

**Gynaecological cancer symptoms: influences on  
women's awareness and medical help-seeking**

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## **ABSTRACT**

This work stems from an increased effort to improve cancer survival rates through earlier diagnosis, which itself may be achieved through prompt medical help-seeking for symptoms. This thesis focuses on responses to symptoms potentially indicative of a gynaecological cancer; a group of cancers that pose a significant threat to women, and yet are under-represented in the literature.

Four studies were conducted. Studies One and Two (n=1392 and n=1000, respectively) were population-based surveys of women, measuring awareness of cervical and ovarian cancer risk factors and symptoms, respectively. Study two also measured hypothetical help-seeking. Study three was a survey of a nationally-representative sample of women (n=911), which explored responses to real symptoms that were potentially indicative of a gynaecological cancer. Building on study three, study four explored responses to symptoms at a deeper level, through in-depth, one-to-one interviews with women who had recently, or were currently, experiencing a symptom potentially indicative of a gynaecological cancer.

Awareness of symptom and risk factors for cervical and ovarian cancer was low overall. Women anticipated seeking help promptly for symptoms of ovarian cancer, however, when faced with real symptoms, outside of the context of cancer, help might not be sought as promptly. I found that women with symptoms respond in many different ways. Mapping my findings onto the Model of Pathways to Treatment, I identified a number of different influences which may be more important at the appraisal stage, including what can be expected as part of being a woman and those which may be more important at the help-seeking stage, such as feeling justified in seeking help.

More education is needed about the symptoms and risk factors for gynaecological cancers. Further, campaigns encouraging women to seek help for symptoms should include messages which target those variables that may lead women to wait longer before seeking help, such as misattribution of symptoms.

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## **CHAPTER ONE – GYNAECOLOGICAL CANCERS IN THE UNITED KINGDOM**

### **1.1 Overview**

Recent European and global publications have demonstrated that one-year survival rates for many cancers, including some gynaecological cancers (a group of cancers consisting of ovarian, cervical, uterine, vaginal and vulval cancers) are lower in the United Kingdom (UK) than they are in comparable countries (Coleman et al., 2011; De Angelis et al., 2014). One-year survival rates are a proxy for stage at diagnosis as lower one-year survival rates suggest that the disease has been growing for some time before being diagnosed, and higher one-year survival rates suggest that the disease was detected earlier in its progression. As such, early diagnosis of cancer is thought to play a key role in survival rates, and consequently in the reduction of mortality rates. A major part of the remit of global and national government policies on cancer (discussed below) is to improve survival rates through earlier diagnosis, and it is thought this may, in part, be achieved through education about the risk factors and symptoms of cancer and through encouraging prompt help-seeking in symptomatic individuals.

Throughout this thesis, I have aimed to answer the following questions:

1. How much do women in the United Kingdom currently know about gynaecological cancer symptoms and risk factors?
2. What variables predict time to hypothetical help-seeking for symptoms of ovarian cancer?
3. How do women respond both behaviourally and emotionally to symptoms which may indicate a gynaecological cancer?
4. What factors explain the different behavioural and emotional responses women may have to an experienced symptom of a gynaecological cancer?

## **1.2 Definition of early diagnosis**

This thesis is concerned with encouraging prompt help-seeking, which may increase earlier diagnosis and, in turn, improve UK survival rates for gynaecological cancers. Throughout this thesis, I have used the term, 'earlier diagnosis'. This term is polysemous, potentially meaning that a cancer is diagnosed soon after patient presentation, or that the cancer is diagnosed earlier in its clinical progression. In the medical literature this term usually means the latter, and it is this definition that I have used in my thesis. I have also referred to the term, 'help-seeking' within this thesis, which refers to seeking medical attention (usually from a GP) following detection of a symptom or a bodily change, which may be indicative of a gynaecological cancer, as opposed to non-symptomatic help-seeking (for example, attending screening for pre-cancerous cells or early cancers).

## **1.3 The importance of the early diagnosis of cancer**

The latest available UK statistics (covering the period from 2008 to 2010) reveal an average of over 320,000 registrations of newly diagnosed cases of cancer per annum in the UK, of which just under 160,000 were in women. Over the same period, there was an average of just under 75,000 cancer deaths in women (156,244 in total) (Office for National Statistics, 2012a).

A number of studies in the past few years have shown that survival rates in the UK are falling behind those observed in countries with similar spending and similar cancer plans for many cancers, including some gynaecological cancers (Coleman et al., 2011; De Angelis et al., 2014). It has been argued that, if Britain equalled the mean European survival rate for cancer during the period 1985 to 1999, up to 7000 deaths a year that occurred within five years of diagnosis could have been avoided; if we matched the highest European survival rates, this figure could have been 13,000 in the period from 1985 to 1994 and 11,500 in the period from 1995 to 1999 (Abdel-Rahman, Stockton,



Rachet, Hakulinen, & Coleman, 2009). Although the authors of the report that made this estimate did not differentiate between the proportion of avoidable deaths attributable to different stages of the diagnostic and treatment pathway (such as time to diagnosis or delays in treatment), it is likely that earlier diagnosis of a number of cancers could considerably increase survival rates in the UK.

Currently screening only exists at national levels for breast, cervical and bowel cancer (Public Health England, 2013), although feasibility trials are currently being carried out for stratified ovarian cancer screening, which are discussed in more detail below. The bowel screening programme aims to detect asymptomatic early stage cancers and bowel polyps, which may develop into cancers. The breast screening programme aims to detect a cancer that has already begun, albeit in the early stages, whereas the cervical screening programme aims to prevent abnormal cells from developing into cervical cancer, rather than detecting existing cancers. However, for the many other types of cancer for which there is no screening programme (including (currently) ovarian, vaginal, vulval and uterine cancers), early diagnosis achieved through prompt patient help-seeking and diagnosis is key. Again, this is discussed further below.

#### **1.4 Cancer policies and NAEDI**

Reducing cancer incidence and mortality and improving outcomes in cancer patients (for example through increasing patient quality of life) is a global issue, and guidance for, as well as publications on, international cancer policies are directed and coordinated by The World Health Organisation<sup>1</sup> (WHO) (within the United Nations system). These policies and guidance are informed by findings from global research on cancer via the WHO's specialised cancer agency, the International Agency for Research on Cancer<sup>2</sup>

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<sup>1</sup> <http://www.who.int/about/en/>

<sup>2</sup> <http://www.iarc.fr/en/about/index.php>

(IARC), who are responsible for promoting international collaboration in cancer research.

WHO recommends that each nation should have a cancer plan that sets goals to improve cancer outcomes through reducing incidence and mortality and increasing quality of life in cancer patients (World Health Organization, Geneva, 2002). These cancer plans may vary between nations, due to different needs, resources and health systems, although WHO advises that, for all cancer plans, the aim should be to lower cancer incidence and improve the lives of cancer patients, irrespective of resource constraints within any given nation (World Health Organization, 2014). To support nations (and in particular lower and middle income countries), between 2006 and 2008, WHO published a series of six modules offering advice on the implementation of cancer control programmes, including a guide for early detection, which states that the two strategies for such are early diagnosis and screening (World Health Organization, 2007).

In keeping with the above recommendations, all four of the constituent countries of the UK have their own cancer plans. The most recent cancer plan in England is the 'Improving Outcomes: A strategy for cancer' (Department of Health, 2011b) document. In Wales, the most recent plan is the document, 'Together for Health – Cancer Delivery Plan' (Welsh Government, 2012), in Northern Ireland it is 'A Cancer Control Programme for Northern Ireland' (Northern Ireland Cancer Network, 2008) and in Scotland it is, 'Better Cancer Care, An Action Plan' (NHS Scotland, 2008).

Each of these plans explicitly mentions the importance of earlier diagnosis of cancer, for example, in the document, 'Improving Outcomes: A strategy for cancer' (Department of Health, 2011b), it is stated that,

*"later diagnosis in England is a major explanation for poorer survival rates and, if patients were diagnosed at the same earlier stage as they are in other countries, up to 10,000 deaths could be avoided every year. We know that*

*95% of patients present with symptoms and that nearly a quarter of all cancers are diagnosed through an emergency route. The scale of the challenge is clear” (p. 42).*

Moreover, each of these plans sets out specific targets for increasing the number of earlier diagnoses, and in turn reducing mortality. For example, the latest ‘Improving Outcomes: A strategy for cancer’ progress report (NHS England, 2013) revealed promising improvements in early diagnosis, partly through the ‘Be Clear on Cancer’ programmes run both nationally and regionally (NHS Choices, 2013a).

Some of these cancer plans have led to, or have been informed by, initiatives and strategies to promote earlier diagnosis. For example, as part of the prioritisation of diagnosing more cancers earlier, the Cancer Reform Strategy in England (Department of Health, 2007), which precedes the current plan, announced the establishment of the National Awareness and Early Diagnosis Initiative (NAEDI) (Cancer Research UK, 2013g).

In 2008 NAEDI was formally launched as a partnership between the Department of Health (DoH), the National Cancer Action Team (NCAT) and Cancer Research UK (CRUK). The aim of the initiative is to support research that seeks to increase earlier diagnoses of cancer in England. Within NAEDI there are four work streams, namely: ‘Achieving early presentation by public and patients’, ‘Optimising clinical practice and systems’, ‘Improving GP (General Practitioner) access to diagnostics’, and ‘Research, evaluation and monitoring’. Work stream 1 (‘Achieving early presentation by public and patients’) is concerned with achieving prompt patient presentation with symptoms to primary care, which includes increasing awareness of the symptoms of cancer. The full NAEDI pathway can be seen in Figure 1.1, below.

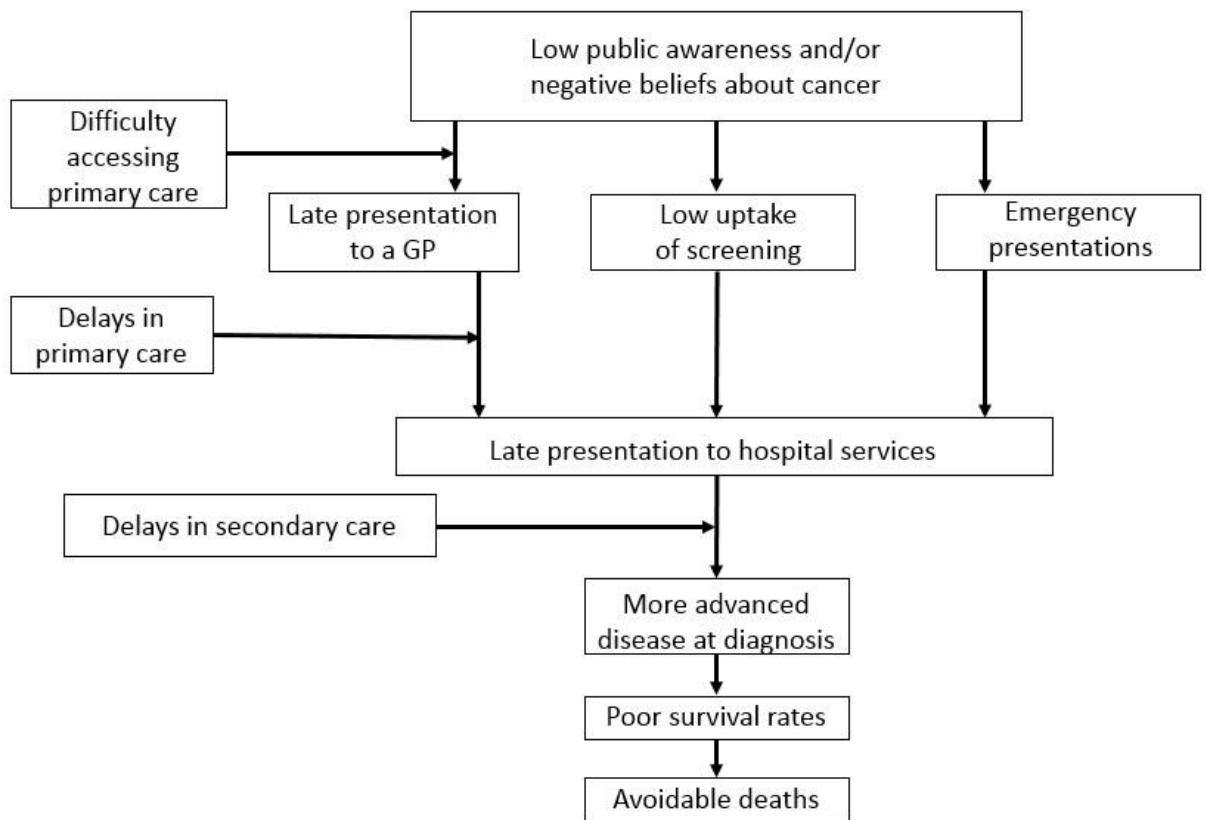


Figure 1.1. The NAEDI pathway (source: Richards, 2009)

As part of work stream 1, the Cancer Awareness Measure (CAM) (Stubbings et al., 2009) was developed. This tool measures cancer awareness (including warning signs and symptoms and risk factors) and can be used in research to help identify relationships between awareness and barriers to help-seeking and intention to seek help. Since the introduction of the CAM, several site-specific CAMs have been developed and implemented in research on awareness in various cancers (for example, Power, Simon, Juszczak, Hiom, & Wardle, 2011; Simon, Wardle, et al., 2012). Two of these site-specific measures were used to collect data in two of the studies presented in this thesis (studies one and two), and can be seen in Appendices 1 and 2.

### 1.5 The importance of a focus on early diagnosis of gynaecological cancers

The importance of early diagnosis of cancer has been demonstrated above. In my thesis I have attempted to identify factors that may influence the early diagnosis of this group of cancers, with a particular focus on patient help-seeking for symptoms that may

indicate a gynaecological cancer. Below I have discussed why increasing earlier diagnosis of gynaecological cancers is a worthy research topic.

## **1.6 Gynaecological cancer incidence in the United Kingdom**

Gynaecological cancers (uterine, vaginal, cervical, ovarian and vulval cancers) as a group are a considerable burden in the UK, accounting for around 12% of new female cancer diagnoses annually (Cancer Research UK, 2013e, 2013f; Office for National Statistics, 2012a). Put in context, gynaecological cancers are equal in incidence to lung cancer and are second only to breast cancer (which accounts for 31% of new female cancer diagnoses (Office for National Statistics, 2012a)). Gynaecological cancers are also responsible for 9% of female cancer deaths, making them the fourth most lethal malignancy in UK women after lung (21%), breast (16%) and colorectal cancers (10%) (Cancer Research UK, 2013e, 2013f; Office for National Statistics, 2012a).

### **1.6.1 Trends in incidence**

The most recent data available for vaginal cancer in UK women shows an incidence level of 0.6 per 100,000 women in 2011, a figure that has remained unchanged since 2004 (Cancer Research UK, 2014b). Incidence of vulval cancer has marginally (but steadily) increased over the last few years, from 2.3 to 2.6 per 100,000 women over the same period (Cancer Research UK, 2014c).

Latest available data on incidence in the UK (Office for National Statistics, 2007, 2012a) show an increase in incidence of cervical cancer from 8.5 per 100,000 in 2001-2003 9.3 in 2008-2010. However, these figures are presented as three yearly averages (to reduce the effects of random variation in small numbers over time), and the 2008-2009 period covers the period during the well-publicised cervical cancer diagnosis and subsequent death of a young reality television star, Jade Goody in 2009, which led to an increase in screening, follow-up and colposcopy attendances (known as 'the Jade Goody effect'),

and likely resulted in an increased number of diagnoses in that year (Lancucki, Sasieni, Patnick, Day, & Vessey, 2012).

Data from Cancer Research UK supports this explanation for the overall increase in incidence during 2008-2009. For example, in 2008 incidence was 8.8 per 100,000, in 2009 it was 10.3 and in 2010 it dropped again to 8.4 (Cancer Research UK, 2014a). However, there is evidence that in some UK populations, incidence has increased, independently of the rise attributable to 'the Jade Goody effect', and independent of a possible effect of the increase in the age at first cervical screening from 20 to 25 years in 2003 (National Health Service Cervical Screening Programme, 2003) (which could have potentially led to more incident cases of cervical cancer). For example, Patel et al. (2012) found evidence of an increase in incidence of cervical cancer in women aged 20-29 in the North-East of England (NE) after excluding cases from 2009 (the period during which 'the Jade Goody effect' was most evident). Moreover, data from Wales (where the age of first screen has not increased, and remains at 20 years), showed a significant and similar increase in incidence to the data from the NE, suggesting that the increase in incidence observed in the latter may not have been a result of the increase in age at first screen. This finding is further supported by analyses carried out by Sasieni, Castanon, and Cuzick (2009), which showed that screening women aged 20-24 has little to no impact on invasive cervical cancer rates in women under 30 years old. Patel et al. (2012) conclude that the rise in incidence in the NE may be the result of an increase in exposure to background risk factors, such as the Human Papillomavirus (HPV), leading to an increase in high grade cervical intraepithelial neoplasia. There is evidence then, that in some UK populations, incidence of cervical cancer may be increasing. However, in the UK as a whole, it seems that incidence is reducing.

Incidence of uterine cancer has increased in recent years, from 15.4 per 100,000 women in 2001-2003 to 19.1 in 2008-2010 (Office for National Statistics, 2007, 2012a). This increase may largely be down to an increase in obesity in British women. In 2007,

Reeves et al. explored cancer incidence in relation to body mass index (BMI) in a sample of over one million women, as part of the Million Women Study<sup>3</sup>. They found that the relative risk (RR) for endometrial cancer (the most common type of uterine cancer (American Cancer Society, 2013)) increased almost three fold for each 10 point increase in BMI after adjusting for other potentially influential factors such as age, geographical region, socioeconomic status (SES), age at first birth, parity, smoking status, alcohol intake, physical activity, and, where appropriate, time since menopause and use of Hormone Replacement Therapy (HRT). Given that the proportion of obese women in England rose from 16.4% in 1993 to 25.9% in 2011 and the proportion of overweight women rose from 48.6% to 58.4% in the same period (Health and Social Care Information Centre, 2013), this explanation of the increase in incidence of uterine cancer seems likely.

Conversely, ovarian cancer incidence has actually reduced steadily (although marginally), from 18 cases per 100,000 UK women in 2001-2003 to 16.6 cases in 2008-2010 (Office for National Statistics, 2007, 2012a). One possible reason for this decrease in incidence is an increase in contraceptive pill use. Behaviours that interrupt the ovulation process, such as oral contraceptive use, have been shown to have a long lasting protective effect for ovarian cancer. For example, in their 2008 study, the Collaborative Group on Epidemiological Studies of Ovarian Cancer obtained and reanalysed original data exploring oral contraceptive use and ovarian cancer risk from 45 epidemiological studies carried out in 21 countries. The reanalysis included data from 23,257 women diagnosed with ovarian cancer and 87,303 women without. The authors found that the overall relative risk of ovarian cancer decreased by a fifth (20%) for every five years of oral contraceptive use, and that the protective effects can last for decades. Furthermore, there is evidence that just under 20% of incident ovarian cancers in the UK are attributable to reproductive factors (Parkin, Boyd, & Walker, 2011).

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<sup>3</sup> [www.millionwomenstudy.org](http://www.millionwomenstudy.org)

It should be noted, however, that the drop in ovarian cancer incidence in recent years amounts to only one case in every 100,000 women and it remains that almost 7,000 women a year are diagnosed with this malignancy. Given the overall burden of gynaecological cancers, and the increase in incidence for some of them, it is important to strengthen efforts to reduce incidence and increase survival rates. The most recent available incidence data for all of the gynaecological cancers can be seen in Table 1.1.

Table 1.1 Latest available statistics on incidence of gynaecological cancers in the UK

Cancer type	Incidence rate per 100,000	Dates covered
Uterine cancer	19.1*	2008-2010
Ovarian cancer	16.6*	2008-2010
Cervical cancer	8.4	2010
Vulval cancer	2.6	2011
Vaginal cancer	0.6	2011

\*Three yearly average, per annum

## 1.7 Gynaecological cancer survival rates and stage at diagnosis

### 1.7.1 One-year survival rates in the UK and comparison with other countries

The most recent available data for the UK (2004–2007) show that the net one-year survival rate for ovarian cancer is 68.6% (Maringe et al., 2012). For cervical cancer it is 87%, for uterine cancer it is 91%, for vulval cancer it is 85% and for vaginal cancer, it is 70% (Elleray, 2013b). These rates can be seen in Table 1.2.



Table 1.2 Latest available statistics on one-year survival rates for gynaecological cancers in the UK

Cancer type	Survival rate	Dates covered
Uterine cancer	90.7%	2005-2009*
Cervical cancer	87%	2005-2009*
Vulval cancer	85%	2005-2009*
Vaginal cancer	70%	2005-2009*
Ovarian cancer	68.6%	2004-2007

\* Followed up to 2010

Logically, any survival rate below 100% would suggest that more could be achieved. However, it is unlikely that any cancer will reach 100% survival at one year in the near future. A better way of determining whether or not there is a realistic probability of improving survival rates for any given cancer in the UK is to compare survival rates to other countries with similar cancer plans. If the UK falls short, this indicates that there may indeed be room for improvement. In 2009, Sant et al. published the results of such a comparison. They reported survival rates across European countries and compared these with the European average one-year survival rates for each cancer in patients diagnosed in 1995 to 1999. The authors found that one-year survival rates across UK countries for ovarian cancer were considerably lower than the European rate (60%-61% versus 67% respectively). This finding was also reflected in more recent data from the International Cancer Benchmarking Partnership, which also reported lower one-year survival rates for ovarian cancer in the UK compared to other countries with similar cancer plans (Coleman et al., 2011).

The cervical cancer one-year survival rate was also lower than the European average (78%-81% versus 84%). For vaginal and vulval cancers (77%-83% versus 79%) and uterine cancers (86%-92% versus 90%), there were no real differences (Sant et al.

2009). However, more recent data have shown that one-year uterine cancer survival rates in England (60%) are significantly lower than the European average (67%). This data also confirmed that one-year survival rates for both cervical (81%) and ovarian cancer (60%) were significantly lower than the European average (84% and 67% respectively) (Thomson & Forman, 2009). Although there appears to be no real difference in survival rates between UK countries and Europe for vaginal and vulval cancers, reported survival rates are still noticeably lower than the highest rates observed in Europe at that time (95% in Iceland) (Sant et al. 2009). These data suggest that better survival rates could be achieved for gynaecological cancers in the UK. Earlier, I demonstrated the importance of earlier diagnosis of cancers in terms of achieving improved survival rates, and below I have discussed how we might improve survival through earlier diagnoses of gynaecological cancers.

### **1.7.2 Survival by FIGO stage and stage distribution at diagnosis**

At diagnosis, gynaecological cancers are categorised by FIGO (International Federation of Gynecology and Obstetrics) stage. Staging enables clinicians to determine how advanced the cancer is and what treatment would be most appropriate. It is also used to provide an indication of the likelihood of survival overall and at one-year or five-years. Earlier stage diagnoses (stages I or II) are generally associated with better prognoses than later stage diagnoses (stages III and IV). Consequently, increasing the proportion of earlier stage diagnoses of cancer is frequently posited as a way of increasing survival rates. For example, ovarian cancers diagnosed at FIGO stage I have a survival rate of 92% compared to those diagnosed at stage IV, which have a survival rate of just 6% (Cancer Research UK, 2013c). It follows that countries with poorer survival rates may have a higher proportion of cancers diagnosed at later stages than comparable countries with better survival rates.

Data on stage distribution (the proportion of cancers diagnosed at each FIGO stage) could confirm the hypothesis that countries with poorer one-year survival rates have higher rates of later stage diagnoses than countries with better survival rates. However, in the UK there is an acknowledged lack of national cancer staging data for many different cancers (House of Commons Committee of Public Accounts, 2011; Welsh Government, 2012), with national staging information only available for around 40% of diagnosed cancers in 2010 (Department of Health, 2011a) (although at least in some areas this is improving (for example, London Cancer Alliance, 2012; NHS Wales, 2013)).

UK gynaecological cancer incidence by stage data could only be found for ovarian cancer (Maringe et al., 2012). For cervical cancer, I could only locate these data individually for Northern Ireland (Donnelly, 2013), Wales (White, 2013), and England (NHS Cancer Screening Programmes, 2012). For uterine cancer, stage distribution data is only available for parts of England covered by the Eastern Cancer Registration & Information Centre (Norfolk, Suffolk, Cambridgeshire, Essex, Bedfordshire and Hertfordshire) (The National Cancer Registration Service (NRCS) Eastern Office, 2013), Wales (White, 2013) and Northern Ireland (Donnelly, 2013). No stage distribution data exist for vulval and vaginal cancers, which is likely to be the result of the rarity of these cancers (Elleray, 2013a). All available data can be seen in Table 1.3 below.

Table 1.3 Proportion of diagnoses by stage in the UK (and by country)

		Ovarian cancer		Cervical cancer		Uterine cancer	
		% <sup>†</sup>	Year*	% <sup>†</sup>	Year*	% <sup>†</sup>	Year*
England <sup>‡</sup>	Stage I	33.6		73.4		71.7	
	Stage II	3.3	2009	14.5	2010-2011	9.1	2009
	Stage III	42.7		5.6		8.1	
	Stage IV	10.7		4.7		5.5	
Northern Ireland	Stage I	21.1		56.4		55.6	
	Stage II	6.6	2007-2010	10.1	2007-2010	9.8	2007-2010
	Stage III	35.3		18.4		9.5	
	Stage IV	16.9		7.1		4.2	
Wales	Stage I	-		51.9		63.6	
	Stage II	-		13.5	2011	8.3	2011
	Stage III	-	-	13.5		9.9	
	Stage IV	-		12.8		4.1	
Scotland	Stage I	-		-		-	
	Stage II	-		-		-	
	Stage III	-	-	-	-	-	-
	Stage IV	-		-		-	
United Kingdom	Stage I	30.5		-		-	
	Stage II	5.6	1995-2007	-	-	-	-
	Stage III	37.8		-		-	
	Stage IV	26.1		-		-	

Note: stage distribution data are not available for some cancers either in England or in the UK. Available data are shown.

\*Most recent data available, <sup>†</sup>Some missing data, where stage was not known or not recorded

<sup>‡</sup>Data shown for England for ovarian and uterine cancers relate to data from the parts of England covered by the Eastern Cancer Registration & Information Centre

In the UK, 64% of ovarian cancers are diagnosed at stages III or IV (Maringe et al., 2012), where five-year survival rates are 22% and 6% respectively (Cancer Research UK, 2013c). In England, over 10% of cervical cancer diagnoses in 2010/2011 were made at stages III and IV (NHS Cancer Screening Programmes, 2012). In Wales and Northern Ireland, this figure was 26% (Donnelly, 2013; White, 2013). At these later stages, five-year survival rates are between 30-50% for stage III and 20% for stage IV (Cancer Research UK, 2012b). However, it should be noted that there are some cases of cervical cancer that were not staged (around 8% in Wales and Northern Ireland (Donnelly, 2013; White, 2013) and 14% in England (NHS Cancer Screening Programmes, 2012)). This could be a result of the cancers being very early stage, which were not recorded, or it could be a result of very late stage cancers that were immediately treated in palliative care and were consequently not a priority for staging (as it would not have informed the patients' care at this stage). Alternatively, missing stage information may be due to procedure within regional registries; some regions complete their audit process before all of the staging data have become available for that period, whilst others may wait until all of these data are available, and consequently delay the audit process (NHS Cancer Screening Programmes, 2012).

In the areas covered by the Eastern Cancer Registration & Information Centre, Wales and Northern Ireland, 14% of uterine cancer cases were diagnosed at stages III and IV (Donnelly, 2013; The National Cancer Registration Service, Eastern Office, 2009; White, 2013), where five-year survival rates are around 45% for stage III and 25% for stage IV (Amant et al., 2005). However as with cervical, there were some unstaged cases (14% in Wales, 21% in Northern Ireland and 6% in Eastern England (Donnelly, 2013; The National Cancer Registration Service, Eastern Office, 2009; White, 2013)), which may possibly have increased the proportion of later stage diagnoses. Moreover, with wide differences in survival from early stage (stage I: around 85%) to late stage (stage IV: around 25%) (Amant et al., 2005), any improvements in the number of women diagnosed in the early stages of uterine cancer could be beneficial.

The higher rate of earlier stage diagnoses for uterine cancer compared to the other gynaecological cancers may be a result of the appearance of easily recognisable symptoms (i.e. post-menopausal bleeding) early in disease progression (Amant et al., 2005)). For example, Barak et al. (2013) found that of 220 women diagnosed with endometrial cancer in their study, 81% had reported bleeding symptoms, of whom 86% were diagnosed at stage I and 14% were diagnosed at stage II or IV. As mentioned above, there is a possibility that these unstaged cases may increase the proportion of later stage diagnoses if they were to be staged. It should also be noted that data on survival rates come from areas that are relatively affluent when compared to the rest of the UK, and survival rates are known to be adversely affected by deprivation (Rachet et al., 2010). Consequently the rates reported here may actually be higher than those in the UK overall. Irrespective, given the differences in survival rates between early and late stage uterine cancer, any increase in earlier stage diagnoses is likely to improve outcomes.

As discussed, staging data are not available in the UK for many diagnosed cancers (House of Commons Committee of Public Accounts, 2011), including vaginal and vulval cancers. The lack of staging data for these cancers in particular may be due to their relative rarity compared to other cancers (in 2010 there were 281 cases of vaginal cancer in the UK (Cancer Research UK, 2013e) and 1,157 cases of vulval cancer (Cancer Research UK, 2013f)), which results in a lower demand for this information. For vaginal cancer in particular, lack of accurate staging data may also be affected by the complexity of the processes involved in diagnosing these cancers as 'true' vaginal cancers and not an extension of an undetected cervical cancer (Greenberg, 2013). Moreover, historically, UK cancer registries have not been mandated to collect data on stage for gynaecological cancers (other than for cervical cancer), although data capture is improving (Elleray, 2013a).

