17.8)	78 (24.3)	<0.001
≥3	5739 (44.4)	311 (47.7)	262 (32.1)	113 (35.2)	
Missing	*482 (3.7)*	*57 (8.7)*	*154 (18.9)*	*27 (8.4)*	
Consideration of future pregnancy, n (%)					
Yes	1310 (10.1)	166 (25.5)	330 (40.4)	85 (26.5)	
No	10496 (81.2)	377 (57.8)	321 (39.3)	168 (52.3)	<0.001
Unsure	831 (6.4)	79 (12.1)	121 (14.8)	53 (16.5)	
Missing	*282 (2.2)*	*30 (4.6)*	*45 (5.5)*	*15 (4.7)*	

Women of non-white ethnicity were more likely to leave full-time education after the age of 18 years, while women of white and Asian ethnicities were more likely to have three or more pregnancies. Ethnicity was strongly associated with consideration of future pregnancy: 40% of those of black ethnicity, 25% of those of Asian ethnicity and 10% of those of white ethnicity answered 'yes' in response to whether they would consider a future pregnancy. This association remained significant after adjusting for age ($P<0.001$).

Women of Asian ethnicity were least likely and women of black ethnicity were most likely to report that they had symptoms for longer than one year (Table Add.2). Women of non-white ethnicity were most likely to report that they had at least four GP visits prior to their first visit to an NHS outpatient gynaecology clinic. Ethnicity remained significantly associated with both duration of symptoms and number of GP visits after adjusting for age ($P<0.001$).

Table Add.2 Primary care and treatment stratified by ethnicity

	White, *n*=12 919 (87.8%)	Asian, *n*=652 (4.4%)	Black, *n*=817 (5.6%)	Other, *n*=321 (2.2%)	*P* value
Duration of symptoms, n (%)					
≤2 months	282 (2.2)	38 (5.8)	14 (1.7)	12 (3.7)	<0.001
>2 months, <1 year	2963 (22.9)	169 (25.9)	146 (17.9)	77 (24.0)	
>1 year	9343 (72.3)	401 (61.5)	620 (75.9)	222 (69.2)	
Don't know/missing	*331 (2.6)*	*44 (6.8)*	*37 (4.5)*	*10 (3.1)*	
GP visits in the last year, n (%)					
None	745 (5.8)	62 (9.5)	71 (8.7)	34 (10.6)	<0.001
1–2	6100 (47.2)	213 (32.7)	306 (37.5)	135 (42.1)	
3–4	3741 (29.0)	171 (26.2)	232 (28.4)	96 (29.9)	
>4	1913 (14.8)	176 (27.0)	170 (20.8)	50 (15.6)	
Don't know/missing	*420 (3.3)*	*30 (4.6)*	*38 (4.7)*	*6 (1.9)*	
Prior treatment, n (%)[a]					
None	3879 (30.0)	204 (31.3)	237 (29.0)	101 (31.5)	0.60
The pill	3557 (27.5)	160 (24.5)	164 (20.1)	88 (27.4)	<0.001
Other medication	5043 (39.0)	190 (29.1)	291 (35.6)	96 (29.9)	<0.001
IUS	2448 (19.0)	79 (12.1)	118 (14.4)	58 (18.1)	<0.001
EA	596 (4.6)	20 (3.1)	21 (2.6)	6 (1.9)	0.002
Other treatment	1286 (10.0)	76 (11.7)	127 (15.5)	38 (11.8)	<0.001

[a] Percentages exclude 418 women who left this question incomplete (2.3% white, 8.4% Asian, 5.9% black and 4.1% other; $P<0.001$)

Around one-third of women stated they had received no prior treatment before their first outpatient visit; this proportion did not vary significantly with ethnicity. However, among those who indicated they did receive prior treatment, women of black ethnicity were least likely to state they had received the pill and were most likely to indicate they had received other treatment. Women of white ethnicity were most likely to report they had received an IUS and/or EA. While the National HMB Audit's *Second Annual Report* had shown a strong association between age and type of treatment received, ethnicity remained significantly associated with type of previous treatment even after adjusting for age.