Where stage distribution data are not available, one-year survival rates can be used as a proxy for later stage diagnoses, as mentioned above (National Cancer Intelligence Network, 2010). Given that there are no data available for vaginal and vulval cancers, we are reliant on these one-year survival rates to provide an indication of whether these cancers are mostly being diagnosed at the later or earlier stages.

As I detailed earlier, the most recent data available show that the one-year UK survival rates for vaginal cancer and vulval cancer are 70% and 85%, respectively (Elleray, 2013b). This would appear to suggest that vaginal and vulval cancers are mostly diagnosed in the earlier stages. However, as this is only an indication, it is not possible to definitively say that the majority of these cancers are diagnosed at the earlier FIGO stages (I and II). For example, data from non-UK countries (including the USA, Canada, Germany, France, Sweden and Australia) suggest that the majority of vulval (55%) and vaginal (67%) cancers are diagnosed at FIGO stages II+, where one-year survival ranges from 39.5% to 87.8% (Beller et al., 2003b) and 44.4% to 82.1% (Beller et al., 2003a) respectively. These data may provide some indication of the stage distribution for these cancers in the UK. In this context, despite the lack of staging data for vaginal and vulval cancers, it may be wise to err on the side of caution and aim to look at ways of encouraging earlier stage diagnoses; particularly given that the difference in survival rate between earlier and later stage cancers is wide (85% for Stage 1 and 25% for Stage IV (Cancer Research UK, 2013d)), and any increase in earlier diagnoses could save lives.

The evidence discussed above shows that the UK has poorer one-year survival rates when contrasted with other, comparable European countries for uterine, cervical and ovarian cancers (Coleman et al., 2011; Sant et al., 2009; Thomson & Forman, 2009), and that this may be the result of an unfavourable stage distribution in the UK for these cancers. Rebalancing the stage distribution in the UK may lead to better outcomes for most of the gynaecological cancers.

For ovarian cancer, however, there has been a strong argument against this conclusion. Recent data show that despite poorer one-year survival rates, the proportion of early stage diagnoses in the UK is comparable to other countries, meaning that differences in survival rates between countries cannot be explained by an unfavourable stage distribution in the UK. In their 2012 study, Maringe et al. looked at cancer registration data collected by the International Cancer Benchmarking Partnership (ICBP<sup>4</sup>) from Australia, Canada, Denmark, Norway and the UK. Just over 20,000 women with a diagnosis of ovarian cancer were included in the study. Age standardised one-year net survival was lowest for UK women (69%) and higher in Denmark (73%), Canada (74%), Norway (74%) and Australia (75%). However, 31% of women in the UK were diagnosed at stage I (after imputation for missing data), compared to 22% in Norway and Canada, and 20% in Denmark. FIGO stage data were not presented for Australia, although SEER<sup>5</sup> summary staging data (Young, Roffers, Ries, Fritz, & Hurlbut, 2001) for all countries was presented. These data showed that 23% of diagnoses in Australia, 14% in Canada, 12% in Denmark and Norway and 22% in the UK were localised disease (limited to the organ of origin (National Cancer Institute, 2013)), which is generally equivalent to FIGO stage I (confined to the organ of origin, Odicino, Pecorelli, Zigliani, and Creasman, 2008). Although fewer women were diagnosed as having SEER defined localised disease than were diagnosed as having FIGO stage I ovarian cancer, the pattern remained broadly the same, with the UK having a higher proportion of earlier stage diagnoses. The disparity in the proportions of early diagnoses between stage I and localised disease is surprising, given the almost identical definitions for both stages. This disparity does not seem to be a result of missing data, as the same amount were missing for both SEER and FIGO staging for all countries (except Norway, where 9% of FIGO stage data were missing compared to 4% of SEER data). The differences in the

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<sup>4</sup> The ICBP is a global partnership of clinicians, academics and policymakers across the UK, Canada, Australia, Denmark, Norway and Sweden, founded to determine why and how cancer survival rates differ between countries or jurisdictions. See <http://www.cancerresearchuk.org/cancer-info/spotcancerearly/ICBP/>

<sup>5</sup> The Surveillance, Epidemiology, and End Results program of the National Cancer Institute in the United States, which groups cancer sites into localised, regional and distant stage, as opposed to the FIGO staging (stages I, II, III, IV) system for gynaecological cancers.



proportions of women diagnosed at stage I and those diagnosed as having localised disease are therefore likely to be due to differences in classification processes between the FIGO and SEER systems (for example, the FIGO system broadly has four stages, whereas the SEER system has three).

These findings suggest that the lower one-year survival observed in the UK for ovarian cancer when compared to the other countries in this study is not attributable to a lower proportion of women being diagnosed with early stage disease; rather, it may be a result of poorer management of the women diagnosed at more advanced stages. However, there were a substantial amount of missing data in this study, which was most evident in the UK registry data (32% of FIGO staging data were missing, compared to 25% in Canada, 23% in Denmark and 9% in Norway). The large amount of missing data in the UK is unsurprising, given the acknowledged deficiency in stage recording in the UK described above (Department of Health, 2011a).

The authors used multiple imputation by chained equations to deal with the missing data, which reduced the proportion of stage I diagnoses in the UK from 33% to 31%, although the proportion was still considerably higher than the proportion of earlier stage diagnoses in the other countries. Although it could be argued that such a large proportion of missing data in the UK may well have led to an overestimation of the proportion of earlier stage diagnoses in that country, even if we were to assume that all of the missing cases were later stage diagnoses, the UK still would have a favourable stage distribution compared to the remaining countries (for example, if all missing cases were stage IV, this would still mean that 26% of cases were stage I, which is still higher than the proportion found in the remaining countries).

Nevertheless earlier diagnosis could still improve outcomes for ovarian cancer. For example, the majority of high-grade serous ovarian cancers (HGSCs) (which are included in Type II epithelial ovarian cancers; responsible for the majority of all ovarian

cancer mortality (Brown & Palmer, 2009)) originate outside the ovaries (possibly in the fallopian tubes (Hunn and Rodriguez, 2012)), spreading to the ovaries as they progress (Gilbert et al., 2012). This results in these tumours becoming advanced-stage earlier in their development (Cho & Shih, 2009). For Type II ovarian cancers, prognosis is influenced by tumour volume, not stage (Kurman et al., 2008), and moving the focus of early diagnosis for ovarian cancer from earlier stage to detection of low volume disease in Type II cancers, or earlier diagnosis of HGSCs, could substantially improve outcomes (Gilbert et al., 2012).

## **1.8 Increasing earlier stage diagnoses**

In light of the evidence that it may be possible to increase the proportion of earlier stage diagnoses (or in the case of ovarian cancer, lower volume disease diagnoses in Type II cancer) for some gynaecological cancers in the UK, which would ultimately improve outcomes, it is necessary to determine how such an improvement might be undertaken.

### **1.8.1 Screening programmes**

In 1988, the NHS introduced the national cervical cancer screening programme, a call-recall programme designed to detect potentially cancerous or pre-cancerous abnormalities in the cervix, which led to a considerable drop in cervical cancer incidence (Peto, Gilham, Fletcher, & Matthews, 2004). In 2008, in a further bid to reduce incidence of cervical cancer, the NHS introduced the HPV vaccination programme, designed to protect women against infection with HPV types 16 and 18, which are known to jointly cause up to 71% of cervical cancer cases (Muñoz et al., 2004). The vaccine is offered to girls aged 12-13 in a bid to protect against HPV infection before they engage in sexual activity, whereby they might contract the virus, although it was also offered to girls aged up to 18 as a catch-up programme (NHS Cervical Screening Programme, 2013).

However, even with the existence of a highly effective screening programme, there were still an average of 951 deaths attributable to cervical cancer annually in the UK during 2008-2010 (Office for National Statistics, 2012a). One possible reason for this is the failure of the programme to reach full coverage; the most recent available statistics show that 27% of women aged 30-34 and 24% of women aged 35-39 (the highest incidence age groups (Cancer Research UK, 2013b)) are not up-to-date with screening (Health & Social Care Information Centre, 2012).

Further, attendance in these age groups has started to show a slight downward trend in recent years, from 72.8% in 2010 and 2011 to 72.7% for women aged 30-34, and from 76.9% in 2010 and 76.5% in 2011 to 76.1% in 2012 for women aged 35-39 (Health & Social Care Information Centre, 2012). Recent data show that the majority of unscreened women who were diagnosed with a cervical cancer in the age groups 20-34 and 35-49 were diagnosed at later stage of cervical cancer (FIGO stage IB+) (NHS Cancer Screening Programmes, 2012). In never-screened women aged 20-29, 80% of those diagnosed with cervical cancer were diagnosed at stage 1B+, including 32% diagnosed at stage II+ (Castanon, Leung, Landy, Lim, & Sasieni, 2013). Although the data show that the stage distribution is favourable for cervical cancer, with most cases diagnosed in the earlier stages, there is still opportunity for improvement in the number of earlier diagnoses in women who do not attend screening.

Moreover, although the HPV vaccination programme will likely reduce incidence further, including in unscreened women, the effects of this vaccine will not be seen until the first vaccinated cohort in England reaches the age group at which cervical cancer begins to peak in incidence (i.e. age 30-39 years (NHS Cancer Screening Programmes, 2011)). The HPV vaccination programme aimed to protect all girls born on or after 1990 (NHS Cervical Screening Programme, 2013). Consequently, a reduction in incidence will not be seen until around 2025, although we should start to see a drop in abnormal cytology earlier than this date.

Currently there are no national gynaecological cancer screening programmes except for cervical, although trials exploring the feasibility of introducing a screening programme for post-menopausal women and for women with a significant family history are underway. These are the UKCTOCS (UK Collaborative Trial of Ovarian Cancer Screening) (UCL and UCLH NHS Foundation Trust, 2008) and UK FOCSS (UK Familial Ovarian Cancer Screening Study (UCL and UCLH NHS Foundation Trust, 2011) respectively.

UKCTOCS is a large, randomised controlled trial with a primary outcome measure of ovarian cancer mortality at seven years from baseline in 202,638 post-menopausal women aged 50-74 years. The trial has three arms; a control group (n=101,359), a group where participants are offered annual screening with serum CA125 as the primary test and CA125 and transvaginal ultrasound scans (TVSs) as the secondary test (n=50,640) and a group where participants are given an annual TVS as the primary test and repeat TVS in 6-8 weeks as the secondary test (n=50,639). Initial findings are promising in terms of feasibility, but final results are awaited (Menon et al., 2009).

UK FOCSS is a slightly smaller trial, with a single arm, but two phases. The primary outcome is the sensitivity, specificity and positive predictive value for the detection of primary epithelial ovarian and fallopian tube cancer in women with a minimum lifetime risk of ovarian cancer of 10% (based on family history or predisposing mutations). Phase I of the trial comprised annual TVSs and CA125 measurements. Phase II of the trial comprised CA125 screening every four months and annual TVS. From the Phase I data, the authors concluded that more frequent screening (<one year between screens), strict adherence to screening schedules and fast responses to abnormal results may increase the proportion of earlier stage diagnoses (Rosenthal et al., 2013), although the results from Phase II are still awaited.

Both the UKCTOCS and UK FOCSS trials are important in determining whether it is feasible to carry out screening for ovarian cancer, both in older women and in women

who have a higher predisposition to the disease. However, at present, it is not possible to say whether screening for ovarian cancer will be a possibility.

### **1.8.2 Help-seeking**

In the absence of effective national screening strategies for most gynaecological cancers, early diagnosis is reliant upon timely patient help-seeking and appropriate action by healthcare professionals at patient presentation (i.e. appropriate investigations and/or referral to secondary care). In the literature, 'patient delay' is defined as the period from first detection of a symptom to the point at which medical attention is sought (de Nooijer, Lechner, & de Vries, 2001). In this thesis, the phrase 'time to help-seeking' has been used where possible, as opposed to the term 'patient delay', except where discussing literature that has used the latter term.

Although widely used in the literature, the term, 'patient delay' is problematic for a number of reasons. For example, it assumes a conscious decision not to seek help, inferring that blame for any delays in help-seeking should be placed on the patient, and ignores other factors which may have led to a longer time to help-seeking such as access to a healthcare provider (Coates et al., 1996). It has been suggested that the term, 'patient delay' should be abandoned altogether and replaced with the terms, 'appraisal interval' (the time taken to interpret bodily changes or symptoms) and 'help-seeking interval' (the time taken to act upon these interpretations and to seek help) (Weller et al., 2012). These terms are also used in the most recent model of help-seeking behaviour, the Model of Pathways to Treatment (Walter, Webster, Scott, & Emery, 2012), which is discussed in detail in Chapter Two.

Another criticism of the term, 'patient delay' is that the term is inconsistently used (Scott & Walter, 2010). Although it is generally understood that 'patient delay' refers to the time period between first noticing a symptom and seeking medical help for that symptom (for

example, Facione, Miaskowski, Dodd, and Paul, 2002), the length of time that constitutes 'delay' has not always been clear or well-defined. The majority of the literature has traditionally used Pack and Gallo's often-cited seminal research paper to determine the period of 'patient delay' (Pack & Gallo, 1938). This paper argues that it is reasonable for a patient to take up to three months to seek help for a symptom that may indicate cancer, but a longer period of time taken to seek help would be deemed 'undue', although these time periods appear to be arbitrary, do not appear to be based on any clinical evidence, and may not be appropriately applied across all patients, all symptoms and all illnesses (for example, Andersen, Vedsted, Olesen, Bro, & Søndergaard, 2009; Bish, Ramirez, Burgess, & Hunter, 2005; Burgess et al., 2006). However, some of the literature has defined 'patient delay' as having occurred after much shorter periods of time (Hunter, Grunfeld, & Ramirez, 2003).

Although an inconsistency with regards to what period of time should be referred to as 'delay' has been noted within this body of literature, perhaps it may be more appropriate to explore what influences a longer time to help-seeking. For example, not all cancer tumours behave in a similar manner; speed of tumour growth and symptom progression can vary (Ford & Mitchell, 1999), meaning that it may be appropriate to seek help sooner for some tumour types than for others. Exploring a longer time to help-seeking then, rather than exploring what influences having waited for longer than a specific time-point may be more appropriate.

Although there is currently a national screening programme for cervical cancer, it is still important to explore reasons for a longer time to help-seeking for this gynaecological cancer, given that not all eligible women are attending and there are still a considerable number of both incidences and deaths from this cancer, as discussed above. Encouraging timely patient help-seeking is particularly important when considering the proportions of women diagnosed with a gynaecological cancer through emergency presentation or by death certificate only (for example, 33% of ovarian and 8% of uterine cancers in 2006-2008, Elliss-Brookes et al., 2012). However, research suggests that

women do not always seek help in a timely manner, nor do they always receive a timely diagnosis (for example, Evans, Ziebland, and McPherson 2007).

We know that at least for some of the gynaecological cancers, there are detectable symptoms in the earlier stages. For example, in ovarian cancer, the evidence shows that abdominal and pelvic pain may be present in over half of women with earlier stage disease (Hamilton, Peters, Bankhead, & Sharp, 2009) and that urinary symptoms are more likely in earlier stage disease than in later stage disease (Webb et al., 2004). Given the existence of detectable, earlier stage symptoms, we need to understand why some women may wait longer before seeking help for symptoms which may be indicative of a gynaecological cancer.

### **1.9 Summary**

The above has established that there is room for improvement in survival rates for gynaecological cancers in the UK, and that this may be achieved through increasing the proportion of lower volume tumour diagnoses in ovarian cancer and increasing earlier stage diagnoses for the remaining gynaecological cancers. Increasing the proportion of earlier stage or lower volume tumours in these cancers may be realised through encouraging prompt help-seeking upon symptom presentation.

In the next two chapters I have explored the literature on variables associated with time to help-seeking for female cancers and the literature on models of health behaviour or help-seeking. This will increase understanding of the help-seeking process, and where the associated variables may be most influential. In Chapter Four, I have laid out the aims of the following chapters (Chapters Five, Six, Seven and Eight) which will report on new data and analyses.

## **CHAPTER TWO – MODELS OF HEALTH BEHAVIOUR AND HELP-SEEKING**

### **2.1 Introduction**

#### **2.1.1 Background**

In the previous chapter, I discussed the importance of early diagnosis of gynaecological cancers, and how this might be achieved through encouraging prompt help-seeking once symptoms appear. I concluded that by encouraging prompt help-seeking, it may be possible to increase the proportion of earlier stage diagnoses of these cancers, and, as such, improve survival rates. However, in order to encourage prompt help-seeking, it is important to understand the processes and stages that women may experience and move through respectively, on the pathway from detection of a symptom to action.

As mentioned in the previous chapter, a longer time to help-seeking (patient delay) is defined in the literature as the time period between becoming aware of a symptom and seeking medical attention for the symptom (de Nooijer et al., 2001). However, this pathway is complex, and many different variables can influence how an individual moves through it. The factors that influence help-seeking behaviour are discussed in-depth in the next chapter.

The idea that a symptom may be perceived and evaluated differently and acted upon (or not), depending upon different factors (such as the socio-demographic characteristics of the person experiencing that symptom) has previously been defined as 'illness behaviour' (Mechanic & Volkart, 1960). More recent research has expanded on this, and has demonstrated that medical help-seeking is not necessarily a linear or simple process (Corner & Brindle, 2011). Individuals may choose routes other than seeking out a medical practitioner, such as self-management or looking for advice on the internet. Models of health behaviours aid our understanding of the complex processes involved in deciding that one is ill, that one needs help, and how one might go about accessing that help.



## **2.2 Models of patient delay (help-seeking)**

Within the health psychology literature, several models have been widely used to provide frameworks within which we can understand or predict responses to a health threat or utilisation of health services. These models often describe a number of different factors that may interact to determine a health behaviour. However, despite the development of models developed specifically to understand 'patient delay', such models have not been used consistently within the literature (Scott & Walter, 2010; Walter et al., 2012). This makes it difficult to determine an overall picture of the variables or factors which are most influential in the decision process to either seek help or not, how one might seek help, as well as the time taken to decide and act on one's decision. Using models when researching time to help-seeking for symptoms of cancer allows comparative research to emerge and a better overall picture of which factors are most influential at what point in time in the process of deciding to seek help. The more prominent models used within the health psychology literature are discussed below, followed by a discussion of the models designed to aid understanding of 'patient delay'.

### **2.2.1 The Socio-Behavioural Model and the Health Belief Model**

Earlier, dominant models of health service utilisation include the Socio-Behavioural Model (SBM) (Andersen, 1968) and the Health Belief Model (HBM) (Maiman & Becker, 1974; Rosenstock, 1974). The SBM describes 'predisposing factors' (including demographic, social and cultural variables), 'enabling factors' (including knowledge and ability to seek care) and 'the need for care' (which may be influenced by the severity of the symptoms experienced) which influence the likelihood of health care utilisation. Later revisions of the model acknowledged the role of the healthcare system, social support and personal health practices and incorporated the outcomes of having sought health care (including consumer satisfaction, evaluated health status and perceived health status), which may then influence subsequent perceived need for health services and predisposing factors (Andersen, 1995).

Unlike the SBM, which focuses more specifically on illness behaviour and the utilisation of health care services at a societal level, the HBM focuses on the social psychology of the individual; the likelihood of health behaviours (such as utilising health services) or prevention behaviours (such as ceasing to smoke) are influenced by individual perceptions and beliefs. Earlier versions of the HBM consisted of four dimensions which accounted for an individual's readiness to act: 'perceived susceptibility', 'perceived severity', 'perceived benefits' and 'perceived costs (or barriers)'. A further dimension, 'cues to action' (which can be internal, such as symptom characteristics or external, such as advice from others and mass media campaigns) are said to convert readiness into action. Later, 'health motivation' (Rosenstock, Strecher, & Becker, 1988) and 'self-efficacy' (Rosenstock et al., 1988) were added to reflect differences in the degree of concern about health matters and confidence in the ability to carry out the health behaviour, respectively. Within the HBM, demographic, sociopsychological and knowledge factors all act to modify perceptions and consequently can indirectly influence behaviour.

Both the SBM and the HBM were influential models in health utilisation research during the 1960's, which was dominated at that time by sociology, rather than health psychology (Pescosolido & Kronenfeld, 1995). However, as stated above, the HBM was originally developed in the field of social psychology, whereas the roots of the SBM appear to lie in medical sociology. The differences in the focus of the models, then, can perhaps be explained by these roots. The SBM cannot adequately explain individual responses to a symptom, as it is assumed that the only options are to either utilise health services or not. Alternatives, such as self-management, which may be appropriate, are not considered. Further, the model does not consider the influences of symptom attribution, nor emotional responses to symptoms in the process of seeking help or not.

The HBM has been used more widely within health psychology, which, again, is likely to be a result of its stronger focus on the individual and its roots in psychology. However,

this model too has been criticised. For example, as with the SBM, the HBM cannot account for the influence of emotional factors on the likelihood of a health behaviour. Further, despite the wide use of the HBM, it is rare that all of the components of the model are explored (Jones, Smith, & Llewellyn, 2014), making it difficult to investigate the overall usefulness of the model, and to determine which variables may hold the most predictive value. Finally, there is evidence that the HBM may not be that useful in predicting future health behaviours. For example, a review conducted in 1992 demonstrated significantly larger effect sizes for some of the HBM components in retrospective studies than in prospective studies (Harrison, Mullen, & Green, 1992). Consequently, the HBM may not be as useful as other models in predicting future help-seeking for symptoms of a gynaecological cancer.

### **2.2.2 The Theory of Reasoned Action / Theory of Planned Behaviour**

The Theory of Reasoned Action (TRA) was developed by Ajzen and Fishbein (1980) to predict health actions, based on the premise that individuals will consider the consequences of their behaviour before carrying it out (or not). As with the HBM, the model was developed within the field of social psychology. The model assumes that behaviour is a function of intention which is influenced by attitudes towards a particular behaviour and subjective norms (i.e. how an individual perceives that the behaviour will be responded to by others important to that individual). Broadly, strong intentions to carry out a behaviour will result from a positive attitude towards the behaviour and a belief that others will respond positively to that individual carrying out that behaviour, although both attitudes and subjective norms will have weights assigned to them by the individual, meaning that either variable may influence intention more than the other.

Although there has been evidence for the predictive value of the TRA (Sheppard, Hartwick, & Warshaw, 1988), the model has been found to be lacking in the ability to explain situations where the behaviour in question may not completely be under an individual's volitional control. As such, the model was revised (and renamed the 'Theory

of Planned Behaviour' or TPB, Figure 2.1) to account for actual control over a behaviour (i.e. an individual's ability to carry out a behaviour based on availability of resources and opportunities) as well as 'perceived behavioural control' (Ajzen, 1985, 1991). Perceived behavioural control describes an individual's perception of how easy or difficult carrying out a particular behaviour would be. The TPB posits that behaviour is a function of both intention and perceived behavioural control.

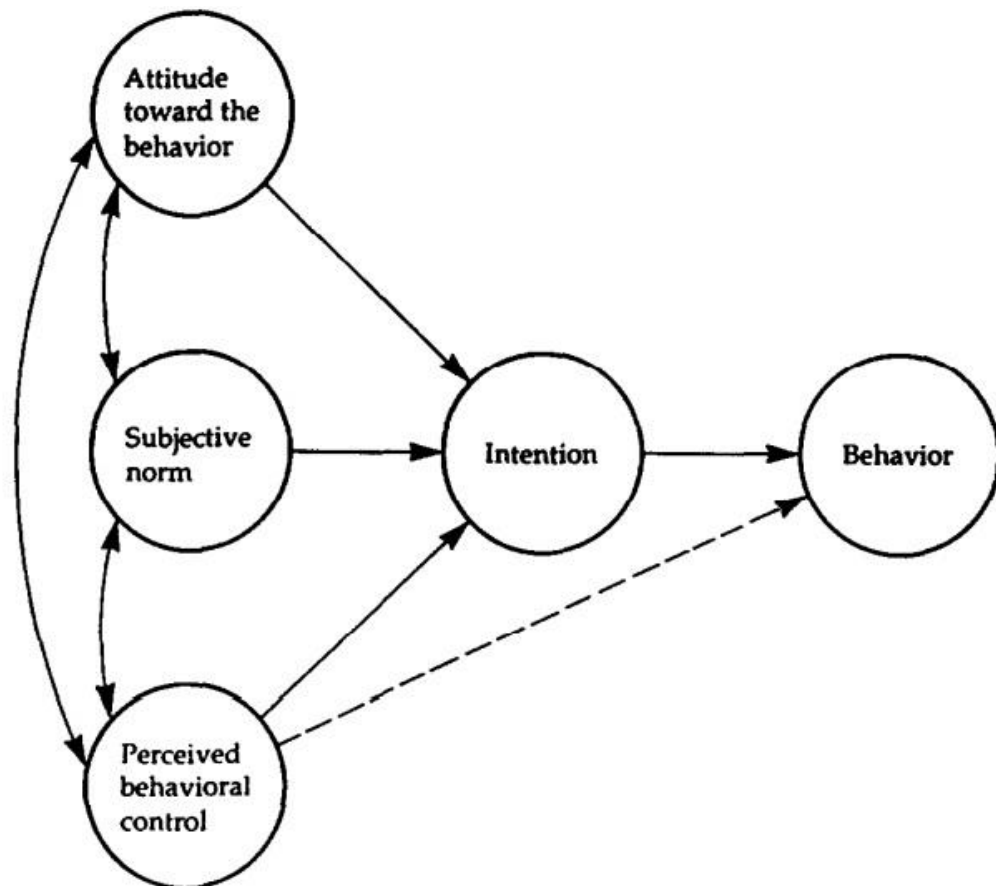


Figure 2.1 The Theory of Planned Behaviour, from (Ajzen, 1991)

However, although there is evidence for the useful application of the TPB in predicting health behaviours (for example Gerend & Shepherd (2012)), this model is only useful in explaining predictors of intention to perform a behaviour and predictors of performing the behaviour itself (Hunter et al., 2003), and there is evidence that intention cannot fully predict behaviour (Sheeran, 2002). It would be difficult, then to explain the whole pathway from initial detection of a bodily change to the response one will have to this new somatic information. Again, as with the models described above, the TPB does not

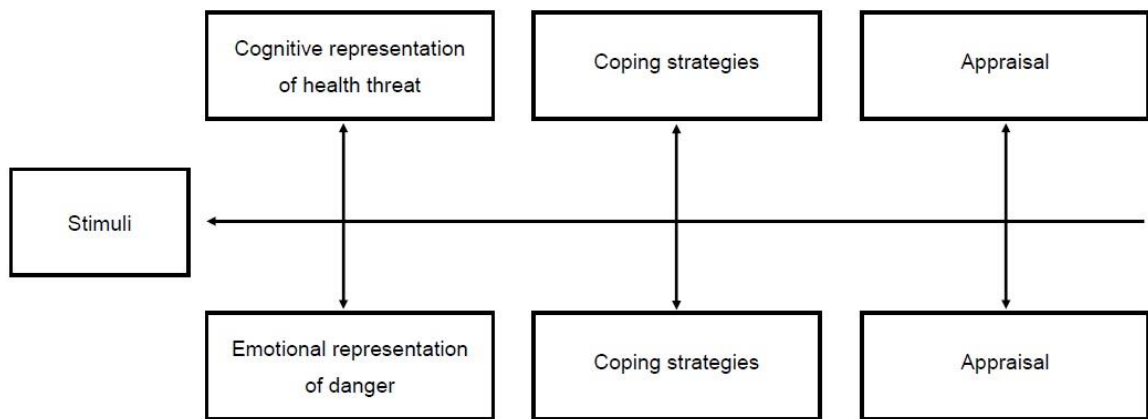
adequately describe the role of emotions, the inclusion of which may increase the predictive power of the model (Perugini & Bagozzi, 2001).

Finally, the TPB assumes that a health threat already exists, and fails to explain how one determines whether there is a health threat or not. Given that our bodies are constantly processing both internal and external sensations, bodily changes may be perceived regularly, and it is important to understand how these are interpreted, either as a health threat or not.

The SBM, HBM and TPB are less applicable to the work undertaken in this thesis for a number of reasons. The SBM's sociological roots make it difficult to explain individual behaviours. Further, it focuses on healthcare utilisation or not, rather than allowing for other, perhaps more appropriate, responses to a symptom. Evidence suggests that the HBM may not be useful in predicting future behaviours, which means that it is less relevant for research attempting to determine factors that may influence potential future help-seeking in women with symptoms. Finally, as described above, the main limitations of the TPB are the evidence for an intention-behaviour gap and its failure to explain how a health threat may come to be appraised as such.

### **2.2.3 The Common Sense Model of Self-regulation of Health and Illness**

The Common Sense Model of Self-regulation of Health and Illness (CSM) (Leventhal, Meyer, & Nerenz, 1980), shown below in Figure 2.2, is an extension of Leventhal's parallel process model (Leventhal, 1970). The three main constructs of this model are the representation of the illness experience, the coping response (or planning of action) and performance of this coping response, and finally an appraisal of the coping efforts.



**Figure 2.2. The Common sense Model of Self-regulation of Health and Illness (Leventhal et al., 1980)**

Unlike the TPB, the CSM aims to explain how an individual processes and responds to a threat to their health (or an illness threat). The model assumes that an individual will be an active problem solver, and describes the active parallel cognitive (the nature of the health threat and how one can respond to it) and emotional processes (how one feels about the health threat, and how one can cope with those emotions) involved in regulating a response to a health threat.

Within the cognitive pathway, there are five domains that all contain specific semantic and perceptual information; ‘identity’ (i.e. symptoms and names), ‘timeline’ (i.e. how long the health threat is expected to last), ‘consequences’ (i.e. what will happen as a result of this health threat) ‘internal and external causes’ (i.e. whether the health threat was caused by something external to the individual or whether it was caused by something internal), and ‘control’ (i.e. whether the health threat is something that the individual has control over, whether it was preventable and whether or not it is curable). In the context of the current research, an individual who believes that the symptom is indicative of cancer, that it will last for a long time, that it may cause pain, disability and eventually death and that the symptom is not something that the individual has control over, but is curable, may be more likely to seek medical attention as a coping strategy. The five domains described are shown below, in Figure 2.3.

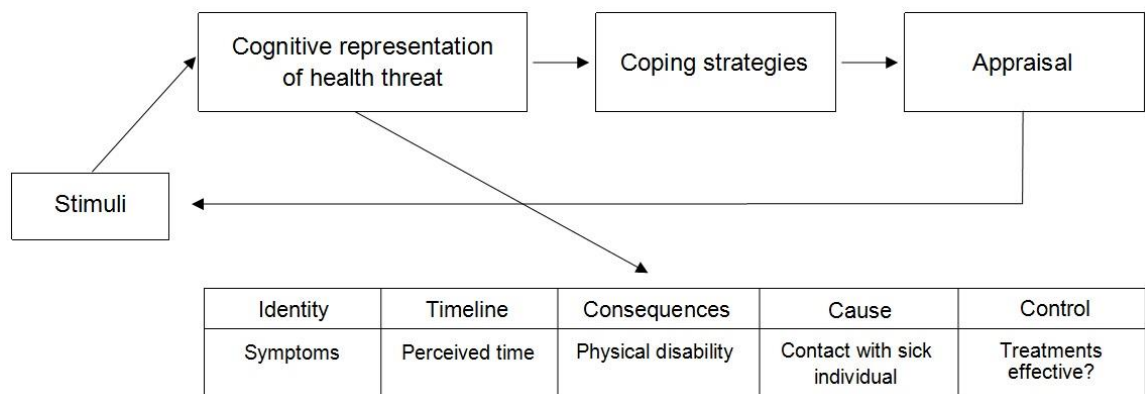


Figure 2.3 The Five Domains of illness representations (based on a figure from Leventhal, Brissette, and Leventhal, 2003)

Further, more recently, ‘rules of thumb’ or ‘common sense’ heuristics which influence the interpretation of a symptom, and the response to it (for example, whether a symptom warrants medical attention or not) have been described. These heuristics can reflect basic understandings of human anatomy, learnt information through universal somatic experiences, or can be based upon social comparisons (Leventhal, Forster, & Leventhal, 2007) (see Table 2.1). In turn, these rules of thumb lead to a cognitive representation of the health threat (or symptom).

The CSM can clearly be applied to help-seeking research, as it describes how an individual processes a cognitive representation of the health threat (for example, a symptom may be interpreted as being indicative of cancer or another illness) and allows for decisions around how one might respond to this, which may or may not include seeking medical attention. Further, unlike the TPB, the CSM explicitly describes the role of emotion through the inclusion of a regulation of emotional control (for example, a feeling of fear, or anxiety, which may be alleviated by seeking medical attention). The model also allows for the influence of social and cultural factors (Diefenbach & Leventhal, 1996; Leventhal et al., 2003), and there is evidence for the influence of these factors specifically in the literature investigating help-seeking for cancer symptoms (for example, Burgess et al., (2006)).

Table 2.1 Rules of thumb (heuristics) for understanding a somatic change

Heuristic	Description of heuristic
Symmetry	Symptoms require labels, and labels need symptoms
Pattern	How the symptom behaves influences interpretation
Location	The location of the somatic change influences interpretation
Rate of change	The speed at which the somatic change progresses (for example, a change that gets worse quickly may lead to an interpretation that something is wrong)
Response to care	If a symptom responds to self-medication, this may indicate that it is not serious
Novelty	If the symptom is unusual, this may lead to an interpretation that it is worthy of further investigation, potentially from a health care professional
Duration	If a symptom lasts a short period of time it may be interpreted as less serious than a symptom that lasts for a longer period of time
Stress-illness	A belief that the somatic change is caused by stress, and therefore nothing can be done medically
Age-illness	A belief that the somatic change is caused by age, and therefore it is just part of the normal bodily processes
Gender	An individual's gender may influence interpretation. For example, if there is a history of heart disease through the male family line, heart pain may be interpreted as serious by a male, but potentially not by a female
Similar exposure	If an individual experiences stomach pains following a meal, and others who ate the same meal experience the same pains, this somatic change may be interpreted as non-serious and due to the meal eaten
Similar vulnerabilities	An individual who smokes and experiences a cough may be more likely to interpret this as indicative of a serious illness if they know another person who smoked, had a cough and was diagnosed with cancer
Prevalence	Rarer symptoms may lead to an increased concern, and, in turn, an interpretation that they are serious

Note: Based on a Table from (Leventhal et al., 2007)



The influence of perceived risk is also explained within this model. For example, the stimulus for a perception of a health threat may come from a media campaign about risk factors for development of an illness, such as cancer. If an individual recognises that they are at a higher perceived risk (for example, because they have a history of breast cancer), this in itself may act as a health threat. Alternatively, an individual may be encouraged to perceive a breast change which had been previously dismissed as nothing serious as a health threat in response to this additional information.

Despite the clear usefulness of the CSM when applied to symptom appraisal and responses to symptoms (which may include medical help-seeking), this model does have some limitations. For example, some authors have argued that the complexity of the model make testing it fully a difficult task; Llewellyn, McGurk, and Weinman (2007) found it difficult to determine the dynamics of how and when outcome changes occurred over time and what factors were specifically related to those changes. Further, it has been argued that the interaction between the emotional representations of a health threat and cognitive factors require more investigation (Diefenbach & Leventhal, 1996), and that the role of emotion is often only considered in terms of anxiety, worry or fear in relation to the meaning of the health threat (Wyke, Adamson, Dixon, & Hunt, 2013). In the context of this thesis, other emotions may be important, such as embarrassment (for example, Marlow, McGregor, Nazroo, and Wardle (2013)) around seeking medical attention. This model is less well equipped to explain this, as it only describes the emotional response to the health threat and how coping with these emotions may involve help-seeking. However, the emotions associated with help-seeking itself are not considered.

Importantly, again in the context of this thesis, studies which have explored the predictive value of the CSM in help-seeking behaviour for female cancer symptoms have found that the model predicted less than a third (7-27%) of the variance (Grunfeld, Hunter, Ramirez, & Richards, 2003; Hunter et al., 2003). Further, the mechanisms by which social or cultural influences influence the development of health representations

and coping mechanisms are not clearly defined within the model. Given that individuals may be influenced by these factors when interpreting a bodily change (for example, (Taib, Yip, & Low, 2011)), it is important to consider them.

#### **2.2.4 The Illness Action Model and the Network Episode Model**

The Illness Action Model (IAM, Dingwall, 1976) and the Network Episode Model (NEM) (Pescosolido & Boyer, 1999) are both rooted in sociology. Bodily changes are experienced within the individual's social networks and a decision to seek help for a symptom is both a product of social influence, cultural beliefs and individual choice. In a similar fashion to the CSM, these models allow for a more dynamic and iterative progression through the processes of symptom detection and the decision to seek help, influenced by many smaller decisions. Both the IAM and the NEM focus on how individuals come to feel unwell and what the responses they have to this.

In Dingwall's model, a symptom or bodily change may cause the person experiencing it to perceive a disruption in the stable relationship they have with their body. This perception, and how these bodily changes are interpreted can be influenced by new external knowledge (for example, an increase in prevalence of a disease, which may then lead an individual to feel at increased risk). Upon experiencing a bodily change, an individual will seek to restore equilibrium.

The model allows for the influence of interpretive work by lay others (within the social context), health professionals and by the individual experiencing the symptom, which may lead to a belief that the symptom is normal or abnormal. If one decides the symptom is normal, no action will be taken. If the symptom is deemed to be abnormal, one may ignore the symptom, self-medicate, seek formal medical attention or informal care (for example from an individual deemed knowledgeable); decisions which are guided by knowledge about oneself, the world around an individual and possible

responses, which in turn may be influenced by personal experience and what is culturally available.

As mentioned above, the IAM is iterative and dynamic, for example, if the decision is made to wait and see, one will move back to interpretive work, which then may lead to a different course of action. This model then is perhaps a little more relevant than the CSM to the research in the current thesis, as, although the CSM describes coping behaviour and appraisal of this coping behaviour, the IAM is explicit about what this may involve, allowing for numerous responses to a bodily change, including seeking formal medical attention or not.

The IAM also explicitly describes the potential for immediate or delayed interpretation of a bodily change, which is clearly relevant in the context of this thesis. However, why interpretation may be immediate or delayed is not adequately explained. Understanding why delays in interpretation, and ultimately why longer times to help-seeking occur, is an integral part of the research undertaken in this thesis. Without a framework for understanding how this may occur, it is difficult to apply this model here.

As with the IAM, the NEM places help-seeking within the context of social networks and influence, and assumes that all health behaviours are social actions. It is constructed of four basic components including 'the illness career', 'social support system', 'treatment system' and 'social context'. According to this model, individuals will approach and respond to others upon symptom presentation. An individual may be encouraged to seek help or discouraged from the idea that their symptom is an inference of illness through their social networks and interactions. The NEM explains how (in a dynamic fashion) an individual may travel through the 'illness career', whilst constantly being influenced by aspects of their social networks, such as their strength of ties to, and the size of the network. This model puts help-seeking in a social context, rather than

attempting to explain the decision to seek help as one made solely by an individual, with no external influences.

As with the IAM, however, the NEM does have its limitations. For example, within the illness career, key entry and exit points are both described. Although these may be influenced by the social support and the treatment system, there is no real explanation of at what point these influences may occur. Further, both the CSM and the IAM are explicit about the purpose of a response to a health threat, such as a symptom, whereas the NEM is not. However, both the IAM and the NEM acknowledge and describe the role of social and cultural factors within the response and appraisal of a symptom or threat, whereas the CSM does not offer an explicit and detailed description of the influence of these factors.

The CSM describes the importance of regulation of the emotional response to a health threat, and appraisal of the efficacy of coping with this emotional response, neither the NEM nor the IAM explicitly mention the role of emotion at an individual level (Wyke et al., 2013). This may reduce the appropriateness of using these models to explain help-seeking within the context of this thesis, given that it is likely that the experience of a potential cancer symptom would involve an emotional response.

Finally, both the CSM and the IAM describe how a stimulus may come to be interpreted as a symptom. For example, within the CSM, there are a number of heuristics which influence the interpretation of somatic information, and within the IAM, an individual must decide whether or not a bodily change is normal (i.e. not a symptom) or abnormal (i.e. indicative of illness). However, the NEM assumes that this interpretive or appraisal work has already been undertaken.

### **2.2.5 The General Model of Total Patient Delay ('Andersen's model')**

A newer, prominent and widely used model explaining time to help-seeking for symptoms is The General Model of Total Patient Delay or 'Andersen's model'

(Andersen, Cacioppo, & Roberts, 1995). This model was a development and expansion of an earlier, three stage model proposed by Safer, Tharps, Jackson, and Leventhal, (1979). Unlike the earlier models described above, Andersen's model (Figure 2.4) consists of stages of delay (longer time to help-seeking) through which one progresses. These include, 'appraisal delay' (time between detecting a bodily change and deciding that it is indicative of illness), 'illness delay' (time between inferring illness to deciding that medical help is needed), 'behavioural delay' (time between deciding to seek medical help and making an appointment), 'scheduling delay' (time between making an appointment and medical consultation) and finally, 'treatment delay' (time between seeking help and beginning of treatment). These stages of decision making and action describe the complexity of the help-seeking process: it is not simply a matter of noticing a symptom and going to see one's GP.

Within the context of Andersen's model, the main stages of interest in the current projects are 'appraisal delay', 'illness delay', 'behavioural delay' and 'scheduling delay' as they determine the process from detecting a symptom to attending a GP appointment. Research has identified the most important stage of delay to be the appraisal stage for gynaecological tumours, contributing to around 79% of the total delay time (Andersen et al., 1995) and the most important factor influencing appraisal delay has been found to be the nature of the symptom experienced (Walter et al., 2012).

Given that with some gynaecological cancers the symptoms of early stage disease can be vague and easily attributed to other, benign illnesses, this is certainly applicable to the current research. For example, Kirwan (2002) found that around half of the women who experienced a delay of three months or more between seeking help and referral (n=36) who were later diagnosed with ovarian cancer were initially misdiagnosed with irritable bowel syndrome (IBS). This was likely to be due to the gastrointestinal nature of the early symptoms for this cancer (bloating and abdominal/pelvic pain may be present in between 50 to 55% of early stage ovarian cancer cases (Hamilton et al., 2009; Rossing, Wicklund, Cushing-Haugen, & Weiss, 2010)). Although this study investigated

referral time, the finding that even health professionals can misattribute symptoms of ovarian cancer to a benign condition suggests that this may be a common occurrence in lay women.

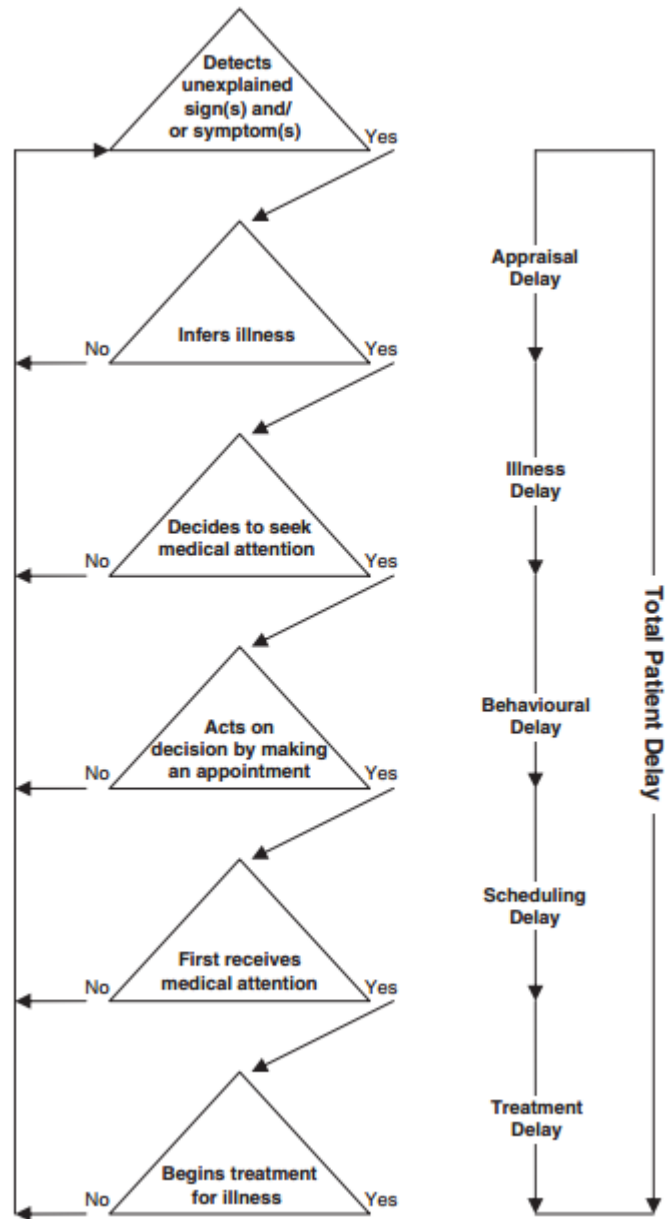


Figure 2.4 The General Model of Total Patient Delay (Andersen et al., 1995)

As a stage model, Andersen's model allows for different influences and different decisions at different points of the help-seeking journey, allowing interventions to focus on these stages, rather than exploring factors which influence time to help-seeking

overall. This more targeted approach may increase the success of such interventions, and there is evidence to support a staged pathway from detection of a bodily change to medical help-seeking (for example, Hedges et al. (1998)). However, the stages in this model are rigid; each patient is believed to only pass through each stage once, and in the same order, which may not reflect the true appraisal and help-seeking process (for example, Moloczij, McPherson, Smith, and Kayes (2008)). Although the CSM, IAM and NEM are not stage models, they do allow for iterative processes in appraisal and responses to a health threat or symptom.

A further limitation of Andersen's Model is that it does not adequately explain in detail the role of emotion, such as fear or anxiety, or alternatives, such as embarrassment, a criticism which also applies to the CSM, NEM and IAM (although the CSM does acknowledge the importance of emotion, it is not detailed and only relates to the emotional response to a symptom, not help-seeking). Further, Andersen's Model also fails to completely describe the influence of social factors, again a criticism also levelled at the CSM. Finally, in a similar fashion to the NEM, Andersen's model cannot explain how a bodily change may come to be interpreted as a symptom, unlike the IAM and CSM, which both describe this process.

### **2.2.6 The Model of Pathways to Treatment**

In 2010, Scott and Walter critically appraised Andersen's Model, highlighting areas for improvement. Some of the suggestions included a bi-directional relationship between detection of a bodily change and interpretation of this and an allowance for the option that those experiencing a symptom may decide to respond in a manner other than help-seeking (such as self-medication). The subsequent year, Walter et al. (2012) proposed a revision of the model, following a review of its application in cancer diagnosis, namely the Model of pathways to treatment (referred to as the MPT from this point onwards, see Figure 2.5). The changes included combining 'appraisal delay' and 'illness delay' into one stage ('appraisal interval'), combining 'behavioural delay' with 'scheduling delay'

(‘help-seeking interval’), adding a ‘diagnostic interval’ (the time between first appointment and formal cancer diagnosis) and including a final ‘pre-treatment interval’ (to describe the time between formal cancer diagnosis and treatment commencement). The authors also drew on relevant domains and heuristics from the CSM. Again, given the focus of the current research, the ‘appraisal interval’ and the ‘help-seeking’ interval are the intervals of interest.

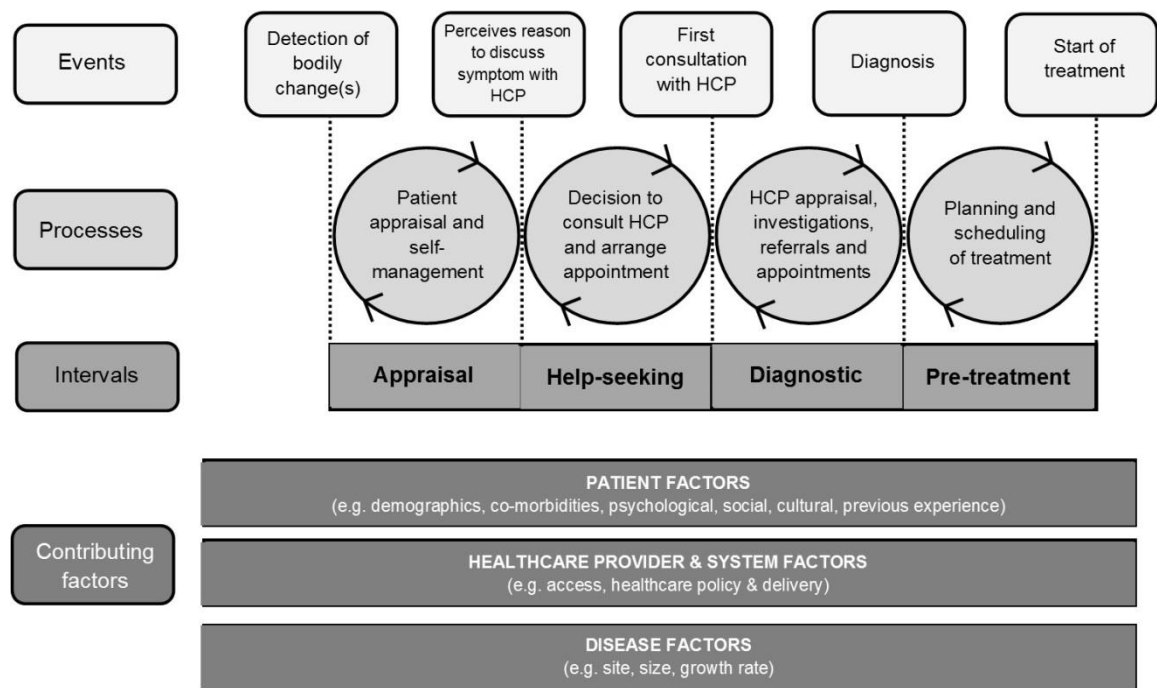


Figure 2.5 The Model of pathways to treatment (Walter et al., 2012)

Walter et al.’s (2012) proposed model of help-seeking may be more applicable to time to help-seeking research in gynaecological cancers than the other models described above. For example, Andersen’s model describes rigid stages through which one moves; there is no iterative process whereby an individual may move backwards or forwards, depending on new information or amendments to bodily change attributions, whereas the MPT is more fluid. The model allows for movement between the stages in a bi-directional manner, which is perhaps more reflective of normal life, where we may receive new information or influences on a daily basis.



As with the Andersen stage model, the MPT also allows researchers to focus on specific areas of the pathway to help-seeking, and as such, allows us to identify which variables may be most influential at which point and consequently allows for the development of targeted interventions. Further, it explicitly allows for responses other than medical help-seeking, such as self-management, which again may be more reflective of real life. For example, if one detects a symptom (referred to as a bodily change) and has inferred illness, but then decides that there is no need to discuss their symptom with a healthcare professional, they would remain in the appraisal stage. The model explains the processes of how this might occur (for example influences such as access to healthcare) and alternative actions that may have been taken (such as self-management).

As described above, the CSM, NEM, IAM and Andersen's model could all be applied to the research within this thesis. However, the MPT may be more appropriate for a number of reasons. A stage model may be more helpful in understanding the influences on or barriers to help-seeking, and when these are most powerful. The finding that the appraisal stage may be most influential in the help-seeking pathway highlights the importance of breaking down help-seeking by interval. However, the static nature of Andersen's model may not reflect real life, and as such, it is less appropriate here.

The main limitations of the CSM are its complexity, which would make it difficult to apply the whole model to the research in this thesis, and its low predictive power for help-seeking behaviour for symptoms of female cancers. However, the authors of the MPT did draw on the CSM when developing their model, and as such, the MPT has allowed for those parts of the CSM which may be applicable specifically in the area of patient delay. Further, although the model explains that there are influences, such as social, cultural and psychological influences at all points of help-seeking (and even prior to detection of the bodily change itself), there is no detailed explanation of how these contributing factors may influence each interval.

The NEM too, would be less appropriate than the MPT here, as it does not allow for interpretation of a bodily change and how this might influence the help-seeking process. Finally, the IAM states that interpretation of a bodily change may be delayed (which may ultimately impact upon time to help-seeking), yet how or why this occurs is not adequately explained, whereas the MPT explicitly describes the processes which may impact upon a longer time to help-seeking, including those which may influence appraisal.

### **2.3 Approach of this thesis**

As detailed, there are a number of models which describe how and why one might seek help for a symptom, the processes by which this occurs, the variables which encourage or discourage help-seeking and the length of time one takes to do so. The MPT is the most appropriate model in the context of this thesis. It was specifically designed to explore factors that may influence time to diagnosis and treatment, including time to help-seeking. As such, this model has been used to direct the research within this thesis, and I have drawn on the model in the study described in Chapter Eight.

## **CHAPTER THREE – PREDICTORS OF HELP-SEEKING IN WOMEN WITH SYMPTOMS OF FEMALE CANCERS: A REVIEW OF THE LITERATURE**

### **3.1 Introduction**

Within the help-seeking literature for female cancers, the focus has largely been on breast cancer, with the focus on gynaecological cancers comparatively small. One explanation for this is the difference in incidence rates between female breast cancer and gynaecological cancers, which may have led to a much higher research interest in the former; the latest available data show that there were over 41,000 incidences of female breast cancer in England in 2011, compared to just over 16,000 incidences of gynaecological cancers as a group (Office for National Statistics, 2013a).

Although the symptoms of breast cancer are different to those of gynaecological cancers, the factors that influence help-seeking behaviour for these types of cancers may well be similar. For example, there is evidence that there are commonalities across many cancers in terms of barriers to seeking medical attention, and that gender may play a role (Smith, Pope, & Botha, 2005). Furthermore, both gynaecological and breast cancers are associated with sexuality and femininity (Emilee, Ussher, & Perz, 2010; Howell, Fitch, & Deane, 2003; Lindau, Gavrilova, & Anderson, 2007) and occur within intimate body parts, and there is evidence that women feel embarrassment about help-seeking for symptoms of both cancers due to this (Marlow, McGregor, et al., 2013). Consequently, the literature on predictors of help-seeking for breast cancer may be useful in furthering our understanding of the variables that may influence help-seeking or abstinence from help-seeking for gynaecological cancer symptoms.

#### **3.1.1 Methodological approaches to exploring help-seeking**

##### ***3.1.1.1 Prospective studies***

Ideally responses to symptoms would be measured prospectively. This would mean following patients from the moment a bodily change is noted, through the appraisal and attribution process, to the response (which may involve seeking help from a healthcare

professional or an alternative response, such as self-medicating). Measuring responses to symptoms prospectively would allow data to be collected on the full patient pathway, including influences at different points in the pathway, without the bias of knowing whether the symptom is indeed indicative of an illness or not. A prospective study would also be able to investigate those variables which lead to either seeking medical attention for a symptom potentially indicative of a gynaecological cancer or not, and, for those individuals who do seek medical attention, the factors that influence the time taken to do so.

Although some studies have attempted to measure responses to symptoms using a prospective method (discussed below), such research designs are difficult in this area. For example, a prospective study would require a very large sample size to detect significant differences (Weller et al., 2012), given the number of potential outcomes (including monitoring a symptom, ignoring it, seeking advice from friends or family, seeking advice online, self-medicating or seeing a medical professional). These large sample sizes can lead to vastly inflated costs when compared to other methods. Moreover, it would be unethical to prospectively follow women with symptoms that may indicate a gynaecological cancer without intervening and advising them to seek medical attention. Consequently this methodology is not often used in the literature.

### ***3.1.1.2 Retrospective studies***

It has previously been noted that most studies in the help-seeking or 'patient delay' literature for cancer symptoms employ a retrospective method of collecting data (Walter et al., 2012; Weller et al., 2012). This method might involve asking patients with a diagnosis of cancer to recall what happened when they discovered a symptom, and how they responded to it (including information on when their symptom started and when they sought help), or may involve the use of patient medical notes to determine key time-points, or sometimes a combination of the two. Retrospective studies require smaller sample sizes than prospective studies (as the response to the symptom, and the outcome is known) and can therefore be easier and more cost-effective to run compared

with prospective studies. However, these types of studies do have associated limitations. It may be very difficult to retrospectively identify and recruit patients who experienced a symptom but never sought help, meaning that it is difficult for these types of studies to explore alternatives to help-seeking, and what factors might influence an individual to fail to seek help at all. Further, studies investigating help-seeking in those women diagnosed with a cancer rely upon accurate patient disclosure. However, some patients with a diagnosis of cancer who waited before seeking help may not want to reveal that they had waited or may not wish to divulge the reasons for waiting if they do not deem those reasons to be valid (in the context of their eventual diagnosis).

Furthermore, even if patients do wish to fully and accurately disclose their journey and experiences, there remains the most common criticism of retrospective data, namely the potential for collecting inaccurate data as a result of patient recall bias (Neal & Allgar, 2005; Weller et al., 2012). The time period between first noticing a symptom and diagnosis can be a long one, and consequently patient recall of dates and influences on help-seeking may well be inaccurate. The effect of the passing of time on recollection of cancer symptoms was demonstrated by Fransson (2005). He asked prostate cancer patients to report their symptoms (using a short form of the validated Prostate Cancer Symptom Scale) before commencing treatment and then asked them to recall the symptoms experienced at that time 12 months later. Patients reported an average (mean (M)) of 1.81 (standard deviation (SD)=1.49) urinary symptoms and 0.55 bowel symptoms (SD=0.86) at baseline, but when asked to recall these baseline symptoms a year later, they reported having had significantly more symptoms (M=2.19 (SD=1.81) urinary symptoms and M=0.88 (SD=1.26) bowel symptoms,  $p<0.001$ ) than they had done originally.

Collecting data from patient notes removes the reliance upon accurate recall and disclosure as these data are not collected from patients, and are recorded at the time the patient sought medical help. However, it is recognised in the literature on diagnosis of gynaecological cancers that, as data in patient medical notes are not collected for

research purposes, they therefore may not contain the level of detail and accuracy of recording required to draw conclusions about medical help-seeking for symptoms of a gynaecological cancer (Tate, Martin, Murray-Thomas, Anderson, & Cassell, 2009). For example, it may be difficult to determine the full patient pathway (such as how long a patient had taken to interpret a change in their bodies as a symptom that may require medical attention, and from that point, how long it took to seek medical help).

Finally, retrospective methodologies may fail to take into account the social and cultural context in which the symptoms were experienced (Andersen et al., 2009), which may be an important part of understanding symptom appraisal and attribution, as well as the help-seeking process for symptoms of cancer (Andersen, Paarup, Vedsted, Bro, & Soendergaard, 2010). Both the NEM (Pescosolido & Boyer, 1999) and the IAM (Dingwall, 1976), discussed in Chapter Two, explicitly highlight the importance of the social and cultural context within which a symptom is experienced, and the MPT (Walter et al., 2012) describes how social and cultural influences can act on how an individual processes a bodily change, and ultimately whether they move forward through the pathway to help-seeking. Although it is possible to ask patients about the context in which their symptoms occurred, as above, these data are limited to recall and full patient disclosure.

It may be possible to mitigate some of the limitations of retrospective research, however. For example, collecting data from patients very soon after diagnosis is likely to reduce inaccurate patient recall, as events will be fresh in the patient's mind. However, it may not always be ethical to approach cancer patients at this point in time. Another possible option is to combine retrospective patient report and data from medical notes. Doing so may help to provide a more accurate, less subjective dataset. However, again, these data may still be limited in accuracy and completeness.