Table Add.3 shows HMB-related characteristics stratified by ethnicity. Women of Asian ethnicity were most likely to report no pain experienced, while over half of those of all other ethnicities reported severe or very severe pain. It is of note that prior treatment received remained significantly associated with ethnicity after adjusting for level of pain experienced. According to the questionnaire responses, only 25% of women of black ethnicity were diagnosed with HMB alone, compared with over half of women of white ethnicity and women of Asian ethnicity. Two-thirds of women of black ethnicity reported they had fibroids together with HMB (compared with just over one-third of women of white and Asian ethnicities). After taking into account HMB group and age, level of pain experienced remained significantly associated with ethnicity ($P=0.004$).

While the number of comorbidities was not associated with ethnicity in this audit, differences did exist with regard to specific comorbidities. Women of black ethnicity in particular were significantly less likely to indicate they had been diagnosed with depression but were more likely to report that they had been diagnosed with high blood pressure. Women of Asian ethnicity were least likely to report excellent/very good overall health, although they were the most likely to be satisfied if their symptoms remained the same over the next five years.

The median severity score was marginally higher among those of black ethnicity, indicating a worse quality of life (65.0 compared with 62.5 for all other ethnicities), although this

Table Add.3 HMB-related characteristics stratified by ethnicity

	White, *n*=12 919 (87.8%)	Asian, *n*=652 (4.4%)	Black, *n*=817 (5.6%)	Other, *n*=321 (2.2%)	*P* value
Pain experienced, n (%)					
None	625 (4.8)	64 (9.8)	58 (7.1)	19 (5.9)	
Very mild/mild	1789 (13.9)	123 (18.9)	121 (14.8)	58 (18.1)	
Moderate	3222 (24.9)	128 (19.6)	155 (19.0)	65 (20.3)	<0.001
Severe/very severe	6729 (52.1)	306 (46.9)	451 (55.2)	164 (51.1)	
Don't know/missing	*554 (4.3)*	*31 (4.8)*	*32 (3.9)*	*15 (4.7)*	
HMB group, n (%)					
HMB alone	6926 (53.6)	383 (58.7)	205 (25.1)	128 (39.9)	
Fibroids and/or polyps	4932 (38.2)	231 (35.4)	562 (68.8)	164 (51.1)	
Endometriosis with or without polyps	748 (5.8)	19 (2.9)	25 (3.1)	14 (4.4)	<0.001
Fibroids and endometriosis with or without polyps	313 (2.4)	19 (2.9)	25 (3.1)	15 (4.7)	
Number of comorbidities, n (%)					
0	8527 (66.0)	430 (66.0)	559 (68.4)	213 (66.4)	
1	3321 (25.7)	163 (25.0)	173 (21.2)	84 (26.2)	0.07
≥2	1071 (8.3)	59 (9.0)	85 (10.4)	24 (7.5)	
Specific comorbidities					
Depression	2133 (16.5)	74 (11.4)	55 (6.7)	39 (12.1)	<0.001
High blood pressure	1245 (9.6)	61 (9.4)	164 (20.1)	40 (12.5)	<0.001
Thyroid disorder	916 (7.1)	47 (7.2)	36 (4.4)	13 (4.1)	0.01
Overall health, n (%)					
Excellent/very good	4961 (38.4)	124 (19.0)	252 (30.8)	87 (27.1)	
Good	5294 (41.0)	287 (44.0)	356 (43.6)	155 (48.3)	<0.001
Fair/poor	2490 (19.3)	233 (35.7)	197 (24.1)	71 (22.1)	
Missing	*174 (1.4)*	*8 (1.2)*	*12 (1.5)*	*8 (2.5)*	
Feeling if symptoms stayed the same for next 5 years, n (%)					
Delighted/pleased/mostly satisfied	128 (1.0)	18 (2.8)	13 (1.6)	6 (1.9)	
Equally satisfied/dissatisfied	684 (5.3)	48 (7.4)	58 (7.1)	25 (7.8)	
Mostly dissatisfied	1187 (9.2)	63 (9.7)	75 (9.2)	34 (10.6)	<0.001
Unhappy	3660 (28.3)	198 (30.4)	226 (27.7)	86 (26.8)	
Terrible	6930 (53.6)	273 (41.9)	404 (49.5)	158 (49.2)	
Missing	*330 (2.6)*	*52 (8.0)*	*41 (5.0)*	*12 (3.7)*	

difference was not statistically significant ($P=0.79$). The median HRQoL scores for those of white, Asian, black and other ethnicities were 32.8, 31.0, 30.2 and 31.0, respectively. Lower HRQoL scores typically indicate a worse quality of life, although again, differences between these scores were not statistically significant ($P=0.28$). Finally, the non-disease-specific EQ-5D score was 0.26 for all ethnicities ($P=0.52$).