### **3.1.1.3 Hypothetical help-seeking studies**

Another less commonly used method for collecting data on help-seeking or 'patient delay' involves measuring intention to seek help for a hypothetical symptom. Such studies usually take the form of surveys or questionnaires. Hypothetical studies may reduce ethical issues associated with prospective and retrospective studies by avoiding the emotional distress potentially caused by discussing a personal cancer diagnosis and by avoiding discussing actual experienced symptoms. However, there is an acknowledged gap between intention and behaviour (Sheeran, 2002), which may make it difficult to apply findings from hypothetical help-seeking studies to actual behavioural responses to real symptoms. Further, as discussed above, the context in which symptoms are experienced may influence help-seeking, and it may be difficult for participants in studies exploring hypothetical help-seeking to imagine the context in which those symptoms might occur.

### **3.1.2 Chapter aims and methods**

The aim of the present chapter was to explore the literature on help-seeking for symptoms of female cancers, with a particular focus on the evidence for predictors of help-seeking and time to help-seeking. This allowed me to identify gaps in the literature that warranted further research.

In order to identify relevant papers, I conducted a literature search using the EMBASE, MEDLINE and PsychINFO databases. I searched for abstracts or titles of journal papers published in English, where the full text was available, and where methods were adequately described. Although I did not limit the publication time period, as I wanted to identify all relevant papers, all of the papers I identified as appropriate were published from 1967 onwards. My initial search used the terms, 'gynaecological', 'gynecological', 'female', 'vulva', 'vulval', 'vulvar', 'womb', 'uterine', uterus, 'endometrium', 'endometrial', 'endometrioid', 'ovarian', 'ovaries', 'ovary', 'vaginal', 'vagina', 'cervix', 'cervical' or 'breast'. I combined these individual search findings with those from a second search, using the terms, 'cancer' or 'carcinoma'. These first two searches allowed me to identify journal

papers covering gynaecological or breast cancers. I then carried out a third search using the terms, 'help-seeking', 'help seeking', 'helpseeking', 'care-seeking', 'care seeking', 'careseeking', 'patient delay' or 'delay', and combined this search with the already combined results from my first two searches. This allowed me to identify papers that had explored help-seeking for symptoms of a gynaecological or breast cancer.

I read the abstracts or titles of all the papers identified during the literature searches to identify relevant studies. Any papers with abstracts which were deemed to be relevant to the interest of the review were read in full. Papers were deemed to be relevant if they had explored variables that predicted, or were associated with, help-seeking or time to help-seeking for symptoms of a gynaecological cancer or of breast cancer. I also searched the reference lists of all relevant articles for additional articles of interest. Finally, I searched for published research from well-known authors within the field. All relevant articles identified are discussed below.

The literature exploring help-seeking for symptoms of a gynaecological cancer has been discussed first, followed by the literature exploring help-seeking for symptoms of breast cancer. Although there may be similarities in the influences on these types of cancers, as stated above, investigating the literature in this way allowed any differences to be teased out. As this thesis focuses on gynaecological cancers, it is important to determine whether there may be any variables influencing help-seeking which are specific to this group of cancers.

### **3.2 Help-seeking for symptoms of gynaecological cancers**

As mentioned above, the literature exploring variables that are associated with, or predict, medical help-seeking for symptoms of gynaecological cancers is narrow. Most of the studies that have been published in this disease area concentrate on ovarian cancer, although there has been some research investigating help-seeking for uterine and cervical cancers and on gynaecological cancers as a whole (discussed below). Nearly all of these studies have been retrospective, in patients with a diagnosis of a



gynaecological cancer, although some have employed a hypothetical or prospective research design. Given the different limitations and strengths associated with each of these methods, I have structured the literature discussed below by methodology.

### **3.2.1 Studies exploring hypothetical help-seeking for symptoms potentially indicative of a gynaecological cancer**

To my knowledge, at the time I reviewed the literature (other than the publication of the study described in Chapter Six), only two studies had previously explored hypothetical help-seeking for symptoms of a gynaecological cancer (Cooper, Polonec, Stewart, & Gelb, 2013; Marlow, McGregor, et al., 2013) (Cooper et al. also included women with actual symptoms). Recently, however, another study was published (Brain et al., 2014). Brain et al. and Marlow et al. both carried out their studies with British women, whereas Cooper et al. conducted their study in the United States (US).

Cooper et al. (2013) conducted fifteen focus groups with 132 women, some of whom had a symptom potentially indicative of a gynaecological cancer, and some of whom did not. The findings related to women with hypothetical symptoms are discussed below, where possible, as the authors did not always distinguish between those women who actually had a symptom, and those who were asked to imagine that they did. The findings relating to experienced symptoms in Cooper et al.'s study are discussed later in this chapter (see section 3.2.1.4).

Women were given a list of symptoms associated with each of the five gynaecological cancers. However, they were not told that these symptoms could indicate a gynaecological cancer and the word 'symptom' was not used on the list. Participants were then asked to indicate whether any of the symptoms would concern them and what they would attribute the symptoms to if they had experienced them. Time to real or intended help-seeking was defined as appropriate if it was within two weeks of symptom onset, in line with guidance from the Centers for Disease Control and Prevention information on gynaecological cancers (Centers for Disease Control and Prevention,

2012). Any women not having sought or intending to seek help within this time period were deemed to have delayed seeking care.

A range of intended times to help-seeking was observed, influenced in some cases by the symptom the participants had imagined experiencing. For example, when asked about their hypothetical response to changes in the skin of the vulva, no women reported that they would wait longer than a couple of weeks before seeking help, whereas for the remaining symptoms, women reported a range of anticipated times to help-seeking, from immediately to never.

Although the authors did distinguish between women with real and hypothetical symptoms for the findings related to time to help-seeking, they did not do so for the findings related to *influences* on time to help-seeking. Women reported that they had or would seek help within a two-week period if they were concerned that the symptom may be indicative of a serious underlying condition, worsening of a current condition or the recurrence of a past condition, if they had a personal tendency to seek care promptly or if they were in pain.

Reasons for waiting (or anticipating waiting) longer than two weeks included a belief that the symptom was indicative of a benign condition, a personal tendency to delay, concerns about the cost of medical treatment and a lack of or a tolerable level of discomfort. Although the participants typically stated that they had or would see a primary care physician or a specialist in response to the symptoms under investigation, women also mentioned using the internet, self-treating or seeking advice from those close to them either alongside medical help-seeking or instead of it.

Cooper et al.'s study is important, as it is currently the only study that has explored hypothetical responses to symptoms potentially indicative of all five gynaecological cancers. Further, the authors explored this in women who had not received a diagnosis

and outside of the context of cancer, or even illness, which may be similar to what occurs in the real world. Moreover, the authors' use of qualitative focus groups means that they were able to investigate any previously unknown influences on help-seeking and time to help-seeking.

However, the study does have some limitations. The authors did not always clearly differentiate between women who had anticipated help-seeking for a hypothetical symptom and those who had experienced actual symptoms (nor did the authors provide information about how many symptoms were hypothetical and how many were real). This makes it difficult to isolate the influences on help-seeking for women with actual symptoms. Further, the study was conducted in the US, which has a different healthcare system to the UK and perhaps other cultural differences in attitudes to help-seeking. For example, cost considerations are unlikely to act as a barrier to help-seeking in the UK, as healthcare is free at the point of delivery.

Brain et al. (2014) also explored hypothetical help-seeking for symptoms of ovarian cancer in a sample of 1,043 Welsh women. Data were collected using the Awareness and Beliefs about Cancer-Ovarian measure (ABC-O), adapted from the Awareness and Beliefs about Cancer measure (ABC) (Simon, Forbes, et al., 2012), the Cancer Awareness Measure (CAM) (Stubbings et al., 2009) and the ovarian specific version of the CAM (Simon, Wardle, et al., 2012). The authors also used the Ovarian Cancer Worry Scale (Andersen et al., 2007).

Most women in the study reported that they would seek help within two weeks (72%), with almost half (49%) stating that they would seek help immediately. Significant predictors of anticipated delay of more than three weeks were being educated to degree level or higher, perceiving more practical barriers, having a lower level of confidence in detecting symptoms of ovarian cancer and anticipating more emotional barriers.

Brain et al.'s (2014) study is subject to the limitations befalling research exploring hypothetical help-seeking for symptoms of cancer, as described above. The authors also suggest that the use of the ABC-O may have led to a dilution of the effects of symptom awareness on anticipated delay, as a function of its adaption from three different measures, as they did not find the relationship between these two variables that has been demonstrated in previous studies (Robb et al., 2009). One of the strengths of this study was the definition of delay. The authors defined delay as having occurred if women had anticipated waiting for more than three weeks before seeking help (based on guidelines relating to symptom frequency and persistency, and a sensitivity analysis that showed that a three week threshold reflected anticipated delay better than a two or one week threshold), rather than using the arbitrary, standard period of three months or more, commonly used in the literature, as discussed above.

Finally, in 2013, Marlow et al. used a qualitative interview methodology to investigate hypothetical help-seeking in a sample of ethnically diverse women from London. The researchers interviewed 54 women about their anticipated responses to experiencing symptoms of either breast or cervical cancer and about factors that might either facilitate, or act as barriers to, help-seeking. The researchers did not specify a delay period, but did state that no women anticipated waiting for longer than three months.

Common barriers to help-seeking were fear of a cancer diagnosis, perceived service, emotional or practical barriers including having a negative attitude towards a GP, not wanting to seek help because of past experiences in the healthcare setting (such as having spent long periods of time in hospital as a child) or being too busy. Specifically relating to a cervical or breast cancer symptom, a few women mentioned that they would feel embarrassment about seeking help because of the personal nature of the location of the symptom, practical barriers, such as being too busy, or having competing priorities such as weddings or holidays which they would put before help-seeking

Marlow et al. also identified some variables that the women anticipated would encourage them to seek help for a symptom of either cervical or breast cancer. Interestingly, although many women stated that fear would act as a barrier to help-seeking, some felt that it would encourage them to seek help quickly. For some this was because they would want to seek reassurance that their symptom was not indicative of a cancer. Perhaps linked to this, many of the women interviewed said that they would seek help quickly because they were aware of the importance of early diagnosis, which itself was, in some cases, influenced by having known someone who had either been diagnosed early and survived or diagnosed late and died.

As with Cooper et al.'s (2013) study, use of a qualitative, semi-structured interview methodology in Marlow et al.'s (2013) study allowed new themes to emerge, which may not have been considered previously, and may not have been identified using a quantitative methodology. However, it is subject to the limitations of hypothetical research, discussed above. Further, the sample of women in this study was much more ethnically diverse than the UK population (86% of the population in England and Wales are from a White ethnicity (Office for National Statistics, 2013b), compared to 20% in Marlow et al.'s study), all were from London, and all were highly educated. Although the aim of the study was to explore anticipated help-seeking in an ethnically diverse sample of women, the findings here may not apply to British women in general.

### **3.2.2 Studies exploring retrospective help-seeking for symptoms potentially indicative of a gynaecological cancer**

As discussed above, the majority of research on help-seeking for symptoms of a gynaecological cancer is in ovarian cancer. I did not identify any studies which had retrospectively explored help-seeking specifically for symptoms of vaginal or vulval cancers. However, I did find a number of studies which looked at all of the gynaecological cancers combined.

The considerably higher incidence of ovarian cancer compared to vaginal and vulval cancers (see Chapter One) is a possible explanation for the higher volume of research in help-seeking for symptoms of ovarian cancer. Moreover, the wide availability of cervical screening, and the introduction of the HPV vaccination means that the majority of potential cervical cancers are prevented, again reducing the need for research exploring help-seeking for this cancer in comparison to the need for such research in ovarian cancer.

Uterine cancer incidence is currently higher than that of ovarian cancer, and is increasing (see Chapter One for all incidence data). It is unusual, then that there is a very small body of research exploring time to help-seeking for symptoms of uterine cancer. One explanation for this may be that, unlike ovarian cancer, there is evidence that uterine cancers are mostly diagnosed at an early stage (Donnelly, 2013; The National Cancer Registration Service, Eastern Office, 2009; White, 2013), leading to a lower perceived need to increase prompt help-seeking for this cancer. However, as discussed in Chapter One, 14% of these cancers are still diagnosed at the later stages and there is a possibility that this number may be higher, given the proportion of missing staging data (21% in some areas of the UK). Further, wide variation in survival rates between early and late stage disease suggest that any improvement in the proportion of earlier stage diagnoses could be beneficial.

#### ***3.2.1.4 Uterine cancer***

The most common type of uterine cancer is endometrioid adenocarcinoma (American Cancer Society, 2013), and as such some of the literature on uterine cancer only focuses on this type. For example, in their 1986 study, (Cochran, Hacker, & Berek, 1986) interviewed 37 women in the US diagnosed with endometrial cancer. They explored variables that may be associated with a longer time to help-seeking for abnormal bleeding (which is the most frequent symptom of uterine cancer (Amant et al., 2005)). The authors found that women typically reported having waited between one and four months before seeking medical attention. Women who attributed the bleeding

to the menopause reported having waited longer before seeking help, while those who reported feeling alarmed by their symptom were more likely to have sought help immediately. Lower levels of social support also acted to increase the time taken to seek help.

In another qualitative interview study conducted in the US ten years later, Coates et al. (1996) explored whether ethnicity could influence time to help-seeking for symptoms of uterine cancer in a population-based sample of 99 Black women and 232 White women who had been diagnosed with uterine cancer. Participants asked about the period between first noticing a symptom and seeking medical attention.

The authors found no evidence that ethnicity influenced time to help-seeking in this sample of women. Both groups of women reported having sought help very soon after noticing a symptom; 38% of White women and 38% of Black women both stated that they had sought help within one week of recognising a symptom, and over 60% in both groups reported having done so at one month. However, the authors did note other characteristics that were associated with a longer time to help-seeking. They found that older women reported having sought help more quickly than younger women, that women with higher grade disease sought help a little quicker than women with lower grade disease, and that women who had experienced vaginal bleeding had sought help faster than women with no bleeding and less identifiable symptoms. This study suggests that women may benefit from a higher awareness of symptoms of uterine cancer which do not involve bleeding.

In a more recent UK-based study, Johnson et al., (2011) carried out a local audit in the South-West of England between March and May 2009, collecting data on all cases of uterine cancer diagnosed during that time. As part of the audit, data relating to time to help-seeking from symptom onset was collected retrospectively. The largest proportion of the patients had waited up to a month before seeking help (49%), although some women reported having waited more than 6 months (12%). Reflecting Cochran et al.'s

findings, women commonly reported having waited because they had not attributed their symptoms to a possible cancer. Other less common reasons for potentially delaying seeking medical attention included feeling scared about the possibility of cancer and experiencing service barriers, such as finding it difficult to access the GP, not being able to see their own GP or not being able to see a GP because work hours coincided with the GP surgery opening hours.

This audit does have some limitations, however. For example, the authors are unclear about what was asked, and how, in the questionnaire given to participants. Further, although the authors collected data about why women may have waited longer to seek medical help, they were not clear about which period of time they had defined as 'delay', nor why. It was also difficult to determine the exact number of women who had responded to the questionnaire about reasons for waiting longer before seeking medical attention for their abnormal bleeding, as different denominators were given for each reason given, without explanation. Finally, this was a local audit, rather than a research study, and as such, the data are not generalisable. Despite this, the findings do reflect the literature on help-seeking for cancer symptoms generally with regards to reasons for a longer time to help-seeking (for example, Macleod, Mitchell, Burgess, Macdonald, and Ramirez, 2009; Robb et al., 2009; Smith et al., 2005).

#### **3.2.1.4 Cervical cancer**

There is very little literature exploring retrospective help-seeking for symptoms of cervical cancer; much of the literature focuses on exploring barriers to screening attendance, rather than barriers to help-seeking following discovery of a symptom. There are, however, some studies in developing countries, such as Africa and India (Dhamija, Sehgal, Luthra, & Sehgal, 1993; Kidanto, Kilewo, & Moshiro, 2002; Sarkar, Konar, & Raut, 2011; van Schalkwyk, Maree, & Dreyer Wright, 2008). However, due to the vast differences in healthcare and culture between these countries and the UK, it would be difficult to generalise the results. As such, these studies are not discussed here.



### **3.2.1.3 Ovarian cancer**

As discussed above, the majority of the literature exploring help-seeking for symptoms of a gynaecological cancer is retrospective, and focuses on ovarian cancer. However, even though this gynaecological cancer is the most researched in the help-seeking literature, I could still only identify six relevant studies, half of which collected qualitative data and half of which collected survey data. Further, only two of the six studies were conducted in the last ten years, highlighting that even this area may need more investigation.

The earliest study was conducted in 1985, by Smith and Anderson. They used questionnaire data to investigate characteristics of symptoms, the perceived cause of those symptoms and time taken to seek medical attention in 83 US women with a diagnosis of ovarian cancer. The authors also collected data on stage, grade and histologic features of the ovarian cancer at diagnosis (using the SEER population-based cancer registry), in order to explore whether there was an association between patient reported factors and clinical factors at diagnosis.

Women who reported having symptoms before diagnosis were asked about which of the symptoms they experienced had encouraged them to seek medical attention. Abdominal swelling and abdominal pain were the symptoms most likely to have convinced the women in this study to seek help. Women aged 40 years or older were significantly more likely to have reported that they had a symptom which convinced them to see medical attention.

On average, the women in this study reported having waited for a month (Median=four weeks) before seeking medical attention for their symptoms, although more than half reported having sought help within one month (53%). The most common reasons for a longer time to help-seeking (defined in this study as more than one week between first recognition of symptom(s) and the date at which medical attention was sought) were

fear (23%), repeat appearance of a previously experienced benign condition (23%) and interpreting symptoms as 'non-serious' (18%). However, using logistic regression, the authors found no association between any of these variables and delay in help-seeking, nor between fear and delay in help-seeking. The lack of significant associations may have been a result of the unusually short period of time referred to as 'delay' (more than one week) or a result of the small sample size, which may have meant that significant differences could not be detected. For example, Chan, Ng, Lee, Ngan, and Wong (2003) also explored help-seeking in just 80 Hong Kong women with ovarian cancer. They explored time to help-seeking and associated variables, reporting that most women had sought help within two weeks, and that there were significant associations between any of the variables measured (symptom type and coping styles) and time to help-seeking.

Flam, Einhorn, and Sjövall (1988) had a much larger sample size (n=362) in their study conducted in a secondary care oncology department with women diagnosed with ovarian cancer in Sweden. However, only descriptive statistics were reported; the authors only assessed how long women had taken to seek help and what had prompted them to do so, rather than exploring associations with time to help-seeking. Further, the methods of data collection were unclear, as the authors only stated that they had 'asked women specific questions concerning their initial symptoms and those leading to medical consultation'. The majority of women reported having sought help within three months of symptom detection (>70%). The main symptoms prompting help-seeking for women with both early and advanced disease were abdominal pain (24% and 23% respectively) and abdominal swelling (18% and 28% respectively).

The more recent studies conducted in this area have used qualitative methodologies to explore the factors that may influence help-seeking behaviour for symptoms of ovarian cancer, possibly in response to the lack of strong evidence supporting any influences in the previous literature. In 2002, Fitch, Deane, Howell, and Gray interviewed 18 women in Canada with a diagnosis of ovarian cancer about their experiences of diagnosis,

treatment, and follow-up care. The women reported that, in some part, delays in their diagnoses were due to a lack of symptom awareness and the vagueness of the symptoms experienced (although no period of delay was specified). For example, the women in the study described often dismissing their symptoms as being part of, or related to, normal bodily functioning, such as childbirth, menopause or responses to stress. As the symptoms of ovarian cancer, such as abdominal bloating and distension are common (for example, Pitts et al., 2011; Sandler, Stewart, Liberman, Ricci, and Zorich, 2000) and can be similar to those of other, benign conditions including irritable bowel syndrome (Jiang et al., 2008), this finding is unsurprising.

In the only UK-based study I found, Evans, Ziebland, and McPherson (2007) conducted telephone interviews with 43 women who had received a diagnosis of ovarian cancer. Women were asked about their experiences, including pre-diagnostic symptoms. The main focus of this study was to explore delays in diagnosis related to the period between seeking medical attention and a diagnosis (often referred to in the literature as 'practitioner delay'), within the context of Andersen's Model of Total Patient Delay (Andersen et al., 1995). As such, although the authors recorded 'patient-attributable delays', they did not provide any further information. Delays reported to be attributable to the patients were a misattribution of the symptom to stress, the menopause or previous benign conditions (such as bowel problems, irritable bowel syndrome and pelvic inflammatory disease) or due to a lack of recognition of symptoms as serious.

The finding that women who attribute their symptom to the menopause tend to wait longer before seek help reflects the findings for influences on delay for symptoms of uterine cancer, discussed above (Cochran et al., 1986), and in other studies investigating delay in help-seeking for ovarian cancer symptoms (Fitch et al., 2002). Misattributions to benign conditions or stress have also been found to influence help-seeking in the literature discussed above (Fitch et al., 2002; Smith & Anderson, 1985).

The most recent study was conducted in 2011 in Denmark (Seibaek, Petersen, Blaakaer, & Hounsgaard, 2011). The authors used registry data covering primary and secondary care in a sample of 666 women who had been diagnosed with either a borderline ovarian tumour, ovarian cancer, or cancer of the fallopian tubes, alongside interview data from 19 women who had been newly diagnosed with ovarian cancer during 2008 – 2009. This study mostly focused on the number of healthcare touch-points (GP or secondary care visits) the women had had before being referred or diagnosed and on symptom interpretation, rather than time to help-seeking. However, during analysis of the interviews, the authors identified three sub-themes, including 'bodily sensations', 'from bodily sensations to symptom' and 'health seeking and treatment start'. The data within the latter theme showed that women with a higher SES and a higher level of education were more likely to have reported seeking help sooner and more likely to have asked their GP for referral to a specialist or secondary care than women from a lower SES, and with lower levels of education.

One strength of this study was the combination of two interviews with the women, both in the hospital setting and in their own homes, pre-surgery and post-surgery respectively. Further, although most of the women interviewed were at stage III+, the sample also included three women who were diagnosed at stages IA-IC. As symptoms may vary, depending upon how advanced the cancer is (for example, Hamilton et al., 2009), the inclusion of women at both earlier and later stages might help to understand the factors that influence help-seeking for women with both early and late stages disease. Moreover, the healthcare systems in Denmark and the UK are very similar (The Commonwealth Fund, 2013), and as such, the data from this study is useful in understanding risk factors for delayed presentation for symptoms of ovarian cancer in a UK population. However, the focus of this study was not to explore the reasons why women might have waited longer before seeking medical attention, and the semi-structured interview guide did not specifically ask women this question. As such, the data on this topic may have been limited. For example, although the authors state that

women from a higher SES were more likely to have sought help sooner, there was no description of the time periods that the women had mentioned.

#### **3.2.1.4 All gynaecological cancers**

Earlier, I discussed Cooper et al.'s (2013) study, which included both hypothetical and actual help-seeking for symptoms of all of the gynaecological cancers (Cooper et al., 2013). I discussed the study methods and results relating to hypothetical help-seeking above (see section 3.2.1), and have discussed the findings relating to actual symptoms here.

The women who had experienced symptoms reported a range of times to help-seeking, from a few days to never. As discussed above, when reporting their findings relating to influences on time to help-seeking and from whom advice was sought, the authors did not differentiate between those women who had anticipated seeking help and those who had actually done so. Consequently, the findings reported in section 3.2.1 for this study are also applicable here.

Above, I discussed the strengths and limitations of this study. An additional strength in the data from women with actual symptoms is that these data are even more likely to reflect what happens in real life, as these women were describing their actual responses to real symptoms outside of the context of cancer or illness.

I also identified one other study which had explored help-seeking for gynaecological cancers retrospectively, and one study which had explored this in a number of different cancers (including gynaecological cancers). In a much earlier study than Cooper et al.'s, (Andersen et al., 1995) also explored time to help-seeking in all five gynaecological cancers, in a total sample of 34 US women with a recent diagnosis (within two weeks of recruitment to the study) of a gynaecological cancer (14 women with cervical cancer, 11 women with endometrial cancer, six women with vulval cancer, two women with ovarian

cancer and one woman with vaginal cancer). Andersen et al. asked the women to identify the dates at which they travelled through the five stages (appraisal, illness, behavioural, scheduling and treatment delay) of Andersen's Model of Total Patient Delay (Andersen et al., 1995), which is described in detail in the previous chapter. They were then interviewed about their experiences. The authors also collected demographic and clinical information about the women from participants themselves, their medical records and their doctors.

Women reported having waited an average (Mean) time of 97 days between first detecting a symptom and first receiving medical attention. The majority of this (77 days, 79%) was attributed to the time taken to appraise a symptom. The authors found evidence for a significant relationship between the number of 'cancer explanations' (a belief that a symptom may have been caused by cancer) reported by patients prior to diagnosis and 'appraisal delay' and 'total patient delay' (i.e. all stages of the model combined), and also between the total number of general, non-specific symptoms experienced initially and appraisal.

This study demonstrates that attributions and the type of symptom experienced can affect time to help-seeking for gynaecological cancer symptoms. This study is valuable in understanding the pathways women travel through prior to diagnosis, and rare by the use of a model to guide the study design and interpret the findings. Further, aside from the potential ethical issues involved in asking women to talk in detail about the events leading up to their diagnosis of cancer so soon after receiving it, this method may have led to an underestimation of the different stages of delay, and inaccurate recall or representation of the events that influenced the women's actions due to the emotions likely experienced as a function of the recentness of their diagnosis.

Finally, Risberg, Sørbye, Norum, and Wist (1996) explored the use of alternative medicine, delays involved in diagnosis, treatment and any psychological distress caused

by a delay in diagnosis in 252 Norwegian patients diagnosed with a cancer. The sample included 122 women, of whom 13 had been diagnosed with a gynaecological cancer. Although the authors did not stratify the results by cancer type, they did report that 33% of the female patients reported having sought medical attention less than a week after symptom onset, and 65% within one month. The authors reported no significant differences overall in time to help-seeking by age, level of education or other patient specific factors. Given that the results were not stratified, and the study included both men and women diagnosed with more than 11 different types of cancer, it is impossible to make any conclusions about help-seeking related specifically to gynaecological cancers here.

### **3.2.3 Predictors of a longer time to help-seeking or a longer anticipated time to help-seeking for symptoms potentially indicative of a gynaecological cancer**

The definition of 'delay' varied by the different studies discussed above. Many of the studies reported the proportion of women who waited for longer than three months, although most did not specify a particular time-point at which women had 'delayed'. Two of the three studies that did specify a time-point (Brain et al., 2014; Cooper et al., 2013) justified having done so. The literature that did not specify a particular cut-off explored those variables which were associated with a longer time to help-seeking. This is reassuring, given the lack of a consensus about what constitutes a 'delay' in having sought medical attention for a symptom of cancer, and the argument made earlier that it may not be appropriate to apply one period of 'delay' to all types of cancer. Further, using a specific time cut-off may mean that some variables that may have been significantly associated with another time cut-off are missed (for example, Smith and Anderson, 1985).

There was evidence for a difference in the variables associated with hypothetical 'delay' and actual 'delay'. Part of this difference may be explained by the intention-behaviour gap, discussed earlier. For example, it may be difficult for women to anticipate those

factors which would actually influence their time to help-seeking, whereas women who have had a symptom and have sought help are able to state what they believed actually influenced their behaviour.

Factors that women believed would lead them to wait longer before seeking help included having a belief that the symptom was indicative of a benign condition, having a personal tendency to delay, having concerns about the cost of medical treatment, a lack of (or tolerable level of) discomfort, perceiving more service barriers (such as finding it difficult to make an appointment with a doctor), emotional barriers (such as a worry about what the doctor might find or embarrassment), and practical barriers (such as being too busy or having competing priorities). Women who had a lower confidence in their ability to detect a symptom and women who had higher levels of education were also more likely to anticipate delay. Finally, having a fear of a cancer diagnosis was associated with anticipating waiting longer before seeking medical help.

A fear of cancer was also associated with anticipating seeking help promptly. Some women expanded on this, stating that seeking help promptly would alleviate their concerns. Women also anticipated seeking help promptly if they had concerns that the symptom may be indicative of a serious condition, worsening of a current condition or recurrence of a previous condition. Other women anticipated seeking help promptly if the symptom was causing them pain, or because they were aware of the importance of the early diagnosis of cancer, often through knowing someone who had been diagnosed with cancer. Finally, women with a personal tendency to seek help promptly or to be conscientious about their health were more likely to anticipate seeking help promptly.

Women who had had symptoms and sought help were more likely to have waited longer before doing so if they had attributed their symptom to something other than cancer, and usually to something that they may have had little concern about. For example, these women reported having attributed their symptom to the menopause, something non-



serious, normal bodily functioning, such as stress or a previous benign condition.

Further, having had a fear of cancer or alarm about the symptom were associated with having waited longer before seeking help. Part of this misattribution may have occurred because of the perceived ambiguity of the symptom. For example, some women reported having waited longer before help-seeking because the symptom was vague or non-specific. Moreover, women with lower grade disease were also found to have waited longer for symptoms of uterine cancer (Coates et al., 1996). It is possible that symptoms associated with lower grade disease may be less painful or alarming and easier to attribute to something benign.

There was some evidence that older women may seek help more quickly than younger women. For example, Coates et al. (1996) reported this finding. However, given that this was a qualitative study, no statistical analyses were undertaken to determine whether this relationship was significant. Further, Smith and Anderson (1985) reported that women aged 40 years or older were more likely to have a symptom that convinced them to seek medical attention for ovarian cancer, however, this finding may simply reflect the differences in symptoms experienced.