Summary

Using results of the first phase of the patient-reported outcomes of the National HMB Audit, the project team has been able to describe important differences in ethnicity among women with HMB. While age is highly associated with ethnicity, with women of white ethnicity more likely to be older than those of non-white ethnicity, adjusting for age in subsequent analyses does not remove the effect of ethnicity on several other factors.

With regard to personal characteristics, women of white ethnicity who responded to the questionnaire were less likely to have stayed as long in full-time education than those of non-white ethnicity. This finding has been well documented in other literature (Dustmann and Fabbri, 2005; Owen et al., 2000). Women of white ethnicity were also less likely to consider future pregnancy, although this may be explained by the higher proportion of women of white ethnicity stating they had two or more pregnancies in the past.

Women of Asian ethnicity were more likely to report having a shorter duration of symptoms, despite being more likely to have had a higher number of GP visits prior to their first outpatient visit. It is likely that these GP visits were for conditions other than HMB, since a significantly higher proportion of women of Asian ethnicity reported fair or poor overall health compared with women of other ethnicities. Despite concerns of inequalities in access to health care, an analysis of the Health Survey for England did show that patients of Asian ethnicity were more likely to visit their GP than those of white ethnicity, particularly for hypertension, cholesterol and diabetes (Nazroo et al., 2009).

The National HMB Audit's *Second Annual Report* acknowledged that the type of previous treatment received was strongly associated with the age of women completing the questionnaire. However, even after adjusting for age in these analyses, differences in the type of previous treatment received existed for women of different ethnic backgrounds. Women of black ethnicity were less likely to indicate they had received the pill and more likely to state they had received other treatment. One possible explanation for this is that women of black ethnicity appeared more likely to consider future pregnancy than other ethnicities, possibly resulting in other treatment being prescribed more frequently than the pill.

Over half of the women included in the analyses reported being in severe or very severe pain – this proportion was slightly lower for those of Asian ethnicity, who were also more likely to state they were diagnosed with HMB alone; this may explain the lower levels of pain experienced. Women of black ethnicity were twice as likely to be diagnosed with fibroids than women of white ethnicity and were also more likely to report being in severe or very severe pain. While other differences discussed above are generally explained by non-HMB-related issues, the high proportion of women of black ethnicity with fibroids is an important HMB-related issue. Uterine fibroids are a common cause of HMB and the pain associated with this condition is well documented (Zimmermann et al., 2012). It is also well recognised that the prevalence of uterine fibroids is significantly higher among women of black ethnicity than it is among women of white ethnicity (Baird et al., 2003). Hence, it will be of interest to see whether the treatment prescribed for these women differs from that prescribed for women without fibroids, and more importantly, whether this results in a proportional improvement in their QoL score.

Depression appeared to be more prevalent among women of white ethnicity than among women of non-white ethnicities. Data on depression and ethnicity is conflicting: while some studies have found higher rates of depression among patients of white ethnicity (Riolo et al., 2005; Kessler et al., 1994), other studies have found the opposite to be true (Neighbors et al., 1983; Shaw et al., 1999). Furthermore, it is likely that, rather than depression itself, it is the diagnosis of depression that differs among ethnic groups. An Australian study has shown that patients of non-white ethnicity are less likely to be diagnosed with depression than those of white ethnicity (Comino et al., 2001) and similar findings have been reported in the UK (Gillam et al., 1989; Bhui et al., 2001).

Despite the differences among ethnic groups outlined above, the National HMB Audit project team found that the median QoL scores were low for all ethnicities. This suggests that, while differences among ethnicities do exist, these differences are likely to be attributable to personal characteristics rather than to disease-specific conditions. The QoL tools used in the questionnaire are well established and results from this study do suggest that a greater focus should be placed on these rather than on differences in, for example, access to care among different ethnicities.

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