As with intention to wait longer, service barriers also acted to negatively influence time to help-seeking in women with actual symptoms. Interestingly, although symptom awareness wasn't associated with hypothetical help-seeking, I did find evidence that it was with actual help-seeking. This may be a result of the differences in the time periods. For example, most of the women in Brain et al.'s (2014) study anticipated seeking help within two weeks, with almost half saying that they would do so immediately, whereas the data from most of the retrospective studies showed that women had waited longer (Cochran et al., 1986; Johnson et al., 2011; Smith & Anderson, 1985).

Again, as with hypothetical help-seeking, there were a number of factors associated with prompt help-seeking. Women who had experienced a bleeding symptom, abdominal

pain or abdominal swelling reported having sought help more promptly or had reported that these were the symptoms that encouraged them to seek help at all. Further, women who attributed more 'cancer explanations' were less likely to spend longer appraising their symptom (appraisal delay has been argued to account for the longest period of 'total delay' (Andersen et al., 1995)). Women with a higher SES and women who were educated to higher level were also more likely to have sought help promptly. This finding may be a result of an increased knowledge of symptoms, or potentially an increased confidence in seeking medical attention.

### **3.3 Help-seeking for symptoms of breast cancer**

#### **3.3.1 Help-seeking for symptoms of breast cancer (including literature published between 1975 and 2004)**

As discussed above, the body of literature exploring help-seeking for symptoms of breast cancer is considerably larger than that exploring help-seeking for symptoms of gynaecological cancers. As a result of this much larger research interest in the former, there have been a number of reviews of the literature. In the literature below, I have discussed these reviews, along with original research papers not included in the reviews, and more recent papers. Again, as mentioned above, there may be similarities in the factors that influence a longer time to help-seeking for symptoms of gynaecological cancers and breast cancers. In examining the breast cancer literature below, I aimed to identify all possible factors that may influence a longer time to help-seeking for symptoms of gynaecological cancers. When discussing the literature relating to gynaecological cancers above, I stratified by research design (studies exploring hypothetical help-seeking and studies exploring retrospective help-seeking). The breast cancer literature discussed in the reviews below mostly relates to retrospective data, in patients with a diagnosis of cancer. Where hypothetical help-seeking data is discussed, this has been made clear.

In 1993, Facione published a critical review of the literature on help-seeking for symptoms of breast cancer, and calculated a frequency weighted average of the time taken to seek medical attention for the women in these studies. This calculation showed that around 34% of the women in the literature had waited for three months or more before seeking help. When applying this frequency weighted average to the studies carried out in Britain (Adam, Horner, & Vessey, 1980; Macarthur & Smith, 1981; Nichols, Waters, Fraser, Wheeler, & Ingham, 1981), Facione reported that the proportion of women who had waited longer than three months was lower (24%).

In her review of the literature, Facione included both studies that explored intention to seek help and actual, retrospective help-seeking. The studies investigating intention to seek help supported an association between a longer time to anticipated help-seeking and having negative beliefs about the consequences of a breast cancer diagnosis and social normative influences (such as perceived social role demands).

In the literature exploring time help-seeking retrospectively in women diagnosed with breast cancer, Facione found support for possible associations between a longer time to help-seeking and attribution of a symptom to a benign process (such as previous benign breast disease), the presence of symptom other than a lump, fear (expressed as fear of dying, of discovering the cause of the symptom and of mastectomy), being from a non-White ethnicity and possibly being older. Facione also reported that economic factors (such as no having medical insurance) may also be associated with time to help-seeking in patients diagnosed with breast cancer, although this finding would not be applicable in the UK, where healthcare is free at the point of delivery, as mentioned earlier. The literature was unclear about whether the attribution of a lump symptom to cancer increased the time taken to seek help, or reduced it.

Facione's review demonstrates evidence for some of the potential influences on both intention to seek help for symptoms of breast cancer, and actual help-seeking. However,

there were some limitations. For example, Facione reported that the majority of the studies included in the review had extracted data from patient medical notes or tumour registries, rather than patient report. I have discussed the limitations of using data from patient medical records to determine time to help-seeking above (see section 3.1.1.2). Similar issues apply to the use of registry data.

During 1996 and 1998, Ramirez et al. (1999) carried out a systematic review of factors predicting delay in help-seeking for symptoms of breast cancer in the literature from 1960 onwards (and therefore covering some of the literature discussed in Facione's (1993) review) to identify factors that may be relevant in modern times. The authors identified 19 papers including original data on risk factors for delayed presentation attributable to breast cancer patients. The literature only showed strong evidence for an effect of older age and strong evidence against marital status as predictors of delay in help-seeking for breast cancer. There was moderate evidence for having fewer years of education, being from a non-White ethnicity, discovery of a symptom other than a breast lump, non-disclosure of symptoms to others and misattribution of the symptom to something other than breast cancer.

The most recent review focusing on factors associated with delay in help-seeking for breast cancer symptoms I identified was carried out by Bish et al. (2005). This review covered the literature discussed in the previous reviews, as well as newer literature (the authors did not describe the time periods from which they reviewed the newer literature, although the most recent study cited was published in 2004). Combining the findings of the reviews described above (Facione, 1993; Ramirez et al., 1999) with newer literature, the authors concluded that older age, reduced knowledge of symptoms, less than prompt disclosure to another person and treatment concerns were all associated with either a longer time to help-seeking for symptoms of breast cancer or an intention to wait longer.

Finally, in 2009, Macleod et al. also reviewed some of the literature relating to a longer time to help-seeking for a number of different cancers, including breast and gynaecological cancers, reporting results from two previous systematic reviews, one focusing on breast cancer (Ramirez et al., 1999, discussed above) and one focusing on a number of different cancers, including breast and gynaecological (Macdonald et al., 2004). Relevant papers relating to gynaecological cancers have been discussed earlier. The review here mainly reported the findings relating to breast cancer reported by Ramirez et al. However, the authors did consider some newer literature (Burgess, Hunter and Ramirez, 2001, discussed below), which used a qualitative methodology to investigate delay in help-seeking for symptoms of breast cancer in women with newly diagnosed breast cancer.

Burgess et al. (2001) interviewed 46 women using semi-structured interview guides, eight weeks after diagnosis. The women were purposively selected from a larger study (Burgess et al., 1998), to represent both women who had waited for a longer (>3 months) and a shorter ( $\leq 2$  weeks) period of time before seeking help. The authors found evidence that women who had waited for a shorter period of time had recognised the seriousness of the symptom more quickly than those who had waited longer, which was, in turn, influenced by the nature of the initial symptom, and how well it matched the individual's expectations of what a breast cancer symptom was. The researchers also reported that women who waited longer were more concerned about bothering the doctor than those who did not. Other factors more commonly mentioned by women who had waited longer included fears about cancer treatments (possibly influenced by past experiences of loved ones with cancer) and competing priorities (such as family, work and holidays). A change in the symptom or disclosure to others seemed to act as a facilitator to recognition of symptom seriousness.

Although this was a qualitative study, and no statistical differences could be determined between those women who waited longer and those who did not, this study is useful in

understanding the complexities of the help-seeking process. Further, this study was conducted two months following diagnosis, which may have led to greater recall on the part of the women involved, without being too soon after to cause increased levels of distress.

### **3.3.2 Help-seeking for symptoms of breast cancer (including literature published after 2004)**

The literature discussed below was published since the reviews described above were carried out. As these are individual papers, I have discussed them by methodology, as I did with the gynaecological cancer literature, above. Some of the literature exploring influences on a longer time to help-seeking or intention to wait longer before help-seeking focuses on very specific groups of women or were carried out in countries with very different health systems or cultures to the UK (for example, Facione, Giancarlo, & Chan, 2000; Facione & Giancarlo, 1998), which would be difficult to apply to a UK population. As such, these studies are not discussed here.

### **3.3.3 Studies exploring hypothetical help-seeking for symptoms potentially indicative of breast cancer**

I identified three studies which explored intention to seek help for a symptom of breast cancer (Facione et al., 2002; Forbes et al., 2011; Hunter et al., 2003). In 2002, Facione et al. investigated a likelihood to delay seeking medical attention for a symptom of breast cancer in a convenience sample of 699 asymptomatic US women.

The authors used a number of different measures in this study, including the J-Delay scale (the Judgement to Delay scale), to measure likelihood to delay. The authors conducted a logistic regression analysis to determine factors significantly associated with anticipated time to help-seeking. The model explained 34% of the variance in likelihood to delay help-seeking for symptoms of breast cancer (correctly predicting 41%

of those likely to delay). Black and Latino women were around twice as likely to delay compared to White women. Being more likely to self-care for breast symptoms, perceiving more role constraints, having more fatalistic views about cancer, being a lower user of health services, and being less likely to engage in complex problem solving were also all significant predictors of an increased likelihood to delay.

This study measured many different variables associated with a likelihood to delay, and showed that many of these predicted a likelihood to delay. Some of these variables, such as ethnicity, symptom awareness and perceived role demands have been explored in the literature discussed above. However the relationships between help-seeking (perceived or real) and cancer fatalism, health services utilisation habits, self-care of breast symptoms and disposition to engage in complex problem solving have been less well explored in the area of time to help-seeking for female cancers.

The role of fatalism in intention to seek help for symptoms of cancer generally, however, has been explored previously. Beeken, Simon, Wagner, Whitaker, and Wardle (2011) explored the effects of fatalism on intention to seek help in a population-representative sample of 2,018 British adults, reporting that fatalism was significantly associated with being less positive about early detection of cancer and with being more fearful about help-seeking for a suspicious symptom. There is evidence that fatalism may be more influential on time to help-seeking in lower SES and non-White ethnic groups (Beeken et al., 2011; Dein, 2004).

Self-care of symptoms, perceived access to healthcare services and a lower use of healthcare services may have been influenced by cost considerations in the sample in Facione et al.'s (2002) study. However, the study was carried out in the US, where healthcare is not free at the point of delivery, and these considerations may not be applicable in the UK. Further, although these variables were not included in the final

model, the authors did report that women who scored higher on the J-Delay scale were significantly more likely to have no health insurance or to have lower income levels.

Between 2009 and 2010, Forbes et al. (2011) explored help-seeking for symptoms of breast cancer, using the Breast Cancer Awareness Measure (Linsell et al., 2010) in an ethnically diverse group of 1515 women in East London, UK. Similar to the findings with the generic Cancer Awareness Measure (Robb et al., 2009), they found that participants reported an intention to seek help quickly (73% reported an intention to seek help within one week). The most common barriers to help-seeking were a worry about what the doctor might find (47%), embarrassment (38%), a concern about wasting the doctor's time (37%) and finding it difficult to make an appointment (35%).

Although there were no ethnic differences in anticipated time to help-seeking, there were ethnic differences in endorsement of anticipated barriers to help-seeking. South Asian women were significantly more likely to report emotional barriers (such as a worry about what the doctor might find), embarrassment and lack of confidence in talking about symptoms than White women. Further, South Asian and Black women were significantly less likely to report that they were worried about wasting the doctor's time than White women.

Although it is interesting to explore the barriers to help-seeking that women anticipate, and in particular, which groups of women this may affect, the authors did not explore the relationship between these anticipated barriers and anticipated time to help-seeking. Further, the authors did not explore the relationship between breast cancer awareness and anticipated help-seeking. This makes it difficult to determine whether symptom awareness and perceived barriers would actually influence anticipated time to help-seeking.



Unusually in the literature on help-seeking for symptoms of cancer, Hunter, Grunfeld, and Ramirez (2003) used theoretical models (the self-regulation model (Leventhal et al., 1980) and the theory of planned behaviour (Ajzen, 1985, 1991)), which were both discussed in Chapter Two) to underpin their research. More than half (59%) of the 546 UK women who completed postal questionnaires for the study stated that they would seek help immediately for a breast symptom, and over a third (38%) said they would within a month. Just 3% said that they would wait for two months or more before seeking help. The authors classed any women who anticipated waiting for a period of time before help-seeking as potential delayers, and found that older age was a significant predictor of intention to seek help.

The authors entered the two models into a hierarchical multiple regression, which revealed that the self-regulation model explained 22% of the variance in intention to seek help, and the theory of planned behaviour increased the variance explained to 29%. Identity, attitude towards help-seeking and perceived behavioural control were all significant predictors in the model. Potential delayers scored significantly lower on the identity scale than those who intended to seek help immediately, suggesting that those who anticipated seeking help promptly had accurately identified more symptoms. Prompt help-seekers were more likely to have positive attitudes towards help-seeking and greater perceived behavioural control about seeking help for a symptom.

The findings here fit with the research discussed above, which also demonstrated an association between recognition and attribution of symptoms and help-seeking. The findings in relation to greater perceived control in seeking help and having a positive attitude about seeking help also reflect some of the findings above. For example, Forbes et al. (2011) found that over a third of the women in their sample had anticipated finding it difficult to make an appointment as a barrier to help-seeking, suggesting a lower level of control over their ability to seek help. The relationship between lower levels of perceived control were also reflected in Facione et al.'s (2002) study, which

demonstrated that women who perceived more constraints and reported more fatalistic views were more likely to delay seeking help.

### **3.3.4 Studies exploring retrospective help-seeking for symptoms indicative of breast cancer**

There were many more studies exploring help-seeking for symptoms of breast cancer retrospectively, in women who had been diagnosed, than studies exploring intention to seek help. As with the body of research investigating an intention to wait for a longer time before seeking help, some of the literature here involved very specific groups of women, or women from very different cultures, which would make the research findings difficult to apply to a UK population (for example, Montazeri, Ebrahimi, Mehrdad, Ansari, & Sajadian, 2003; Norsa'adah, Rahmah, Rampal, & Knight, 2012). Again, these studies are not discussed here.

Since the reviews discussed above were conducted, a number of studies have been published exploring help-seeking for symptoms of breast cancer. These will now be discussed, in order to achieve an understanding of the most recent evidence for factors which influence delay.

Freidman and colleagues (Freidman et al., 2006) explored help-seeking in women who had been referred to a medical oncology breast surgery clinic, but who had not been diagnosed with cancer. They collected data at one time-point, asking 99 mostly Hispanic (57%) women to complete a number of questionnaires while waiting for their appointment. The authors explored symptoms, time to help-seeking, risk perception, spirituality, barriers to help-seeking and initial emotional response to the symptom.

Analyses showed that the women had reported waiting a mean of nine months from symptom onset to help-seeking, and that almost half (45%) of the women had waited for

more than three months. The most common reason for delay (defined here as three months or more between symptom onset and help-seeking) was a worry that the symptom might indicate cancer, endorsed by 39% of the women. Other common reasons, cited by around a quarter of the women were difficulty making an appointment (28%) and cost (24%).

Although education level alone was not predictive of number of months to help-seeking, there was a 'lump by education' interaction. Having a non-lump symptom was a significant predictor of number of months to help-seeking, but only in women with a low education. This interaction explained 13% of the total variance in number of months to help-seeking. Additional predictors were cost (11.5%), lower perceived risk (7.4%) and lower levels of spirituality (6.5%). The total model explained 38.4% of the total variance in number of months to help-seeking.

The authors also used a logistic regression to explore time to help-seeking as a dichotomous variable, dichotomising number of months into  $\leq 3$  months and  $> 3$  months. Again, the overall model was significant, with younger age, less education, perceived risk and endorsing cost as a barrier to treatment all significant predictors of having waited longer than three months from symptom onset before seeking medical attention.

Freidman et al.'s (2006) study was the only other study I found (alongside Cooper et al., 2013) that had explored time to help-seeking in women who had symptoms, but had not yet received a diagnosis. As discussed above, most of these retrospective studies explored help-seeking in women who had been diagnosed with breast cancer. However, these women had probably seriously considered the likelihood that they would have such a diagnosis, given their referral to an oncology centre. As such, it is likely that the results here would have been similar to those found in studies exploring retrospective help-seeking in women with a diagnosis of cancer. For example, these women may still

have felt that they did not want to divulge how long they waited before seeking help from symptom onset, given their referral to an oncology centre.

As stated above, most of the literature characterises 'patient delay' as having waited for three months or more before seeking medical attention. Although the authors in this study also do this, their inclusion of the analysis of variables that may predict number of months waited before seeking help is unusual. Interestingly, the predictor variables were different in both models. For example, although cost, perceived risk and education level played a significant role in both models, education alone only predicted waiting for more than three months before help-seeking. The effect of education on number of months taken to seek help was only significant if women experienced a non-lump symptom. Further, although age was a significant predictor of whether women took longer than three months to seek help, it was not a predictor of number of months taken to seek help, and although level of spirituality was a significant predictor of a higher number of months taken to seek medical attention, it was not a predictor of having waited more than three months. Again, as mentioned earlier, for some cancers, it may be important to seek help sooner than three months. As such, the results relating to a specific time period (i.e. three months or more) may be less relevant than the results exploring predictors of longer to help-seeking.

A number of studies that have explored predictors of (or variables associated with) a longer time to help-seeking for breast cancer have done so in groups of women who may be at a higher risk. For example, Burgess et al. (2006) focused on women aged 65 years and older (45% of new cases of breast cancer diagnosed in 2011 occurred in this age group (Office for National Statistics, 2013a)). Burgess interviewed 69 women 4-8 weeks post-diagnosis, and delay was defined as having waited for three months or more from symptom onset to help-seeking.

Less than half of the women (42%) reported having waited for three months or longer before seeking medical attention for their symptom. Women were significantly more likely to have waited for three months or more before help-seeking if the first symptom experienced was a non-lump symptom, if they had attributed their symptom to nothing or a vague cause, if they had reservations about seeing their GP or if they had fears about the consequences of the diagnosis and treatment of cancer. Women who had disclosed their symptom to someone else within a week of discovery were significantly more likely to have sought help within three months, as were women who were self-motivated to seek help (as opposed to being prompted by another).

In 2010, Rauscher et al. (2010) examined factors associated with a longer time to help-seeking in a population-based sample of 436 women diagnosed with breast cancer. The authors reported that 16% of the women said that they had waited for more than three months before seeking medical attention. Logistic regression analyses showed that women with a greater number of misconceptions about breast lumps were significantly more likely to have reported waiting for three months or more, as were women who had a history of benign breast problems, women who did not have a regular health provider, and women who had a lower score on the recency of care scale.

The authors did not report any demographic differences between women who had waited longer and women who had waited for a shorter time before help-seeking. However, they did note that the participant response rate was 56%, and analyses showed that non-responders were significantly different in terms of ethnicity and age to responders. Although the authors did use analytic weights in their models to adjust for ethnicity, it is possible that age and ethnicity could have been significant predictors of a longer time to help-seeking (particularly as there is evidence for the effects of these variables in the literature described above). Some of the findings here would not be relevant in a UK population (such as having medical insurance). It was interesting, however, that misconceptions about breast symptoms were predictive of a longer time to

help-seeking. In the research discussed above, it is a common finding that attributing a symptom to something non-serious is likely to lead to a longer time to help-seeking. Misconceptions, such as believing that a lump should only be checked out if it is painful or growing, may suggest that women do not believe that these symptoms are indicative of something serious unless they exhibit these characteristics.

A study conducted by (Taib et al., 2011) reflected some of the findings in the studies discussed directly above (Burgess et al., 2006; Rauscher et al., 2010). The researchers qualitatively explored the experiences of 19 women who had been diagnosed with breast cancer using semi-structured interviews. Although not explicitly stated, delay appeared to have been defined again, as three months or more. The authors found evidence of symptom non-recognition (both for lump and non-lump symptoms). As with the women in Rauscher et al.'s (2010) study, Taib et al. found evidence that women appraised non-painful symptoms (including a lump) as being harmless. Women also believed that family history needed to be present in order to be at risk of breast cancer, suggesting that they felt at lower risk if they had a symptom, but no family history of breast cancer. Again, women believed that breast cancer would present as a lump, and consequently did not attend to non-lump symptoms. There was also evidence here that women felt at lower risk of developing breast cancer if they had had previous symptoms which had been benign.

Marcus, Lunda, and Fernandez (2013) investigated factors associated with having waited for three months or longer before seeking medical attention from symptom onset in 103 women presenting with a diagnosis of stage IIb or higher breast cancer. The authors performed two logistic regressions to demonstrate the significant predictors of either having sought help within three months versus three to six months or having sought help within three to six months versus having sought help more than six months after symptom discovery, as the authors felt that the variables which influence a longer time to help-seeking may vary by periods of time. Only having had a previous history of

cancer was a significant predictor of having waited for less than three months versus three to six months, with women more than three times as likely to seek help within three months if they did have a previous history. This was also a significant predictor of having waited for between three and six months (compared to more than six months) as well as age (women aged 55-64 were almost three times as likely to have waited between three and six months before seeking help than younger women). The authors also reported that having a secondary education or higher and being aged 45-54 were significant predictors of waiting for less than six months (but more than three). However, these predictors were significant at the 0.10 level, which is not usually accepted as statistically significant in the literature. A level of 0.05 is typically the highest level at which a finding is argued to be significant (for example, Coolican, 2014).

The authors acknowledge that their findings may have been different if women with more localised disease had been included in the sample. However, they do suggest that the observed relationship between having had an experience of cancer and having sought help promptly may indicate a higher awareness of signs of cancer in these women. As many women who discover symptoms may not have had an experience of cancer, the authors recommend that those who have, share their experiences with other women in a bid to encourage them to seek help more promptly.

More recently, O'Mahony, McCarthy, Corcoran, and Hegarty (2013) developed a conceptual framework, based on a review of the literature exploring variables that may influence time to help-seeking for symptoms of breast cancer (Figure 3.1).

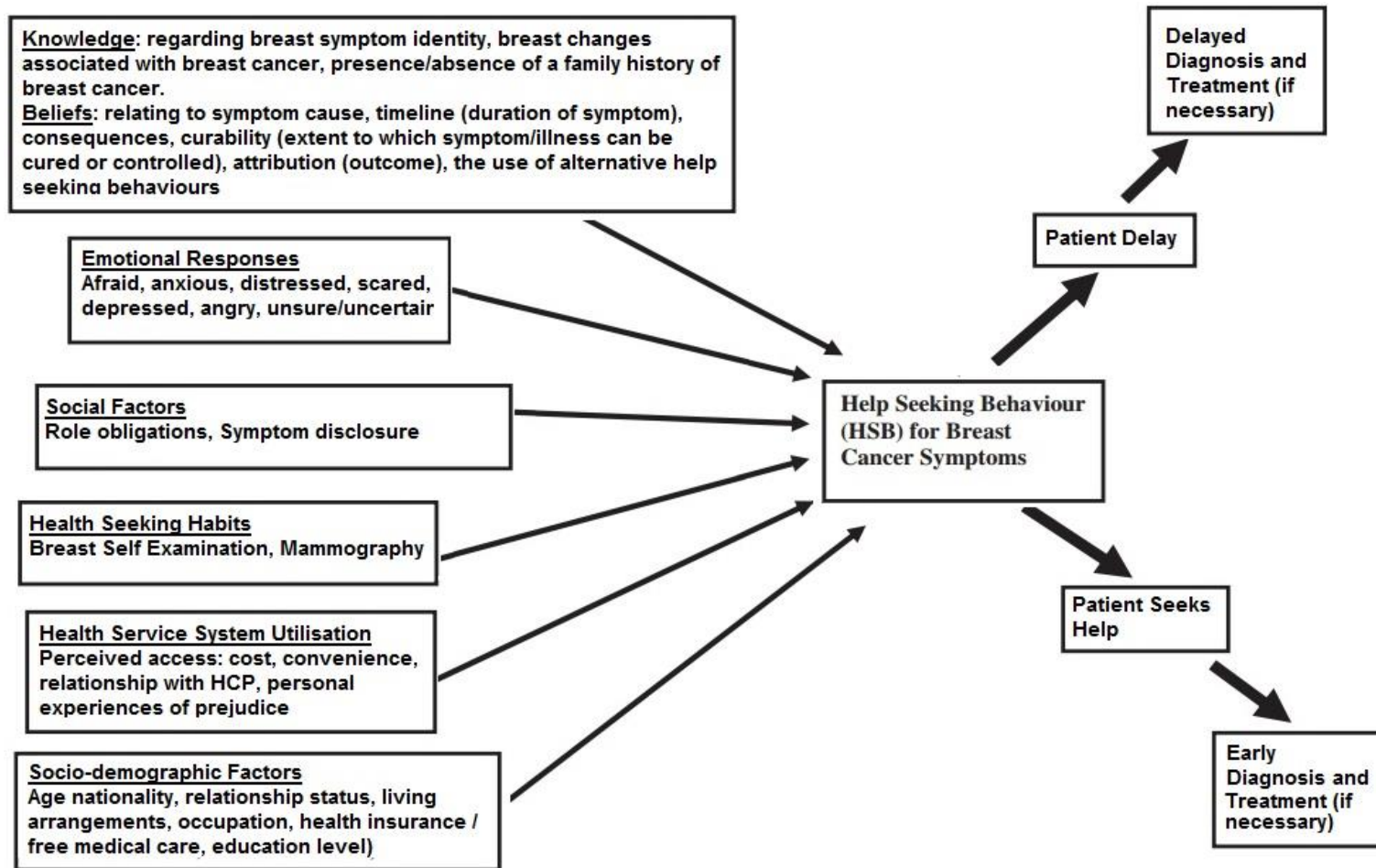


Figure 3.1, A conceptual framework of 'factors potentially influencing women's help-seeking behaviour on self-discovery of a breast symptom (reproduced from O'Mahony et al., 2013)



The aim of their study was to explore women's help-seeking behaviour within the Republic of Ireland, and the variables that may influence this, as depicted in Figure 3.1. The authors underpinned their research with the common sense model (described in Chapter Two), using a cross-sectional survey design to collect data from 449 symptomatic women who were visiting a hospital for the first time, but who had not yet had a diagnosis.

As described above, it is usually not possible to determine alternatives to help-seeking when exploring responses to symptoms retrospectively in women with a diagnosis of cancer, as all of the women in these studies have participated by virtue of their diagnosis, made after seeking medical attention. However, O'Mahony et al. (2013) did attempt to explore alternatives, finding that just under 80% of women had monitored their symptom, 43% had listened to the advice of others about visiting the GP, and the same proportion had prayed to God about their symptom. Although this information is interesting and important, and it is admirable that the authors collected these data, it must be noted that all of these women had eventually sought help, as they were recruited from a hospital setting. It is still important to explore the influences on women who never seek help. Knowledge relating to breast symptom identity (for example, a presenting symptom of 'nipple indrawn/changes'), a belief in a longer symptom duration and a belief in 'ignoring the symptom and hoping it would go away', as opposed to seeking medical attention were all significant predictors of having waited for three months or more before seeking help. Prompt help-seeking was associated with being afraid upon symptom discovery.

Again, as with some of the research discussed above, the authors found no relationship between any of the socio-demographic variables and time to help-seeking, nor any relationship between awareness of symptoms and time to help-seeking. However, the presence of a breast lump was associated with prompt help-seeking, whereas the presence of a non-lump symptom, such as nipple inversion or breast pain, were

associated with a longer time to help-seeking. This suggests that knowledge does play a part in time to help-seeking, in line with the research described above.

Interestingly, the authors found evidence for an association between a belief that symptoms would last longer and a longer time to help-seeking. This finding is converse to expectations. The authors offer a number of possible explanations, including that these women may have had a more fatalistic, pessimistic outlook, leading them to a resignation that their symptom would be prolonged or that they believed that the symptom was due to a long-term condition, such as breast cancer, and consequently were likely to delay. Alternatively, women may have just wanted to monitor their symptoms and wait and see what happened. Having a pessimistic or fatalistic outlook seems to be the most likely explanation. Perhaps the women here felt that breast cancer would be a death sentence, and so there was little point in seeking medical attention, although they eventually did. Wanting to monitor the symptom seems like an unlikely reason for delaying seeking help if one believes that the symptom will last a long time, as monitoring implies that one is waiting to see whether the symptom continues or worsens.

It was unsurprising that a belief in ignoring the symptom and hoping it would go away was a significant predictor of a longer time to help-seeking. This may have been driven by fear or by competing priorities (Facione, 1993). Fear has been found to be related to both prompt and delayed help-seeking, suggesting that other factors may mediate this relationship. The finding that disclosure of a symptom to another is associated with prompt help-seeking has been reflected in the research described above. Perhaps disclosure of a symptom may encourage discussion around possible causes, and lead to a deeper level of consideration of the symptom. Further, disclosure of a symptom to another person may lead to a sanctioning of help-seeking, which has also been found to be related to prompt help-seeking.

### **3.2.5 Predictors of a longer time to help-seeking or a longer anticipated time to help-seeking for symptoms potentially indicative of breast cancer**

As with the literature exploring factors associated with help-seeking for symptoms of gynaecological cancers, the time periods defined as 'delay' varied between studies exploring factors associated with help-seeking for symptoms of breast cancer, although the majority of research defined 'delay' as having waited for three months or more. Again, there were also some differences in the variables associated with an intention to wait longer before seeking help and actual time to help-seeking in women who had a diagnosis of breast cancer. A longer time to help-seeking in women with a diagnosis was associated with misattribution of a symptom (usually to something benign, vague or nothing at all). Women also reported non-recognition of their symptom, particularly if the symptom was a non-lump symptom. Given that reduced knowledge of symptoms was also associated with a longer time to help-seeking, this was unsurprising. Similarly, women who had had a history of benign breast problems were more likely to have waited longer. This is probably due to a reassurance built up by the non-seriousness of their previous symptoms.

Other factors associated with a longer time to actual help-seeking were having competing priorities, a belief in ignoring the symptom and hoping it goes away, and non-disclosure, or less than prompt disclosure of a symptom to someone else. Women with less education, no recent health checks (including mammography or breast health checks), those who did not have a regular healthcare provider, women from a non-White ethnic background and older women were all more likely to have waited longer before seeking help. A couple of service barriers also acted to negatively influence time to help-seeking (difficulty in making an appointment to see a doctor and being concerned about bothering the doctor). In a few of the studies described above, fear of discovering the cause of the symptom, of dying and of treatment were all associated with a longer time to help-seeking.

As with symptoms of gynaecological cancers, fear also acted to influence prompt help-seeking, as did having had a history of cancer, being self-motivated to seek help, and a change in the symptom. As non-disclosure of a symptom acted to influence a longer time to help-seeking, disclosure acted to reduce this time, as it helped women to recognise the seriousness of a symptom.

Intention to wait longer was also associated with older age, being from a non-White ethnic background, reduced knowledge of symptoms, non-disclosure to another person, treatment concerns, concern about wasting the doctor's time and perceived role demands. Additional influential factors were having negative beliefs about the consequences of a breast cancer diagnosis, embarrassment and concern about what the doctor might find. Individual factors such as being more likely to self-care, having a lower use of health services, and being more likely to engage in complex problem solving were all associated with a longer time to help-seeking. Intention to seek help promptly was associated with having more positive attitudes towards help-seeking and perceiving greater behavioural control about seeking help.

### **3.4 Summary of the literature exploring variables associated with help-seeking for symptoms of female cancers**

In section 3.1, I discussed the possibility that the factors which were associated with a longer time to help-seeking for gynaecological cancers may be similar to those associated with a longer time to help-seeking for breast cancers. There seemed to be some evidence of this, as there were many variables associated with both hypothetical and actual help-seeking for all of these cancers. However, there were some variables that seemed to be specific to a longer time to help-seeking for gynaecological cancers, such as attributing the symptom to stress or the menopause and being younger.

There were also a number of interesting findings applicable to all of these cancers. For example, fear seems to act both to encourage prompt help-seeking and to delay it, which may be a product of what the fear relates to. For example, if women feared a cancer diagnosis, they seemed to be more likely to wait longer, although some women wanted to or had sought help sooner in order to receive reassurance. The idea, however, that these women would seek help sooner to seek reassurance suggests that they may not believe that their symptom is cancer as strongly as those women who would not seek help due to a fear of a cancer diagnosis. Interestingly, women in the breast cancer literature were afraid of the treatment for this cancer, which acted to elongate the time taken to seek care, whereas this was not a factor in the gynaecological cancer literature. This may be a result of a higher awareness of the treatment for breast cancer due to the much larger levels of incidence.

#### **3.4.1 Model of Pathways to Treatment**

In Chapter Two, I discussed the MPT (Walter et al., 2012; see page 57), which is the most recent model to be applied to the help-seeking literature. In this model patients go through processes to move through intervals in the help-seeking pathway. The model also mentions contributing factors which may influence the transition from one interval to another. Within my thesis I am interested in the processes involved in detection of a bodily change, appraisal and help-seeking.

Although none of the literature discussed above has used this model to explore time to help-seeking for either breast or gynaecological cancers, two studies (Andersen et al., 1995; Evans et al., 2007) did underpin their research with the General Model of Total Patient Delay ('Andersen's Model') (Andersen et al., 1995). However, Evans et al. (2007) only used the model to explore those 'delays' attributable to practitioners, whereas Andersen et al. (1995) explored influences on the full model.

As mentioned above, the majority of the time taken to seek help occurred in the appraisal stage, which is also evident in the MPT. A number of variables were identified in this review which could affect the time taken to appraise a symptom potentially indicative of a gynaecological cancer. For example, there was evidence for a relationship between a longer time to help-seeking and the influence of patient factors such as attributing the symptom to the menopause, something non-serious or benign (such as the menopause or stress, which may be influenced by previous experience or comorbidities) and a lack of symptom awareness. Disease factors also play a role, as women with a lack of (or tolerable level of) discomfort (which may have led women to misattribute their symptom to something benign) were more likely to wait longer, whereas women experiencing alarming symptoms such as bleeding or abdominal pain were more likely to seek help promptly.

Variables which may affect the time taken to seek help, once a symptom has been appraised as potentially requiring medical assistance or advice, seemed to also include some disease factors, such as fear of a cancer diagnosis or alarm about the symptom. Patient factors also play a part, with feeling embarrassed, being younger, having a higher level of education and a personal tendency to delay all being associated with a longer time to help-seeking. There was evidence for the contribution of healthcare provider and system factors, as women who perceived or anticipated more service barriers (such as not wanting to bother the GP), emotional barriers (such as a worry about what the doctor might find) and practical barriers (such as being too busy or having competing priorities) were more likely to wait longer before seeking help.

### **3.5 Summary and links to next chapter**

The literature exploring help-seeking behaviour for symptoms of gynaecological cancers demonstrates a lack of consensus about the time period defined as 'delay'. Most studies investigate variables associated with a longer time to help-seeking, although I did find some studies that did use a specific time-point at which 'delay' was deemed to have

occurred. Reassuringly, two of the three studies that did this justified having done so (Brain et al., 2014; Cooper et al., 2013). It may be more appropriate to explore time to help-seeking, rather than defining 'delay' as having occurred at a specific time-point. As discussed above, one period of 'delay' may not always be appropriate for all cancers, or indeed, all types of illness. It may be more appropriate to determine whether a patient has 'delayed' seeking help within the context of different cancers or illnesses, and at what time-point from symptom onset it becomes harmful to have waited. Further, different factors may be associated with different periods of delay, for example, Marcus et al. (2013) found that a number of variables influenced seeking help within three to six months (compared to six months or more), which did not influence help-seeking in less than three months (compared to three months or more). In assigning an arbitrary cut-off at which one is deemed to have delay, potentially influential factors may be missed.

This review has highlighted the scarcity of research exploring help-seeking for symptoms of gynaecological cancers. In Chapter One I highlighted the importance of improving the proportion of earlier diagnoses in these cancers, and that the absence of a national screening programme for all but cervical cancer creates a need for prompt help-seeking in women who develop symptoms and prompt action on the part of the healthcare professional from whom help is sought. As such, it was surprising to discover the dearth of research investigating the factors associated with prompt help-seeking, or those associated with a longer time to help-seeking.

It is clear that more research is needed in this area, particularly for cervical, uterine, vulval and vaginal cancers. Many of the variables which influence a longer time to help-seeking seem to be related to misattribution, non-recognition of symptom seriousness or lack of awareness of symptoms, and there is evidence that a higher awareness of cancer symptoms can increase the likelihood of help-seeking for that cancer (Quaife et al., 2014). Further, GPs have reported that, from their experience, the most common reason for a longer time to presentation for gynaecological cancer symptoms is low

symptom awareness, which results in women failing to understand the significance of symptoms when they arise (Evans et al., 2014). However, to my knowledge, at the point I began research on this thesis, there were no studies which had explored symptom awareness and the relationship between this and time to help-seeking for symptoms of gynaecological cancers. Exploring this relationship may be most important in ovarian cancer, as this is the most lethal gynaecological malignancy (see Chapter One), and there is potential for increasing survival rates through earlier detection of low volume disease. However, it is also necessary to determine levels of awareness before efforts to increase awareness are made. With this in mind, Chapters Five and Six will explore symptom awareness for cervical and ovarian cancers. The data in these chapters were collected prior to my commencement of this PhD. As such, I was only able to explore the relationship between symptom awareness and help-seeking for ovarian cancer. Data were also collected for risk factor awareness for both these cancers, and these data are discussed further in Chapters Five and Six.

The studies reported in Chapters Seven and Eight discuss data collected during my PhD. They explore responses to symptoms potentially indicative of the five gynaecological cancers quantitatively (Chapter Seven) and qualitatively (Chapter Eight). In Chapter four, I have described the four novel studies carried out and reported as part of this thesis.



## **CHAPTER FOUR – THESIS AIMS AND RESEARCH QUESTIONS**

In Chapter One I determined that survival rates for gynaecological cancers could be improved in the UK. It may be possible to achieve an improvement through increasing the proportion of earlier FIGO stage diagnoses (stages I and II) for uterine, cervical, vaginal and vulval cancers, and by reducing the proportion of high grade serous ovarian cancers, possibly through earlier diagnosis or increasing diagnoses of low volume tumours. I established that this may be realised through increasing prompt help-seeking in symptomatic women.

In Chapter Two I discussed the existing models of health behaviour and help-seeking. The most recent model, the MPT (Walter et al., 2012), was developed from the General Model of Total Patient Delay or 'Andersen's Model' (Andersen et al., 1995), which itself was an extended and expanded version of an older model, proposed by Safer et al. (1979). I established that Andersen's Model is the most widely used model in the time to help-seeking literature. However, the recently developed MPT aimed to address some of the limitations of Andersen's Model, and as such I have used this model to underpin the research described in Chapters Seven and Eight, and I have explored how this model might help explain help-seeking specifically for symptoms of a gynaecological cancer in Chapter Nine.

In Chapter Three, I explored the literature on help-seeking for female cancers. The aim of this chapter was to underpin the research in Chapters Seven and Eight. Although the data had already been collected for the studies described in Chapters Five and Six, prior to the commencement of my PhD, the literature discussed in Chapter Three helped to guide the analysis and discussion within these chapters.

To reiterate the questions I laid out in Chapter One, I have addressed the following questions within this thesis, using original data and analyses:

1. How much do women in the United Kingdom currently know about gynaecological cancer symptoms and risk factors?
2. What variables predict time to hypothetical help-seeking for symptoms of ovarian cancer?
3. How do women respond both behaviourally and emotionally to symptoms which may indicate a gynaecological cancer?
4. What factors explain the different behavioural and emotional responses women may have to an experienced symptom of a gynaecological cancer?

I have addressed question one in Chapters Five and Six, and question two in Chapter Six, building on the literature discussed in Chapter Three. Questions three and four are addressed in Chapters Seven and Eight.

## **CHAPTER FIVE - CERVICAL CANCER SYMPTOM AND RISK FACTORS AWARENESS (STUDY 1<sup>6</sup>)**

### **5.1 Introduction**

#### **5.1.1 Background**

In Chapter Three I established that two of the biggest influences on help-seeking behaviour symptoms of female cancers were symptom misattribution and non-recognition of symptom seriousness (for example, O'Mahony, McCarthy, Corcoran, & Hegarty, 2013; Seibaek, Petersen, Blaakaer, & Hounsgaard, 2011), which may be the product of low symptom awareness. Risk factor awareness is also important as it allows women to make informed lifestyle choices and to modify any behaviours that may increase risk, such as not attending cervical screening appointments (Cancer Research UK, 2012a). Awareness of risk factors might also allow women who are at increased risk due to non-modifiable factors (such as age (Cancer Research UK, 2013b)) to be more sensitive to changes in their bodies. For example, as discussed in Chapter Three, there is evidence that women who perceive themselves to have a lower risk of developing breast cancer are more likely to intend to wait for a longer period of time before seeking medical attention for symptoms (Bish et al., 2005).

The influence of risk factor awareness on help-seeking can also be understood in the context of the models discussed in Chapter Two. For example, within the IAM, new external knowledge, such as knowledge about risk factors for a disease, can influence interpretation of a bodily change and within the CSM, the representation of a health threat may also be influenced by an increased perceived risk. Further, the MPT describes how the influence of previous experience, psychological, social and cultural factors can all influence help-seeking or appraisal, and perceived risk certainly fits within these variables (for example having previously had a cancer may make an individual more likely to perceive themselves at risk of a future cancer). This suggests that by increasing awareness of symptoms and risk factors for cervical cancer, it might be possible to increase prompt and appropriate help-seeking.

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<sup>6</sup> A version of this chapter has been published elsewhere and can be found in Appendix 3 (Low, Simon, Lyons, Romney-Alexander, & Waller, 2012)

However, before attempting to increase awareness, it is necessary to establish current levels of awareness. In doing so, it will be possible to determine areas of poor knowledge (such as specific risk factors or symptoms) and demographic groups who may benefit from targeted health education programmes.

### **5.1.2 Existing literature on cervical cancer symptom awareness**

In 2010 the Department of Health launched their key messages for cervical cancer (NHS Choices, 2011). The messages include information about symptoms and risk factors for cervical cancer, with unusual bleeding (particularly post-coital or post-menopausal bleeding) and blood stained or unpleasant smelling discharge highlighted as the most common symptoms. Other symptoms include pain during sex, blood in the urine or stool, unexplained weight loss, changes in bowel habits (including persistent diarrhoea) and lower back or pelvic pain (Cancer Research UK, 2013b; A. Neal & Hoskin, 2009; Turkington & Edelson, 2005).

There has not yet been not been a systematic attempt in the UK to assess population levels of cervical cancer symptom awareness, either for established common symptoms such as unusual vaginal bleeding or for less common ones, such as pain or discomfort during sex (NHS Choices, 2012a). However, there is evidence that cancer symptom awareness in general is low in British women (for example, Robb et al., 2009)). As such, it is likely that a low level of awareness will also be found in the current study.

The lack of research in this area may be a result of the dramatic reduction in cervical cancer mortality and incidence in the UK overall in recent years, as described in Chapter One, which in turn is a result of the establishment of a national screening programme in 1988 (Sasieni & Adams, 1999). In the context of declining incidence of cervical cancer and a national screening programme, it seems logical that symptom awareness may be a less important area of research. However, again, as described in Chapter One, the latest data show there are still almost 1000 deaths attributable to this cancer in the UK annually (Office for National Statistics, 2012a) and that incidence may still be rising in some groups (Patel et al., 2012). Consequently, it is necessary to attempt to encourage prompt help-seeking through increasing awareness of symptoms.

### **5.1.3 Existing literature on cervical cancer risk factor awareness**

There are a number of established factors that increase the risk of developing cervical cancer (Parkin et al., 2011). These mostly include factors related to sexual activity, including having many sexual partners, early sexual debut (Appleby et al., 2009), early age at first pregnancy (Louie et al., 2009) increasing parity, taking the contraceptive pill and HPV infection (Berrington de González, Green, & International Collaboration of Epidemiological Studies of Cervical Cancer, 2007), as well as number of previous sexual partners of partner (Burk et al., 1996), unprotected sex or contracting a sexually transmitted infection or disease (STI/STD) or virus (Binswanger, Mueller, Clark, & Cropsey, 2011) including Chlamydia (Dahlström et al., 2011). There are also some factors unrelated to sexual activity that may increase the risk of developing cervical cancer such as smoking, not attending regular cervical screening (Berrington de González et al., 2007), having a weakened immune system (Sun et al., 1997) and family history of cervical cancer (possibly as a function of shared genetic susceptibility or lifestyle factors, rather than direct heritability) (de Freitas, Gurgel, Chagas, Coimbra, & do Amaral, 2012).

Although there is evidence that all of the above increase the risk of developing cervical cancer, some of these factors are associated with a higher risk than others. It is now accepted that HPV is the most important risk factor for cervical cancer, with evidence that this virus is present in almost 100% of invasive cervical carcinomas (Walboomers et al., 1999), and that 100% of cases can be attributed to infections in the UK (Parkin et al., 2011). As HPV is sexually transmitted, the sexual behaviours discussed above could also be classed as having a higher risk than non-sexual behaviour risk factors, as they increase the chances of HPV infection (Burk et al., 1996; Dunne et al., 2007). Research suggests that risk factors unrelated to sexual behaviour, such as smoking (which may only be related to 7.2% of cervical cancers (Parkin et al., 2011)), may aid the transition of HPV-infected epithelia to cervical pre-cancer (Luhn et al., 2013).

In contrast to symptom awareness, there has been a larger research interest in awareness of cervical cancer risk factors, although this has been slow-growing. In 2003 Adlard and Hume conducted a literature review exploring cancer knowledge literature in

the British population between 1982 and 2002. They found just eleven studies, of which only two had explored cervical cancer risk factor awareness (Wardle, Waller, Brunswick, & Jarvis, 2001; Yu & Rymer, 1998), although neither study primarily aimed to determine cervical cancer risk factor awareness specifically.

The first of these studies (Yu & Rymer, 1998) investigated awareness of cervical cancer and attitudes towards screening in 650 UK women aged between 15 to 75 years as part of a cross-sectional survey at two hospitals in London. Women were presented with a list of possible risk factors and asked which they thought increased the risk of cervical cancer. Awareness was highest for having many sexual partners (44%) and smoking (37%), but endorsement of the remaining risk factors was lower. Just under a fifth of participants endorsed genetic causes (inherited risk) (19%) and bad luck (12%). A small number of participants believed that alcohol (6%), lack of exercise (3%) and pollution (2%) were risk factors.

The second study (Wardle et al., 2001) investigated prompted awareness of risk factors for a number of different cancers, including three risk factors related to cervical cancer (having many sexual partners, a virus or infection and smoking) in a population representative sample of men and women aged 16 years and older. Awareness that having many sexual partners could increase the risk of cervical cancer was higher in the female participants in this study than was reported in Yu and Rymer's (1998) study (67%), although awareness of the link between cervical cancer and smoking was lower (28%). Awareness of virus or infection was low in female participants (31%). This suggests that although many women knew about the link between cervical cancer and sex, they did not understand the role of HPV in the relationship, particularly as the awareness reported in this study reflects knowledge of the link between a generic virus or infection and cervical cancer, not specifically the link between HPV and cervical cancer, which may have been lower still.

The differences in awareness between Wardle et al.'s (2001) study and the findings presented by Yu and Rymer's (1998) could be the result of the timing of the studies. For example, Wardle et al.'s study was conducted more recently than Yu and Rymer's

study. It may be the case that awareness of the potential health implications of risky sexual behaviour had increased during this time. Secondly, women may have been more likely to endorse smoking as a risk factor in Yu and Rymer's study due to their presence in a healthcare environment at the time they were asked about their knowledge of risk factors. It is possible that these women had been exposed to health messages regarding smoking at the time they were asked about risk factors for cervical cancer (due to their immediate environment), which led them to endorse this risk factor more than the women in Wardle et al.'s study, who participated from within their homes.

Since Adlard and Hume's (2003) review was conducted, there has been an increase in studies exploring cervical cancer risk factor awareness. This is possibly in line with the increased interest in ensuring that girls and women are aware of the relationship between sexual activity, HPV and cervical cancer with the advent of HPV testing and the availability of the HPV vaccination in the last decade.

In 2003 Philips and colleagues (Philips, Johnson, Avis, & Whyntes, 2003) asked female university students aged 18-23 about their knowledge of a number of risk factors for cervical cancer using a multiple-choice questionnaire. Again, as with previous research, participants demonstrated high levels of awareness for the role of sexual activity, with 79% of the sample aware that multiple sexual partners and 56% aware that early sexual debut act as risk factors, but lower awareness of HPV (51%). Just under half of the sample (49%) identified smoking.

Awareness of both multiple sexual partners and HPV as risk factors for cervical cancer was higher in this study than in Wardle et al.'s (2001) (compared to awareness of a virus or infection). However, the pattern of awareness was similar: women were more aware of the relationship between sexual activity and cervical cancer, but less aware of the processes involved in that relationship (i.e. infection with a virus (HPV)). Awareness of smoking was also considerably higher. It should be noted however, that while 51% endorsed HPV as a risk factor, the authors reported that only 31% said that they had heard of HPV, suggesting that 20% of the participants who endorsed HPV as a risk also said they had not heard of it. The high level of endorsement of HPV as a risk factor may

have been because the framing of the question effectively prompted agreement in participants.

This study was the first to investigate awareness of other variables related to sexual activity which can increase the risk of developing cervical cancer. The researchers found that the majority of women in their study could identify early sexual debut (56%), but found lower awareness for the link between the contraceptive pill (48%), Chlamydia (43%), increasing number of pregnancies (31%) and early first pregnancy (29%) and cervical cancer risk.

The higher awareness of having many sexual partners, HPV (compared to virus or infection) and smoking observed in this study compared to previous research (discussed above) may have been reflective of the high level of education of the participants (all were university students). Further, due to their age and surroundings, these students may have been given information on general and sexual health, including information on smoking, STIs and STDs when they started university, which may have increased their awareness compared to the general population. Finally, this study focused specifically on cervical cancer, whereas Wardle et al.'s (2001) focused on a number of different cancers. This focus may have led participants to consider their knowledge about cervical cancer in a bit more depth.

Waller, McCaffery, and Wardle (2004a) were the first group to explore unprompted awareness of cervical cancer risk factors in a British population consisting of 846 men and 1091 women aged  $\geq 16$  as part of the Office for National Statistics (ONS) monthly omnibus survey. Participants were asked about what they thought either increased or reduced the risk of cervical cancer. Just under half of the women in the study mentioned any link with sex, STIs (sexually transmitted infections) or condom use (46%), 41% mentioned sexual activity, 30% identified many sexual partners, 13% knew that early first intercourse was a risk factor, and 5% mentioned frequent sexual activity. Very few women mentioned HPV (<1%), although more explicitly mentioned STI, STD or lack of condom use (9% mentioned 'STD' or named an STD, 6% said 'STI/STD', 15% said 'STI or not using condoms', 5% named an STI and 7% stated 'Not using condoms').



Awareness of risk factors related to sexual activity was considerably lower in this study than in previous studies (for example, Philips et al., 2003; Wardle et al., 2001), as was awareness of smoking (15%). This was likely to be a function of the open question used in this study, compared to the prompted questions used in previous research. It is well established that recall and recognition scores vary widely, with studies using the latter method reporting considerably higher awareness scores (for example, Power et al., 2011; Simon, Juszczak, et al., 2012). However, despite the lower awareness, as with previous research, participants were still most aware of the influence of having many sexual partners.

In 2005 Philips et al. conducted a self-complete questionnaire study with 1244 women in east-central England aged 20-64, exploring awareness of the same risk factors as those investigated by Philips and colleagues (2003), as well as awareness of unprotected sex. Women eligible for cervical screening were invited to complete the questionnaire while attending a GP consultation (not related to screening) or when being called for screening. Participants were shown twelve risk factors and asked to label them as a major risk, minor risk or no risk for cervical cancer, or to state that they did not know.

Awareness of smoking as a risk factor (either minor or major) was considerably higher (79%) than had been observed in previous studies (15% to 49%) (Philips et al., 2003; Waller et al., 2004a; Wardle et al., 2001; Yu & Rymer, 1998), although the proportion of women identifying smoking as a major risk factor was comparable (46%). Endorsement of sexual behaviours as risk factors varied, with 77% reporting many sexual partners, 73% reporting unprotected sex and 63% stating early sexual debut. The majority of women believed that having unprotected sex and early first intercourse were either minor risk factors, posed no risk or they did not know (61% and 64% respectively), but that having had many sexual partners was a major risk factor (56%).

Few women believed that reproductive or contraceptive factors were major risk factors (17% said using the contraceptive pill, 12% said early first pregnancy and 7% reported number of pregnancies). Around a third of the women in the sample knew that HPV was a major risk factor (33%) (51% endorsed HPV as either a major or a minor risk factor),

which was similar to the proportion of women who endorsed Chlamydia (35%). The findings in relation to HPV compared to findings from previous studies appear to show that awareness is steadily increasing for this risk factor, although there is perhaps room for education about the significance of it, given the lower endorsement of HPV as a major risk factor here, and the finding that almost half (47%) of the women said that they did not know whether HPV was a risk factor at all. Despite the apparent increase in awareness, however, it still appears that the relationship between sexual behaviour, HPV and cervical cancer was not fully understood in the sample, as although most women endorsed having many sexual partners as a major risk factor, the majority did not do so for other sexual behaviours explored here. Further, although the percentage of women endorsing HPV as a risk factor was the same as it was in Philips et al.'s (2003) (51%), fewer women in this study knew that HPV was a major risk factor.

In 2007, Marlow et al. tested unprompted recall of several risk factors for cervical cancer (including not going for regular screening) and prompted recognition of HPV in a population-representative sample of women aged 16-97 years. The findings in this study were analysed along with the data from Waller and colleagues' study (Waller et al., 2004a), collected in 2002, to analyse change in knowledge over time.

Marlow et al found that recall was low for all of the risk factors, including HPV (3%) and not going for regular screening (5%) and even when prompted, only 24% of participants endorsed HPV, although 7% were aware that an STD or STI could act as a risk factor for cervical cancer when unprompted. Few women were able to spontaneously identify a risk factor associated with sexual activity (14% said that having many sexual partners was a risk factor, 7% said young age at first intercourse, 5% said unspecified sexual activity, 3% identified not using a condom and 3% mentioned having more frequent sex). There were significant improvements in awareness between 2002 and 2007 for HPV and for all the risk factors associated with sexual activity except unspecified sexual activity. However, although unprompted awareness of HPV had improved since 2002 (3% vs. 1%), prompted awareness was lower in this study compared to previous studies using prompted questions, which may have been a result of participant characteristics. For example, although the prompted awareness of HPV was higher in Philips et al.'s

(2007) study and in Philips et al.'s (2005) study, the samples in these studies were not representative of the British population.

#### **5.1.3.1 Existing literature on HPV awareness**

The studies discussed above explored awareness of various risk factors related to cervical cancer. However, more recently a number of studies have concentrated exclusively on awareness of HPV. In 2008, Klug and colleagues (Klug, Hukelmann, & Blettner, 2008) completed a systematic literature review which aimed to summarise awareness of HPV in a number of different groups (the general public, students, patients and health professionals). They identified six studies in the UK (Philips et al., 2005, 2003; Pitts & Clarke, 2002; Waller et al., 2003, 2004a; Wardle et al., 2001) (five of which explicitly explored HPV risk factor awareness, and one of which (Wardle et al., 2001) explored awareness of 'virus or infection'). Pitts and Clarke (2002) and Waller et al. (2003) were the first studies to explore HPV awareness in more depth, including awareness of how the virus is contracted and awareness of factors that might increase the risk of contracting it.

Pitts and Clarke's study (2002) explored understanding and knowledge of HPV as a risk factor for cervical cancer in 400 English women aged 19-64, using a questionnaire. Their sample consisted of female staff at a university in the North West of England. The majority of women in their study (70%) had not heard of HPV. Of those who had, 38% knew that cervical cancer was a possible long-term effect of HPV, meaning that overall only 11% of the women in this study both were aware of HPV and knew that it was a risk factor for cervical cancer.

In 2003, Waller et al. explored HPV awareness in 1032 women aged 16 years and older who had attended an NHS well woman clinic in central London using a questionnaire. Again, around a third of women (31%) had heard of HPV. Of those women, 65% knew that HPV was sexually transmitted and 40% knew that it was the main cause of cervical cancer. These findings showed a slight increase in the proportion of women who were both aware of HPV and aware that it is a risk factor for cervical cancer (12%), compared to data collected a year earlier (Pitts & Clarke, 2002).

In 2009, Marlow, Wardle, Forster, and Waller explored ethnic differences in the awareness of HPV in 950 women (750 of whom were from ethnic minority backgrounds). Women were asked whether they had heard of HPV prior to the study, with 39% of White British women saying that they had. Awareness was much lower in the minority ethnic groups. It might be expected that awareness would have risen between this study and the previous one (Marlow et al., 2007), as in the interim the HPV vaccination was introduced in Britain, which this study demonstrates in White women. However, caution must be taken when interpreting these findings, as, again, the sample was not population-representative.

The most recent study exploring cervical cancer risk factor awareness (specifically HPV) was conducted in 2013 by Marlow and colleagues (Marlow, Zimet, McCaffery, Ostini, & Waller, 2013), with 2409 participants aged 18-70 recruited from the UK, US and Australia. HPV awareness was the highest recorded in studies with British women at 62%, and awareness that HPV can cause cervical cancer was very high in those women who had heard of the virus (86%). It is likely that the increased awareness observed in this study compared to previous studies may be a result of the ongoing awareness campaigns for the national HPV vaccination programme.

Across the above literature, it seems that women are most aware of the risks for cervical cancer associated with sexual activity (in particular, having multiple sexual partners) and smoking. Awareness appears to be much lower for the main risk factor, HPV, across the board. Overall, it appears that risk factor awareness was not particularly high, especially when considering risk factors which were not related to sexual activity. Even when considering these risk factors, the highest levels of awareness (79% for having had many sexual partners) would still mean that 20% of women were not aware of this risk factor.

Almost all of the previous studies using recognition to measure awareness of risk factors have not done so in a population-representative sample; instead exploring awareness in students (Philips et al., 2003) or university staff (Pitts & Clarke, 2002), women attending

a well woman clinic (Waller et al., 2003) or in patients from one GP practice in one area of England (Philips et al., 2005). Those in education or in an academic institution may have higher levels of knowledge than the population at large due to their higher education levels or exposure to more information on STDs/STIs or cancer through literature available in their surroundings. Women attending a well woman clinic may naturally have a higher level of interest in sexual health, and may be prone to looking for information relating to this. Similarly, a population from one GP practice is unlikely to be representative of the population.

As they explored awareness in a population representative sample, Marlow et al.'s (2007) findings may be closer to the actual level of cervical cancer risk factor awareness in the British population when unprompted. However, these data were collected in 2006 and consequently may not be reflective of current awareness. Moreover, while recalled awareness was measured across a number of risk factors, recognition awareness was only tested for HPV.

#### **5.1.4 Factors associated with awareness of cervical cancer risk factors and symptoms**

As may be expected, given the proximity of the disease, a personal or family history of cancer has been associated with higher awareness of cancer in general (Adlard & Hume, 2003), as has a higher SES (Robb et al., 2009). Higher awareness of some cervical cancer risk factors has also been found in women with higher levels of education and income (associated with a higher SES) (Marlow et al., 2007; Waller et al., 2004a). This is possibly because women who are more educated have a propensity to seek out health information more than those who are less educated (Tu & Hargraves, 2003).

Higher awareness of HPV in particular has been found in women from a White ethnic background, which may be due to a reluctance to discuss topics related to sexual activity (Marlow et al., 2009) or an avoidance of places where one might be exposed to such information in women of a non-White ethnic background. Research exploring age differences in awareness of a number of different cervical cancer risk factors has found

that while participants aged 16-24 were significantly more likely to be aware of not attending for regular cervical screening than the oldest age group (75 and over), they fared poorly in awareness of most other risk factors compared to the other age groups in the study (Waller et al., 2004a). However, other research has found the opposite, that younger women displayed a higher awareness of HPV than older women (Marlow et al., 2009). This would appear to contradict Waller et al.'s (2004a) findings. However, Marlow et al (2009) only recruited women to their study, whereas Waller et al. (2004a) recruited both men and women and did not stratify awareness by both age and gender, making it impossible to determine awareness in women by age group. The evidence relating to awareness by age then suggests that younger women would be more aware of at least some of the cervical cancer risk factors.

I was unable to find any literature exploring predictors of symptom awareness for cervical cancer symptoms specifically. However, there is evidence that predictors of higher symptom awareness for cancer in general include older age, White ethnicity and higher SES (Robb et al., 2009). There is also evidence that having known close family members or friends who have experienced cancer can increase awareness of some symptoms of cancer (Adlard & Hume, 2003).

A higher awareness of cancer symptoms in general in older women compared to a lower awareness of cervical cancer symptoms in older women may be a result of health promotion campaigns. Given that cervical cancer occurs most commonly in younger women (incidence is highest in women aged 30-34 years at 17.7 per 100,000 women, but is almost as high in women aged 25-29 at 17.4 per 100,000 (Office for National Statistics, 2012b)), it is likely that risk factor awareness literature would be aimed at these groups. Further, medical knowledge about cervical cancer risks factors was much lower when the older women were younger than it is today and consequently these women may have never been targeted by health campaigns aimed at increasing cervical cancer risk factor awareness.

The higher awareness of symptoms observed in older women in the literature exploring generic cancer symptom awareness may be a function of the inclusion of a number of

different cancer types. Generally cancer is much more common in older people, and consequently this may have led to a higher level of awareness in older participants through targeted health literature.

#### **5.1.5 The current study**

As mentioned above, there has not yet been any research which has attempted to determine awareness of a number of known cervical cancer symptoms in a population-representative sample of English women. Although some research has attempted to explore risk factor awareness, much of this research tends to involve samples which are not population-representative, making it difficult to apply these findings to the population. Research which has recruited a sample representative of British women has tended to focus on HPV awareness, rather than other known risk factors.

The present study aimed to explore awareness of both symptoms of and risk factors for cervical cancer in a population representative sample of English women. Both open and closed questions were used to measure recall and recognition respectively.

#### **5.1.6 Hypotheses**

- i. Risk factor awareness will be low, particularly for HPV
- ii. Symptom awareness will be low
- iii. Both higher symptom and risk factor awareness will be associated with higher education level, having a personal or close experience of cervical cancer and White ethnicity
- iv. Older age will be associated with symptom awareness, while younger age will be associated with risk factor awareness
- v. Higher occupational social class will be associated with higher risk factor and symptom awareness

## 5.2. Methods

### 5.2.1 Recruitment

English women aged  $\geq 16$  years were recruited through the social research agency, BMRB (now TNS BMRB<sup>7</sup>) using random location sampling. The sample was stratified by ACORN characteristics (CACI, 1975) and region. Respondents were then selected from a small group of homogenous streets with probability proportional to population. The survey (the Cervical Cancer Awareness Measure (Cervical CAM)<sup>8</sup> (Simon, Wardle, et al., 2012) formed part of BMRB's omnibus survey. This survey runs weekly and consists of different modules from various clients merged into a common questionnaire. Just under 1400 (1392) women completed the Cervical CAM survey module in the omnibus. Women self-completed the Cervical CAM (a site-specific version of the generic CAM; Stubbings et al., 2009), at home using Computer Assisted Personal Interviewing (CAPI) in the presence of fully trained interviewers.

The study was exempt from ethical approval as no identifiable information was collected from participants, and data were completely anonymous. This is in line with the UCL Research Ethics Committee Exemptions guidelines, which state that 'Research involving the use of non-sensitive, completely anonymous educational tests, survey and interview procedures when the participants are not defined as "vulnerable" and participation will not induce undue psychological stress or anxiety' is exempt (UCL Research Ethics Committee, 2013).

Data were collected between November and December 2009, prior to the commencement of this PhD. All background literature discussion, analyses and discussion of the findings were undertaken as part of this PhD thesis.

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<sup>7</sup> [www.tns-bmrb.co.uk](http://www.tns-bmrb.co.uk)

<sup>8</sup> The full Cervical Cancer Awareness Measure can be download from the NAEDI website at [www.naedi.org.uk](http://www.naedi.org.uk)



## 5.2.2 Measures

### 5.2.2.1 Participant characteristics

Ethnicity was dichotomised into 'White' or 'non-White'. White non-British women were included in the 'White' category. A level of spoken English adequate to understand the survey was a pre-requisite for participation. Age was measured as a continuous variable. Education was grouped into 'low-level/none' (women educated to ONC, BTEC, O Level/GCSE A-G and those with no formal education), 'mid-level' (women educated to A-Levels/Highers, Higher education below degree and those who answered 'Other' or were still studying) and 'high-level' (degree level or higher). The small number of women who answered 'other' (N=48) were placed into the 'mid-level' education group. Analysis of variance showed that these women were not able to recall or recognise significantly more symptoms or risk factors than any of the other education categories, suggesting that these women were not significantly different to any of the other education categories. However, Table 5.1 shows that, at face value, the mean awareness for risk factors and symptoms for women who endorsed 'other' was most similar to the 'mid-level' education group, overall.

Table 5.1 Mean recall and recognition for risk factors and symptoms by education group (n=1392)

	Recalled symptoms		Recognised symptoms		Recalled risk factors		Recognised risk factors	
	M	(SD)	M	(SD)	M	(SD)	M	(SD)
Low-Level/None	0.52	(0.70)	5.88	(3.00)	0.45	(0.70)	4.78	(2.60)
Mid-Level	0.56	(0.73)	6.22	(2.67)	0.56	(0.75)	4.87	(2.40)
High-Level	0.84	(0.91)	6.59	(2.56)	0.77	(0.99)	5.54	(2.30)
Other	0.62	(0.84)	5.37	(2.91)	0.55	(0.79)	4.99	(2.36)

SES was measured using the National Readership Survey (NRS) social grading system (National Readership Survey, 2007). In this system, social grade is divided into six different classifications (see Figure 5.1) based on occupation of the chief income earner (CIE) for each household. Income is not used to determine social grade within the NRS system. For the analyses in the current study, participants were dichotomised into those with a high-level occupation (A, B, and C1) and those with a low-level occupation (C2, D, and E), as is the convention in the literature (for example, Waller et al., 2009). Further, this dichotomy allows professionals and non-professionals to be analysed separately.

I decided to analyse the data using two markers of SES: education and occupation (measured using the NRS system, as described above) rather than one or the other as, although there is evidence that the two are correlated, there is an argument that these two variables measure different phenomena and that they may each be better predictors of different types of health outcome (for example, Geyer, Hemström, Peter, & Vågerö, 2006). In order to explore all effects on risk factor and symptom awareness, I deemed it appropriate to explore the relationship between both education level and occupation and awareness.

Finally, respondents were asked whether they had had cervical cancer and/or whether they had known a close family member or friend with cervical cancer. Respondents scored '1' if they had and '0' if they had not.

		% of population (NRS 2010)
A	Higher managerial, administrative and professional	4
B	Intermediate managerial, administrative and professional	22
C1	Supervisory, clerical and junior managerial, administrative and professional	29
C2	Skilled manual workers	21
D	Semi-skilled and unskilled manual workers	15
E	State pensioners, casual and lowest grade workers, unemployed with state benefits only	8

Figure 5.1. National Readership Survey (NRS) social grading system (source: [www.nrs.co.uk/lifestyle-data](http://www.nrs.co.uk/lifestyle-data))

### 5.2.2.2 Awareness of cervical cancer risk factors

Risk factor awareness was measured with both open and closed questions. The open question (presented before the closed question to reduce bias) measured recall and read, *‘What things do you think affect a woman’s chance of developing cervical cancer?’*. Respondents were given a blank space to freely respond. The closed question (measuring recognition) read, *‘The following may or may not increase the chance of getting cervical cancer. How much do you agree or disagree that the following can increase the chance of getting cervical cancer?’*. Participants were presented with 10 cervical cancer risk factors (see Table 5.3) and the response options, *‘strongly agree’*, *‘agree’*, *‘neither agree nor disagree’*, *‘disagree’* or *‘strongly disagree’*. A refusal to answer was coded as *‘missing’*.

For the open question, the responses were dichotomised into *‘recalled’* (mentioned) or *‘not recalled’* (not mentioned) and for the closed question responses were dichotomised into *‘recognised’* (response *‘strongly agree’*, *‘agree’*) or *‘not recognised’* (responses *‘neither agree nor disagree’*, *‘disagree’* or *‘strongly disagree’*). Scores from the open and closed questions were each summed to create an overall score for recall and for recognition (range for both questions = 0-10).

### **5.2.2.3 Awareness of cervical cancer symptoms**

As with the risk factor questions, awareness was measured using both open and closed questions. Symptom recall was measured using the open question: *'There are several warning signs and symptoms of cervical cancer. Please type in as many as you can think of.'* Participants were presented with a blank space for responses and were also given the option of answering 'Don't know' or 'Refuse'. Again, recognition was measured with a closed question: *'The following may or may not be warning signs for cervical cancer. We are interested in your opinion.'* Participants were presented with 11 symptoms of cervical cancer (see Table 5.5) and offered response options 'Yes', 'No', 'Don't know', as well as the option to refuse to answer the question. If participants chose this option, their data were coded as 'missing'. Responses to the closed question were dichotomised into 'recognised (response 'yes') or 'not recognised' (responses 'no'/'don't know') and responses to the open question were dichotomised into 'recalled' (mentioned) or 'not recalled' (not mentioned).

Each recognised or recalled risk factor or symptom was given a score of '1'. For each risk factor or symptom which wasn't recalled or recognised, a score of '0' was given. Scores were summed for both recognition and recall of both symptoms and risk factors to give overall four overall scores (ranging from 0-10 for risk factors and 0-11 for symptoms). A full list of the risk factors and symptoms measured can be seen in Tables 5.3 and 5.5 respectively.

Responses to the open questions for risk factor and symptom awareness were coded by the BMRB interviewers according to a coding frame developed during the interview stage. Coding was verified by another BMRB team member, allowing any errors or inconsistencies to be corrected. To allow comparisons between levels of recalled and recognised awareness, I have reported all those responses from the open risk factor question that corresponded with the closed question list of risk factors. In addition, I have reported awareness of 'virus/STI/STD/infection', 'unprotected sex' and 'hereditary/genetics/in the family'. Although these risk factors did not match the closed question responses, they are not incorrect. In a similar manner, I have reported responses from the open question for symptom awareness that directly corresponded

with the closed question responses, as well as a number of responses that are not incorrect ('unusual/irregular bleeding', 'spotting' and 'bleeding (no detail)').

### **5.2.3 Analyses**

Data were analysed using SPSS version 19 (IBM Corporation, 2010). Two multiple linear regressions<sup>9</sup> were run; firstly to determine independent predictors of awareness (recognition) of symptoms and secondly to determine independent predictors of risk factor awareness. Recognition score was used in the regression as opposed to recall score as both recall and recognition of cancer symptoms have been shown to have similar correlates; however, recognition levels are usually considerably higher than recall (for example Power et al., 2011; Robb et al., 2009; Simon, Juszczak, et al., 2012). I decided to use recognition scores rather than recall scores to determine group differences in the regression analyses, as an overall floor effect was observed in the recall scores, with many symptoms achieving a recall rate of zero. Further, in their 2009 study of generic cancer symptom awareness using the Cancer Awareness Measure, Robb et al. (2009) reported that symptom recognition scores were an independent predictor of time to help-seeking.

To determine those variables which were significantly associated with either the total symptom recognition score or the total risk factor recognition score (shown in the results section) before entering those variables into the two linear regressions using the forced entry method, I performed a number of bivariate analyses. I tested the relationship between age and awareness of both risk factors and symptoms using a Pearson's correlation. To explore differences in awareness between education and occupational groups, I used analysis of variance and t-tests respectively. I also used t-tests to explore differences in awareness between ethnic groups and those who had had a close experience of cancer or not. These analyses (reported below) allowed me to identify the predictive value of each of the variables independently.

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<sup>9</sup> Linear regression is appropriate when both the predictor variables and the outcome variables are continuous data.

For both regression models, age, ethnicity, education level, occupation and experience of cervical cancer were entered as predictor variables. Although ethnicity and experience of cervical cancer were not associated with risk factor recognition score in bivariate analyses, the literature suggests that these variables may be related to risk factor awareness and so they were kept in the model.

As HPV is the most important risk factor for cervical cancer, and previous research seems to suggest that there is a lack of understanding of the relationship between sexual activity and HPV (for example, Waller et al., 2004a), I explored whether those who were aware that sexual activity was a risk factor were also aware that HPV was a risk factor.

#### **5.2.3.1 Weighting**

Weights were provided by BMRB. Data were weighted using a rimb weighting technique, in which target profiles were set for five separate demographic variables (occupational status, parity, age group, social grade and geographical region) to achieve a demographic profile within the sample which was representative of women aged 16 and over in England. Weighting had the biggest effect on occupational social class (with 51% of the unweighted sample in the C2DE group, compared to 43% in the weighted sample) and on the 25-39 years age group (with 11% of the unweighted sample in this age group, compared to 15% in the weighted sample). Smaller effects were observed in all of the other demographic variables (see Table 5.2).

#### **5.2.3.2 Missing data**

Although each question in the survey offered participants the option to refuse to answer, there were few missing data. The highest amount of missing demographic data were observed for the education variable, where 0.9% of data were missing. There were a very small amount of missing data for ethnicity (0.2%) and no missing data for experience of cervical cancer or age. For each of the risk factor and symptom awareness closed questions, less than 0.02% were missing. Where a case was missing data, I excluded that case from any analyses in which the missing value would have

been required. Given the small amount of missing data it is unlikely that this would have affected the findings.

### **5.2.3.3 Parametric assumptions**

Data were tested for normality and homogeneity of variance to be certain that any significant results were down to genuine group differences in means. Linear regressions were used as the skewness and kurtosis of the outcome variables (number of symptoms participants were aware of and number of risk factors participants were aware of) were both within normal distribution ranges (-1 – 1+).

## **5.3. Results**

### **5.3.1 Participant characteristics**

The sample consisted of 1392 women. Participants were aged 16-94, with a Mean age of 47 years (range=16-94, SD=18.70). Most were from White ethnic backgrounds (91%), which meant that the number of non-White women was very small. Consequently these women were grouped together into the 'non-White' category. Women from a non-White ethnic background were slightly over-represented compared to the female population in England and Wales (9.2% versus 12%, respectively) (Office for National Statistics, 2014b). Most women either had no formal education or were educated to a low level (51%) and fell into the higher SES group (ABC1) (57%). Although the women here were similar to the British population in terms of SES (56% of the British population fall into this group (Ipsos MediaCT, 2009)), the highest education group was under-represented when compared to the female population of England and Wales (21% compared to 36%, respectively) (Office for National Statistics, 2014a). However, the data from Office for National Statistics is only presented as a combination of males and females. Consequently, it is difficult to state how different the population here were compared to the female population in England. It is likely that, the weights applied by BMRB were applied to all of the participants who took part in the whole survey, and not just the Cervical CAM module, and this may explain the demographic differences in the sample here compared to the British population.

The majority of participants had not had cervical cancer themselves, nor had they known anyone close to them who had (85%). A more detailed description of the sample characteristics can be found in Table 5.2 (which presents both weighted and unweighted data).

Table 5.2. Sample Characteristics (Weighted/Unweighted  $n=1392$ )

	Unweighted		Weighted	
	<i>N</i>	%*	<i>N</i>	%*
<i>Age</i>				
16-24	158	11.4	208	14.9
25-39	425	30.5	343	24.7
40-59	416	29.9	431	30.9
60 +	393	28.2	410	29.5
<i>Ethnicity</i>				
White	1240	89.1	1261	90.6
Non-White	149	10.7	128	9.2
<i>Education</i>				
High-Level	256	18.4	285	20.5
Mid-Level	230	26.9	233	27.9
Low-Level/None	749	53.8	705	50.7
<i>Socioeconomic status</i>				
ABC1	687	49.4	794	57.0
C2DE	705	50.6	598	43.0
<i>Close experiences of cancer</i>				
No-one	1171	84.1	1179	84.7
At least one person	221	15.9	213	15.3

\* where %<100%, this is due to missing data

### 5.3.2 Awareness of cervical cancer risk factors

Two-thirds of respondents (65%,  $n=905$ ) were unable to recall any of the target risk factors ( $M=0.44$ ,  $SD=0.67$ ), but when open responses 'virus/STI/STD/'infection' (and 'unprotected sex' were included, this figure dropped to 764 (55%). The remainder correctly recalled at least one ( $n=487$  35%, and  $n=628$ , 45% respectively). 'Having many sexual partners' was the most recalled target risk factor (20%,  $n=272$ ). The least



recalled were 'having many children' (<1%, n=3) and 'having a weakened immune system (for example, because of HIV/AIDS, immunosuppressant drugs or having a transplant)' (<1%, n=2). Mean recall score was slightly higher ( $M=0.52$ ,  $SD=0.78$ ) when open responses 'virus/STI/STD/'infection' (recalled by 1%, n=20) and 'unprotected sex' (recalled by 7%, n=101) were included. See Table 5.3.

Just under a third (28%, n=392) of the sample were able to recall at least one of the risk factors relating to sexual activity (starting to have sex at a young age; having many sexual partners; unprotected sex or having a sexual partner with many previous partners). Although I attempted to explore whether women who recalled a sexual activity risk factor were significantly more likely to endorse HPV as a risk factor than those who did not, the numbers of women in these groups were too small for a meaningful difference to be detected using statistical analyses (n=12 and n=3, respectively).

Overall awareness was substantially higher when measured by recognition (with 95% able to identify at least one risk factor), however on average women still only correctly identified half of the risk factors presented (50%,  $M=4.96/10$ ,  $SD=2.50$ ). The most recognised risk factors were 'Not going for regular smear (Pap) tests' (75%) and 'Having many sexual partners' (64%). The least recognised was 'having many children' (12%) (Table 5.3).

When prompted, 1029 (74%) of the women were able to recognise at least one risk factor relating to sexual activity. As with recall, women who recognised at least one risk factor relating to sexual activity were significantly more likely to also endorse HPV (n=563, 55%) than women who did not recognise any risk factors related to sexual activity (n=79, 23%) ( $\chi^2(1,1375)=106.73$ ,  $p<0.001$ ).

In bivariate analyses, older age was significantly correlated with a higher knowledge of risk factors when prompted ( $r(1377)=.10$ ,  $p<0.001$ ). Those with a higher level of education were able to recognise significantly more risk factors ( $M=5.54$ ) than those with a mid ( $M=4.88$ ) or lower level of education ( $M=4.78$ ) ( $F(2, 1371)=9.67$ ,  $p<0.001$ ), as

were those in the occupational group ABC1 ( $M=5.15$ ) compared to those in the occupational group C2DE ( $M=4.72$ ) ( $t(1377)=-3.19$ ,  $p=0.001$ ).

There was no difference in recognition of risk factors between the women who had had cervical cancer or had known someone with cervical cancer and those who had not. Similarly, there was no difference in risk factor recognition between White and non-White groups.

Table 5.3. Number of recalled and recognised cervical cancer risk factors (weighted  $n=1392$ )

Risk factor	Recalled		Recognised	
	(n)	%	(n)	%
Having many sexual partners	272	19.5	884	63.5
Hereditary/genetics/in the family	177	12.7	-	-
Smoking any cigarettes	121	8.7	706	50.7
Starting to have sex at a young age	111	8.0	758	54.4
Unprotected sex	101	7.3	-	-
Not going for regular smear (Pap) tests	78	5.6	1046	75.2
Infection, STI/STD or virus	20	1.4	-	-
Infection with Chlamydia	19	1.4	748	53.7
Infection with HPV	15	1.1	643	46.2
Long term use of the contraceptive pill	4	0.3	460	33.0
Having a sexual partner with many previous partners	4	0.3	740	53.1
Having many children	3	0.2	167	12.0
Having a weakened immune system	2	0.1	692	49.7

When risk factor recognition score was regressed onto the demographic and cancer experience variables the model accounted for a small but significant proportion of the variance (Adj.  $R^2=0.03$ ,  $F(5,1365)=7.94$ ,  $p<0.001$ ). Older age and a higher level of education significantly predicted higher awareness of cervical cancer risk factors in the

model, whereas ethnicity, SES and cancer experience did not. The standardised beta for age (beta=0.12,  $p<.001$ ) and education level (beta=0.11,  $p<.001$ ), were similar suggesting a roughly equal influence on risk factor awareness (Table 5.4).

Table 5.4 Regression for predictors of cervical cancer risk factor knowledge (recognised) (*weighted n=1372*)

	Beta <sup>†</sup>	SE	p
Constant	-	0.32	<.001
Age	0.12	<.0001	<.001
Ethnicity	-0.03	0.24	0.28
Occupation	0.04	0.15	0.18
Education	0.11	0.09	<.001
Cancer experience	0.04	0.18	0.14

Adj R<sup>2</sup> = 0.03,  $p<.001$ . <sup>†</sup>Standardised

Note: Ethnicity, occupation and cancer experience are categorical variables, coded as Non-White=0, White=1, 0=Group C2DE, 1=Group ABC1 and 0=no-one, 1=Me or someone close, respectively. Education is an ordinal variable, coded as Low-level=1, Mid-level=2 and High-level=3.

### 5.3.3 Awareness of cervical cancer symptoms

Two thirds of the women were unable to recall any of the target symptoms (75%, n=1049). This figure was lower (55%, n=764) when responses 'irregular bleeding'/'spotting'/'non-specific bleeding' were included (M=0.59, SD=0.77). Recognition of the target symptoms was better than recall, with 93% (n=1287) correctly recognising at least one symptom of cervical cancer. On average however, women only recognised just over half of the symptoms (55%, M=6.08/11, SD=2.85).

Although not on the target list, unusual vaginal bleeding (including responses: 'irregular bleeding'/'spotting'/'non-specific bleeding') was the most recalled symptom of cervical cancer (29%), followed by 'persistent, abnormal or unusual vaginal discharge' (15%).

Patterns were different when women were asked to recognise symptoms, with recognition highest for ‘vaginal bleeding between periods’ (73%), and ‘persistent pelvic pain’ (70%). Few women knew that ‘persistent diarrhoea’ was a symptom of cervical cancer as it was both the least recalled (0%) and recognised (12%) symptom (Table 5.5).

Table 5.5. Awareness of cervical cancer symptoms (weighted  $n=1392$ )

Symptom	Recalled		Recognised	
	( <i>n</i> )	%	( <i>n</i> )	%
Unusual vaginal bleeding*	397	28.5	-	-
Persistent/abnormal/unusual vaginal discharge	202	14.5	861	61.9
Vaginal bleeding between periods	61	4.4	1020	73.3
Heavier/longer periods than normal	46	3.3	723	52.0
Vaginal bleeding during/after sex	32	2.3	886	63.7
Pain/discomfort during sex	28	2.0	864	62.0
Persistent pelvic pain	20	1.4	971	69.8
Unexplained weight loss	14	1.0	778	55.9
Blood in stool/urine	12	0.9	598	43.0
Persistent lower back pain	11	0.8	602	43.3
Vaginal bleeding after the menopause	4	0.3	923	66.3
Persistent diarrhoea	0	0.0	164	11.8

\*Includes any reference in the open responses to non-specific vaginal bleeding, including ‘unusual/irregular bleeding’, ‘spotting’ and ‘bleeding (no detail)’ that did not match with the target symptoms in the closed question

In bivariate analyses, an older age was significantly correlated with a higher knowledge of symptoms when prompted ( $r(1379)=.07$ ,  $p<0.01$ ). Those with a higher level of education were able to recognise significantly more risk factors ( $M=6.59$ ) than those with a lower level of education ( $M=5.88$ ) ( $F(2, 1372)=6.37$ ,  $p<0.01$ ), as were those in the occupational group ABC1 ( $M=6.35$ ) compared to those in the occupational group C2DE ( $M=5.71$ ) ( $t(1379)=-4.17$ ,  $p<0.001$ ). Women from a White ethnic background ( $M=6.22$ ) were able to recognise significantly more symptoms than women from a non-White ethnic background ( $M=4.76$ ) ( $t(1376)=-5.61$ ,  $p<0.001$ ), as were women who had had a

close experience of cancer (M=6.56) compared to those who hadn't (M=5.99) ( $t(1379)=-2.70, p<0.01$ ).

The multiple linear regression model explained 4% of the variance in symptom recognition ( $\text{Adj } R^2=0.04, F(5,1366)=1.7128, p<.001$ ). A White ethnic background, being in the occupational group ABC1, a higher level of education and having a close experience of cervical cancer all predicted higher cervical cancer symptom recognition. The standardised beta value was highest for ethnicity (beta=.15,  $p<.001$ ). Occupation (beta =.08,  $p<.01$ ), education level (beta =.09,  $p<.01$ ) and having a close experience of cervical cancer (beta =.07,  $p<0.01$ ) all had lower beta values, suggesting that they have a weaker influence on risk factor awareness than ethnicity (Table 5.6).

Table 5.6. Regression for predictors of cervical cancer symptom recognition (weighted  $n=1373$ )

	Beta <sup>†</sup>	SE	P
Constant	-	0.36	<.001
Age	0.05	<.0001	0.072
Ethnicity	0.15	0.26	<.001
Occupation	0.08	0.16	0.008
Education	0.09	0.10	0.002
Cancer experience	0.07	0.21	0.005

Adj  $R^2= 0.04, p<.001$ . <sup>†</sup>Standardised

Note: Please see note under Table 5.4

#### 5.4. Discussion

This was the first study to explore cervical cancer symptom awareness in an English female population-based sample, and to attempt to determine predictors of symptom awareness. It was also the first study to explore cervical cancer risk factor awareness (including awareness of HPV) in this sample, along with predictors of awareness, following the introduction of the HPV vaccination, Cervarix® in 2008, although since this study was conducted, further research exploring awareness of HPV has been conducted

(Marlow, Zimet, et al., 2013). Further, the data in the current study were collected just prior to the launch of the Department of Health's key messages on cervical cancer in 2010 (NHS Choices, 2011). Measuring awareness at this unique point in time and using a validated measure (the Cervical CAM), allows for a comparison of awareness following the introduction of these messages, therefore enabling a measurement of the impact of the key messages, particularly as no formal evaluation of the impact of these key messages has been undertaken.

Women demonstrated very poor knowledge of symptoms and risk factors for cervical cancer when they were not prompted, with most unable to recall any. Awareness was much higher for both when prompted; although even then women were only able to recognise around half of the symptoms and risk factors presented. These findings are reflective of existing research that has used both recall and recognition questions to explore awareness of cancer symptoms (for example, Power et al., 2011; Simon, Juszczak, et al., 2012; Waller, McCaffery, & Wardle, 2004b). That these two types of measurement produce different results in the present study highlights the differences in the cognitive processes involved in recall and recognition. Not only was recall much lower, but the patterns of those risk factors and symptoms for which participants were most and least aware of was different when the two different measurements were used. For example, the most recalled risk factor was having many sexual partners, whereas the most recognised risk factor was not going for regular smear tests.

Recalled knowledge is an active retrieval of memory, whereas recognition could be argued to be more passive and less taxing in terms of cognitive processes. There is even evidence that the two processes are dealt with by different brain areas (Rugg & Yonelinas, 2003). However, whilst recall could be argued to be a more accurate measure of 'true' memory, given that no prompting is required to elicit this information, these measurements should be assessed in the context of this research. With symptoms in particular, the symptom itself would act as a prompt to recognise that this may be a sign of cervical cancer. Again, with risk factors, the act of risky behaviour itself may act as a prompt to recognition. Therefore recognition may actually be a more

ecologically valid measure of awareness in this particular study and other similar studies.

Although the most recognised risk factor was 'not going for regular smear (Pap) tests' (>75%), a quarter of women were not able to identify this risk factor even when prompted. It has been suggested that lack of awareness of the function of the cervical cancer screening programme can negatively affect attendance (Hansen et al., 2011). Currently around 20% of eligible women are not participating in screening and coverage for women in the higher risk age group (25-49 years) is falling (Health and Social Care Information Centre, Screening and Immunisations team, 2012). Increasing awareness that the cervical screening programme can reduce the risk of cervical cancer may help to increase attendance, resulting in lower incidence and consequently lower mortality.

Recognition of 'smoking' (51%) and 'infection with Chlamydia' (54%) as risk factors for cervical cancer appears to have improved in this study compared to earlier research (Philips et al., 2005), with over half of respondents able to recognise each. It was disappointing however, that unprompted awareness of HPV in particular was very low (1%) and that, despite the introduction of the HPV vaccine in 2008 and the associated publicity, unprompted awareness of this risk factor was similar to that recorded in 2004 (<1%) (Waller et al., 2004a) and lower than it was reported to be in a survey carried out in 2006 (2.5%) (Marlow et al., 2007).

Previous studies have highlighted the apparent lack of understanding about the link between cervical cancer and sex and the mechanism for this (i.e. HPV infection) (for example, Marlow et al., 2007). In the current study I attempted to explore whether women were significantly more likely to mention HPV if they also mentioned a risk factor related to sexual behaviour than if they did not. This analysis would have been interesting, as it would have provided an indication of whether the relationship between sexual activity, HPV and cervical cancer is now better understood than it has been in the past (Waller et al., 2004a). However, it was not possible to carry out these analyses due to the small numbers of women in each group. However, even if the results here had shown an increased understanding, there is still more work to be done as a substantial

amount of those who endorsed a sexual activity risk factor either when prompted (45%) or unprompted (97%) did not endorse HPV. Previous research on public understanding of the link between cervical cancer and smoking has highlighted the importance of having a coherent model linking a risk factor to an outcome (Hall, Weinman, & Marteau, 2004), and future research might investigate ways of helping women understand the role of sexual activity in cervical cancer aetiology.

In contrast to my hypothesis, I found that younger, not older women had lower awareness of risk factors for cervical cancer. This is concerning, as incidence is highest in women aged 30-34 (NHS Cancer Screening Programmes, 2011; Office for National Statistics, 2012b) and there is evidence that younger women may be more vulnerable to some risk factors such as infection with Chlamydia (Health Protection Agency, 2010). One explanation for these findings may be the use of a composite risk factor score, whereas previous research has investigated awareness of individual risk factors for cervical cancer (for example, Marlow et al., 2007) or cancer risk factors in general (Adlard & Hume, 2003). A composite score may lead to higher awareness in older women as younger women may be more aware of specific risk factors (such as HPV (Marlow et al., 2009)) but less aware of risk factors overall.

The most recalled symptoms were 'unusual vaginal bleeding' (29%) and 'Persistent/abnormal/unusual vaginal discharge' (15%). This was particularly reassuring given that they are the most common symptoms of cervical cancer and are highlighted in the Department of Health's Key Messages (NHS Choices, 2011). However, less reassuring was the fact that most women were unable to recall any symptoms and even for these common symptoms recall was still quite low.

Recognition was good for the 'bleeding' and 'pain' symptoms (Table 5.5), reflecting earlier findings that, when participants were presented with symptoms of cancer more generally, two of the three most recalled symptoms were bleeding and pain symptoms (Robb et al., 2009). This suggests that women think of cervical cancer symptoms as relatively alarming or dramatic. As they are not necessarily so, it may be useful to raise awareness of the less dramatic or vaguer symptoms of cervical cancer, such as



'unusual vaginal discharge' as recognition was not as high for this common symptom (62%) as it was for the bleeding symptoms. Studies of help-seeking behaviour support this conclusion; women are more likely to seek help promptly for gynaecological cancers if they perceive their symptom to be alarming (for example bleeding) or serious (for example pain) and are less likely to do so for cancer symptoms in general if they experience a symptom which is perceived as more common or vague (Macleod et al., 2009). These findings can be explained within the MPT, described in Chapter Two, which posits that 'contributing factors' can explain how an individual moves from the 'appraisal interval' to the 'help-seeking interval'. Patient or disease factors may contribute towards the appraisal of a symptom as alarming, serious, common or vague. For example, if an individual knows of a number of other women who have experienced a similar symptom which was found to have a non-serious cause, they may be less likely to appraise their own symptom as serious.

As expected, White ethnicity, having a higher level of education, working in a higher level occupation group and having had a close experience of cervical cancer all predicted higher recognition of symptoms, reflecting earlier research for cancer symptoms in general (Robb et al., 2009). We know that lower SES and non-White women have poorer outcomes when diagnosed with cancer (Jack, Davies, & Moller, 2009; Rachet et al., 2010). We also know that GPs are less likely to refer these groups of women to secondary care (Morris, Sutton, & Gravelle, 2005). If women are unaware of the symptoms for cervical cancer, they may be less likely to insist on referral for further investigation. Increasing awareness in these groups could ultimately affect survival rates by increasing confidence when seeking help for symptoms, and thus increasing referrals for these women.

#### **5.4.1 Strengths and limitations**

This study was strengthened by the use of a validated tool to systematically measure both risk factor and symptom awareness for cervical cancer. Further, these data were collected just prior to the launch of the cervical cancer key messages; using the validated cervical CAM to assess awareness again in the future may give an indication of the impact of these key messages on awareness.

As the sample was population representative, the proportion of non-White participants was inevitably small (in 2011 approximately 12% of the population of was non-White (Office for National Statistics, 2011)). Given that women from non-White backgrounds had lower symptom awareness than White women, future research may explore ethnic differences in samples with a higher proportion of non-White women.

Another limitation of this study was the small amount of variance explained by each model, suggesting that there are other, stronger influences on awareness that were not measured. Further work should be carried out to identify these variables. Further, one of the aims of the study was to explore awareness of symptoms and risk factors. However, the structure of the question exploring risk factor awareness in particular may have meant that personal opinion was tapped into, rather than awareness that each risk factor was related to cervical cancer. Awareness was measured using a Likert scale, which gave women the option of agreeing or disagreeing on a sliding scale about whether an option was a risk factor or not. This may have led to women who had heard of a particular risk factor, but did not agree that it increased the chances of developing cervical cancer disagreeing. This would then incorrectly be measured as a lack of awareness. It is recommended that in future research, wording of questions designed to measure awareness is considered carefully.

A number of potential risk factors for cervical cancer were not explored in this study; namely early age at first pregnancy, family history of cervical cancer and unprotected sex. Although early first pregnancy also indicates early sexual debut, which is a known risk factor, and was explored here, there is some evidence that suggests that a shorter period between age at sexual debut and first pregnancy may increase the risk of cervical cancer over and above that posed by a younger age at sexual debut alone (Louie et al., 2009). As such, future research might explore awareness of this as a separate risk factor to early sexual debut.

The role of family history of cervical cancer is not yet fully understood and the genes associated with this process are not yet clear (de Freitas et al., 2012). However, there is evidence that risk factors for developing cervical cancer associated with lifestyle may

run in families. For example, Fidler, West, Jaarsveld, Jarvis, and Wardle (2008) found that children with just a non-biological parent who smoked (i.e. their biological parent did not smoke) when they were aged 11-12 were almost three times as likely to be smokers themselves between the ages of 11 and 16 compared to those who had neither a biological or non-biological parent who smoked. Future versions of the Cervical CAM might include family history or cervical cancer as a risk factor once this relationship becomes clearer.

Finally, the literature exploring protective effects of condom use was far from consistent at the time the Cervical CAM was developed (Manhart & Koutsky, 2002), and as such, awareness of this risk factor was not included. However, a recent review has concluded that there is evidence for a partial, but good level of protection against HPV associated with condom use (Lam et al., 2014). Again, future versions of the Cervical CAM might include this risk factor.

There were a small proportion of missing data (<1%) for education and ethnicity, and those cases with missing data were removed from analysis. However, the size of the missing data meant it was very unlikely that removing these cases would have affected my overall findings. As such, I feel it was not necessary to run sensitivity analyses. Finally, I was unable to accurately report a response rate for this survey as TNS do not record the number of addresses they attempt to recruit from.

#### **5.4.2 Conclusions**

Awareness of both risk factors and symptoms of cervical cancer is low in English women. Future research in this area should investigate awareness of the link between sexual behaviour, HPV and cervical cancer as it was not possible to explore this relationship here.

Some population subgroups may benefit from more education on risk factors and symptoms in general – including younger women, ethnic minorities, those from a lower SES and those with less education. It is hoped that by improving awareness in these

groups, prompt help-seeking will be encouraged, reducing the chances of a poor outcome.

The study discussed in the present chapter provides useful information about data gaps and where additional education may be needed. Further, as discussed in Chapter Two, perceived risk and symptom awareness may play a part in time to help-seeking. For example, the CSM aims to explain how an individual appraises and responds to a threat to their health, and then attempts to cope with this threat. If an individual believes themselves to be at risk of an illness, a coping strategy may involve seeking medical help. Again, within the MPT, perceived risk may be influenced by contributing factors within the model, which in turn may lead to movement from the appraisal interval to the help-seeking interval. Further, it is important to identify those factors that may influence levels of awareness. In Chapter Three, I also discussed the lack of literature exploring help-seeking for symptoms of female cancers. In the next chapter, therefore, I have explored symptom and risk factor awareness, and the relationship between these two variables and anticipated time to help-seeking for symptoms of ovarian cancer.

## CHAPTER SIX - OVARIAN CANCER SYMPTOM AWARENESS AND ANTICIPATED TIME TO HELP-SEEKING FOR SYMPTOMS (STUDY 2)<sup>10</sup>

### 6.1 Introduction

#### 6.1.1 Background

In Chapter Three I discussed the literature exploring predictors of help-seeking for symptoms of female cancers. The literature revealed a strong evidence base for the negative effects of symptom misattribution and non-recognition of symptom seriousness on help-seeking for symptoms of female cancers, including ovarian cancer. I also found inconclusive evidence for the effects of age and fear. Factors that may *encourage* prompt help-seeking include fewer perceived barriers to help-seeking (Robb et al., 2009) and a personal experience of cancer (Macleod et al., 2009).

In Chapter Five I discussed how increasing awareness of symptoms for cervical cancer might lead to a higher level of symptom recognition, and therefore increase the likelihood of accurate symptom attributions, leading to appropriate and timely help-seeking. However, although I explored symptom and risk factor awareness in Chapter Five, I did not investigate this in relation to help-seeking, as I was limited by the data produced by the Cervical CAM (collected prior to this PhD), which only included the question, 'If you had a symptom that you thought might be a sign of cervical cancer how soon would you contact your doctor to make an appointment to discuss it?', rather than asking women about each symptom. Given the evidence that help-seeking may be influenced by symptom type (as discussed earlier), I did not use this data and therefore, I was unable to explore influences on help-seeking for cervical cancer symptoms.

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<sup>10</sup> A version of this chapter has been published elsewhere and can be found in Appendix 4 (Low, Waller, et al., 2013)

Given my conclusions in Chapter Three, I would expect that higher levels of awareness of symptoms of ovarian cancer may lead to a reduced chance of symptom misattribution and consequently a reduced time to help-seeking. As the existing data for this chapter (collected in 2009, prior to the commencement of my PhD) included awareness of symptoms and anticipated help-seeking for hypothetical symptoms of ovarian cancer, I was able to test the relationship between awareness of symptoms and anticipated time to help-seeking. As discussed in the previous chapter, before awareness can be increased, current levels of awareness must be established.

### **6.1.2 Existing literature on ovarian cancer symptom awareness**

As mentioned above, higher symptom awareness may play a part in time to help-seeking for symptoms of ovarian cancer, although in Chapter Three I only found the effects of this in actual help-seeking, and not in intention to seek help. Nevertheless, given that the area is under-researched, and that there is evidence that symptom awareness may influence actual help-seeking for symptoms of ovarian cancer and intention to seek help for other cancers (for example, Quaife et al., 2014), it is worth investigating this relationship.

To my knowledge, there was very little literature that had explored awareness of symptoms of ovarian cancer, and none that had done so in the UK, prior to the undertaking of the study reported here. The two studies that I did find were both published in the US (Cooper, Polonec, Stewart, & Gelb, 2013; Lockwood-Rayermann, Donovan, Rambo, & Kuo, 2009). Since a version of this chapter has been published, however, one study was published in the UK (Brain et al., 2014).

Lockwood-Rayermann et al. (2009) surveyed 1,211 US women in 2006 to determine their awareness of ovarian cancer, including symptoms. They found that very few women felt familiar with the symptoms (15%). Women were most familiar with 'pelvic and/or abdominal swelling, bloating and/or feeling of fullness' (47%), 'ongoing unusual

fatigue' (36%), and 'unexplained weight gain or weight loss' (36%). Women were least familiar with 'unexplained changes in bowel habits' (28%) and 'frequency and/or urgency of urination in the absence of an infection' (26%). However, women were prompted, as they were presented with symptoms and asked to identify them. Unprompted awareness may have been lower still.

In Chapter Three, I discussed the focus group study findings presented by Cooper et al. (2013). A second study was published using data from the same women, collected at the same time. Although, again, all five gynaecological cancers were investigated, I have only discussed the findings related to ovarian cancer here. Reflecting Lockwood-Rayermann et al.'s (2009) findings, Cooper et al. (2013) found that the majority of women in the focus groups had heard of ovarian cancer, although overall, women were mostly unaware of all of the symptoms. Overall then, prior to the commencement of this study, the existing research indicated that awareness was generally low.

In a similar fashion to Lockwood-Rayermann et al.'s (2009), Brain et al. (2014) surveyed 1043 Welsh women about their knowledge of ovarian cancer (the findings relating to help-seeking have been discussed in Chapter Three), asking them to identify symptoms from a list. The mean awareness score was 6.85 of the 11 symptoms investigated. Women were most aware of abdominal bloating (72%), increased abdominal size (69%) and back pain (68%) and least aware of difficulty eating (36%), and a change in bladder habits (32%). Interestingly, these levels of awareness were considerably higher than those reported by Lockwood-Rayermann et al.'s (2009). This is likely to be a result of varying levels of awareness in these different populations, which may also explain the differences in levels of awareness for individual symptoms. Low awareness of urinary frequency does seem to be a particular problem in both samples, however.

### **6.1.3 Existing literature on ovarian cancer risk factor awareness**

A number of factors may increase the chances of developing ovarian cancer, and just over a fifth (20.2%) of incident ovarian cancer cases in the UK may be attributable to lifestyle and environmental factors (Parkin et al., 2011). For example, there is evidence that the risk of ovarian cancer increases along with an increase in BMI (Reeves et al., 2007) and with smoking status (Gram et al., 2012). Some research has suggested a link between talcum powder use and increased risk of ovarian cancer, although this relationship is not clear (Huncharek, Geschwind, & Kupelnick, 2003; Wu, Pearce, Tseng, Templeman, & Pike, 2009).

Evidence also suggests a role for increasing number of ovulatory cycles (or factors which reflect longer exposure to ovulation) and increased ovarian cancer risk (Cramer, 2012). For example, rates of ovarian cancer have been found to be higher in women who are nulliparous or have fewer children (Merritt et al., 2013), have undergone IVF (van Leeuwen et al., 2011) and hormone replacement therapy (HRT) (Tsilidis et al., 2011). The increased risk associated with HRT may increase the risk of ovarian cancer in menopausal and post-menopausal women (along with the increase in incidence with age (94% of incident cases registered in 2011 in women aged  $\geq 45$  years, compared to just 11% (n=632) in women under 45 years (Office for National Statistics, 2013a)).

Unsurprisingly, given the known risks associated with inheriting the BRCA1 and BRCA2 genetic mutations for both breast and ovarian cancer (Welch & King, 2001), having a close relative who has also had ovarian cancer is a risk factor for developing the disease (Stratton, Pharoah, Smith, Easton, & Ponder, 1998), as is having a history of breast cancer (Borgfeldt et al., 2002). Finally, conditions that cause damage to the reproductive system have also been associated with an increase in risk of developing ovarian cancer, such as ovarian cyst removal surgery and endometriosis (Borgfeldt & Andolf, 2004).



Although there is a large body of literature exploring risk factors associated with ovarian cancer, the literature on awareness of these risk factors is small. In fact, I could only find one paper that had explored this area. In 2010, Fallowfield et al. asked a large sample of women (n=21,715) aged 50-74, who were participating in the UKCTOCS trial (UCL and UCLH NHS Foundation Trust, 2008, see Chapter One) to complete a number of measures exploring awareness of ovarian cancer risk factors, anxiety levels, general emotional health, and sexual activity. A high percentage of women were aware of the association between a family history of ovarian cancer and increased risk of the disease (87%), but not between a family or personal history of breast cancer and risk of ovarian cancer (27% and 20% respectively). Less than half of the women in this study were aware of the increased risks associated with being post-menopausal (38%), nulliparous (14%) or having had a benign ovarian cyst (20%). The authors also explored awareness of having refrained from breast-feeding (6.2%) and awareness of false risk factors, such as having had an abnormal smear (37%) and having taken the contraceptive pill (26%). Fallowfield et al. (2010) reported that awareness was higher in women who were younger, more educated and who had had more than one relative with breast cancer, versus none.

Whilst the study described above is useful in understanding levels of risk factor awareness for ovarian cancer, the authors do acknowledge that these levels of awareness may have been inflated by the pre-recruitment information provided to these participants, as part of their participation in the UKCTOCS trial. Further, the women were given a list of the potential risk factors, and were consequently prompted for their answers. As evident in my previous chapter, levels of recognition of risk factors are considerably higher than levels of recall. However, the sample was similar to that of the general UK population, and may reflect at least the risk factors which were most commonly endorsed, if not the level to which they were endorsed.

#### **6.1.4 The current study**

As described above, there has been very little research which has attempted to explore awareness of ovarian cancer symptoms or risk factors in a population-representative sample of English women. None of the research published on symptom awareness prior to the undertaking of this study was conducted in the UK. Although I did identify one study which had explored awareness of risk factors, the study sample consisted of women who were participating in a larger trial exploring the feasibility of screening for ovarian cancer, and may have consequently received information which could have increased their awareness above what would have normally been expected.

The present study aimed to explore awareness of both symptoms of and risk factors for ovarian cancer in a population representative sample of English women. Both open and closed questions were used to measure recall and recognition respectively.

#### **6.1.5 Hypotheses**

Given the literature discussed in Chapter Three and in section 6.1, here, I tested the following hypotheses:

- i. Risk factor awareness will be low
- ii. Symptom awareness will be low
- iii. Lower symptom awareness, a personal experience of cancer or having known someone close with cancer (such as a close friend, partner or family member), and more perceived practical barriers to help-seeking will be associated with a longer anticipated time to help-seeking for symptoms of ovarian cancer

I was unsure of the direction of the relationship between age and help-seeking and fear (measured here as an emotional barrier to help-seeking) and help-seeking due to inconsistent or inconclusive previous findings. Consequently I made no specific hypotheses with regard to these variables. As the incidence of ovarian cancer begins to rise at around age 45 (Cancer Research UK, 2013c), I tested the above hypotheses both in a population-based sample of women aged 16 years and over, and in a

subgroup of women aged  $\geq 45$ . Finally, the relationship between awareness of risk factors for ovarian cancer and time to help-seeking has not been explored in the literature. As such, although I explored this relationship below, I had no hypotheses relating to this factor.

## **6.2 Method**

### **6.2.1 Recruitment**

As part of the Target Ovarian Cancer Pathfinder Study (Target Ovarian Cancer, 2009), females aged  $\geq 16$  were recruited via Synovate (a global market research company) using random digit dialling. Quotas (i.e. target recruitment numbers for specific demographic groups) were used to achieve a population-based sample of women from different age groups, regions and working statuses. 1000 women<sup>11</sup> were interviewed over the telephone by Synovate interviewers, using landlines only. Respondents were interviewed for approximately 15 minutes using the Ovarian Cancer Awareness Measure (Ovarian CAM) (Simon, Wardle, et al., 2012). The Ovarian CAM is a site-specific version of the generic Cancer Awareness Measure (Stubbings et al., 2009). The Ovarian CAM was specifically designed and validated to be used for both telephone and face-to-face surveys (Simon, Wardle, et al., 2012); in the current study, telephone interviews were conducted as opposed to face-to-face interviews as this allowed faster and relatively inexpensive data collection.

The study was exempt from ethical approval as no identifiable information was collected from participants, and data were completely anonymous. This is in line with the UCL Research Ethics Committee Exemptions guidelines (UCL Research Ethics Committee, 2013). See page 121.

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<sup>11</sup> Synovate does not record the number of people approached in order to fulfill quota samples.

## **6.2.2 Measures**

### **6.2.2.1 Awareness of ovarian cancer symptoms**

Respondents were asked one open question and a set of closed questions to measure awareness of ovarian cancer symptoms. The open question (which was asked before the closed question to avoid bias) measured recall and read: *“There are several warning signs and symptoms of ovarian cancer. Please name as many as you can think of”*. The closed questions measured recognition and read: *“The following may or may not be warning signs for ovarian cancer. We are interested in your opinion”*. Respondents were read a list of 10 known symptoms of ovarian cancer (see Table 6.1) taken from the Department of Health’s (DoH) Key Messages for ovarian cancer for health professionals (Department of Health, 2009). Response options to each symptom were ‘yes’, ‘no’ and ‘don’t know’. If participants refused to answer, this was recorded as ‘missing’. Each open question response was dichotomised into ‘recalled’ (mentioned) or ‘not recalled’ (not mentioned) and each closed question response was dichotomised into ‘recognised’ (response ‘yes’) or ‘not recognised’ (responses ‘no’/‘don’t know’).

### **6.2.2.2 Awareness of ovarian cancer risk factors**

Awareness of risk factors was measured in the same way as symptom awareness, with both open and closed questions. The open question read: *“What things do you think affect a woman’s chance of developing ovarian cancer?”* with the aim of again, eliciting recalled knowledge. The closed question, again used to measure recognition of risk factors listed 12 known risk factors for developing ovarian cancer (see Table 6.3), which were generated using the scientific literature, cancer information materials and websites available at the time the measure was developed (Simon, Wardle, et al., 2012) and asked participants to identify those they believed were risk factors with the question, *“These are some things that can increase a woman’s chance of developing ovarian cancer. How much do you agree that each of these can increase the chance of developing ovarian cancer?”*. Response options were ‘strongly disagree’, ‘disagree’, ‘not sure’, ‘agree’, and ‘strongly agree’. As with the symptoms data, each open question

response was dichotomised into 'recalled' (mentioned) or 'not recalled' (not mentioned) and each closed question response was dichotomised into 'recognised' (responses 'agree' or 'strongly agree') or 'not recognised' (responses 'not sure', 'disagree' or 'strongly disagree'). Again, refusal to respond was recorded as 'missing'.

Participants were given a score of '1' for each recognised or recalled symptom or risk factor, otherwise they were given a score of '0'. Scores were summed to give overall scores for risk factor recall and recognition (range 0-12 for both) and symptom recall and recognition (range 0-10 for both). The full list of ovarian symptoms and risk factors included can be seen in Tables 6.1 and 6.2, respectively. For both the open risk factor and symptom questions, responses were recorded verbatim and coded into a framework by Synovate interviewers. Coding accuracy was verified by a separate Synovate team who specialise in coding interviews. For ease of analysis, and to allow comparisons between numbers of recalled and recognised symptoms and risk factors, I have only reported those responses from the open questions that corresponded with those from the closed questions.

### **6.2.2.3 Barriers**

Respondents were read a list of ten barriers and the question, "*Sometimes people put off going to see the doctor, even when they have a symptom that they think might be serious. These are some of the reasons people give for delaying. Could you say if any of these might put you off going to the doctor?*". Responses were dichotomised into 'yes' (responses 'Yes sometimes'/'Yes often') and 'no' (responses 'Don't know'/'No'). As previously described (Robb et al., 2009), barriers were grouped into emotional, service and practical barriers (Table 6.4). Responses were summed to give total scores for each group of barriers. Scores ranged from 0-4 for emotional barriers, 0-3 for service barriers and 0-3 for practical barriers.

#### **6.2.2.4 Anticipated time to help-seeking**

For each symptom from the closed list, respondents were asked, '*how soon would you contact your doctor to make an appointment to discuss it?*'. There were ten response options on an ordinal scale ranging from '*1-3 days*' to '*never*'. For ease of analysis I coded each time period in ascending order from 0 to 10 to measure anticipated time to help-seeking. I dichotomised the sample into those who anticipated waiting more or less time before help-seeking for each symptom. To do this, I calculated the median anticipated time to help-seeking for each symptom (using the scale from 0-10) and then dichotomised responses into a 'longer anticipated time to help-seeking' ( $>$ median; score=1) and a 'shorter anticipated time to help-seeking' ( $\leq$ median; score=0). I used a dichotomous, as opposed to a continuous variable as the increments in time periods were unequal, making it an ordinal rather than an interval scale.

Dichotomising the sample in this way allowed me to identify those women who were likely to wait longer than average before seeking help for each of the symptoms, rather than focusing on the length of time to help-seeking, as I acknowledge that responses may not reflect actual responses to symptoms. Further, I discussed the benefits of avoiding using a specific time cut-off in Chapter Three. Scores for each symptom (1 or 0) were summed to create a scale of anticipated time to help-seeking (range 0-10). A higher score indicated that the respondent would anticipate waiting longer than the median before seeking help for a greater number of symptoms.

#### **6.2.2.5 Participant characteristics**

Age was measured as a continuous variable. I created a subgroup of women aged  $\geq 45$  years for analysis who were at high risk of developing ovarian cancer due to their age (incidence of ovarian cancer begins to increase at this age (Cancer Research UK, 2013c)). SES was categorised into low (score=0-1), mid (score=2) and high (score=3) based on a combined index incorporating education level, car ownership and home

ownership. This index was used as it is recommended for a sample including older, retired respondents (Wardle et al., 1999). One point is given for owning a home, having a car and having any formal education (score range 0-3).

As only 7.1% of respondents were non-White, these ethnicities were grouped together and the sample was dichotomised into 'White' or 'non-White'. Respondents were asked whether they had known a close family member, close friend or partner with cancer. Responses were dichotomised into 'yes' (score=1) or 'no/don't know' (score=0) and summed to give a score of 'cancer experience' (range 0-3). Respondents were also asked whether they had experienced cancer themselves ('no' or 'yes').

### **6.2.3 Analyses**

Data were analysed using SPSS version 19 (IBM Corporation, 2010). I carried out bivariate analyses (using ANOVA, t-tests and correlations) to determine those demographic variables which were significantly associated with either risk factor or symptom awareness. To select variables for the multivariate models, I first used bivariate analyses and analysis of variance (ANOVA) to test for significant associations between anticipated time to help-seeking and my hypothesised predictor variables as well as demographic factors (reported below).

Demographic variables (SES, ethnicity and age) and variables that were significantly associated with anticipated time to help-seeking were entered into two multiple linear regressions (using the sample as a whole and the subgroup of women aged  $\geq 45$  years) to identify significant independent predictors of score on the scale.

#### **6.2.3.1 Weighting**

Small sampling weights were provided by Synovate and were applied to adjust for non-response bias in terms of government office region, age and occupational status to

achieve a population-based sample of women. Weighting had the biggest effect on the 25-38 age group, but even this effect was very small. Although there were effects of weighting observed in the other demographic characteristics, these effects were all smaller than 1% (see Table 6.1 for the weighted and unweighted sample characteristics).

### **6.2.3.1 Missing data**

Despite the option to refuse to answer for each of the questions in the Ovarian CAM, there were amount small amounts of missing data for some of the variables. The highest amount of missing demographic data (3%) were in the homeowner variable (which was used to create the SES variable). The other two variables used to create the SES variable were also missing small amounts of data (both the education and homeowner variables were missing 2% of data). For the time to help-seeking questions, the biggest amount of data were observed when women were asked about how long it would take them to seek help for passing more urine than usual (4.6%), although all of the questions were missing small amounts of data. There were no missing data for any of the closed symptom or risk factor questions, any of the emotional, service or practical barrier questions or age.

As with the missing data observed in Chapter Five, where a case was missing data, I excluded that case from any analyses in which the missing value would have been required. Again, given the small amount of missing data it is unlikely that this would have affected my findings.

### **6.2.3.2 Parametric Assumptions**

Data were tested for normality and homogeneity of variance. As the skewness and kurtosis of the outcome variable (number of symptoms participants anticipated waiting longer for) were both within normal distribution ranges (-1 – 1+), linear regressions were appropriate here.



## **6.3 Results**

### **6.3.1 Participant Characteristics**

The sample consisted of 1000 women. The mean (M) age of the women who participated was 47 years (range=16-91, SD=18.56). Most respondents were White (93%) and around half had a high SES (54%). Although, as in Chapter Five, non-White women were under-presented here, compared to the female population in England and Wales (7.1% versus 12%, respectively) (Office for National Statistics, 2014b), the proportion of women with a high SES was similar to the levels of British people who fall into the higher ABC1 category according to the NRS social grading system (56%) (Ipsos MediaCT, 2009; National Readership Survey, 2007). As with the data in Chapter Five, the differences observed between the sample here and the British population are likely to be a result of the application of weights to the whole survey sample, and not just those that completed the Ovarian CAM module.

Almost two-thirds of the women (63%) in the sample overall had known someone close with any type of cancer, but few (5%) had experienced cancer themselves. The subgroup of women aged  $\geq 45$  years ( $n=510$ ) had a mean age of 62 years (range 45-91). Again, most were White (97%) and high SES (60%). Nearly three quarters (72%) had known someone with cancer, and 8% had had cancer themselves. See Table 6.1 for participant characteristics.

Table 6.1 Sample Characteristics (Weighted/Unweighted  $n=1000$ )

	Unweighted		Weighted	
	<i>N</i>	(%*)	<i>N</i>	(%*)
<i>Age</i>				
16-24	154	(15.4)	150	(15.0)
25-39	231	(23.1)	244	(24.4)
40-59	320	(32.0)	312	(31.2)
60 +	295	(29.5)	294	(29.4)
<i>Age Groups</i>				
≥45	515	(51.5)	510	(51.0)
<45	485	(48.5)	490	(49.0)
<i>Ethnicity</i>				
White	928	(92.8)	928	(92.8)
Non-white	71	(7.1)	71	(7.1)
<i>Socioeconomic status</i>				
High	513	(51.3)	515	(51.5)
Mid	325	(32.5)	324	(32.4)
Low	108	(10.8)	108	(10.8)
<i>Close experiences of cancer</i>				
Someone close	633	(63.3)	632	(63.2)
Personal experience	49	(4.9)	49	(4.9)

\* where %<100%, this is due to missing data

### 6.3.2 Symptom Awareness

Symptom recall was low, with 58% ( $n=582/1000$ ) of the whole sample and 54% ( $n=275/510$ ) of the subgroup of women aged  $\geq 45$  years unable to recall any of the 10 symptoms listed in Table 6.2 ( $M=0.6/10$  for the whole sample,  $SD=0.8$  and  $M=0.6/10$ ,  $SD=0.9$  in the older subgroup). 'Pain in the abdomen' was the most commonly recalled symptom in both the sample overall and in the subgroup (24% and 26% respectively). 'Feeling full' was the least recalled overall (<1%) and in the subgroup it was 'difficulty eating on most days' (<1%). Recognition scores were much higher with almost all (99%)

able to identify at least one of the 10 symptoms in the overall sample (M=6.3/10, SD=2.2) and in the subgroup (M=6.1/10, SD=2.2). Recognition was lowest for 'difficulty eating' (25% in the overall sample; 21% in the subgroup) and highest for 'pain in pelvis' (87% in the overall sample; 84% in the subgroup) (Table 6.2).

White women were able to recognise significantly more symptoms than non-White women (M=6.35/10, SD=2.16 versus M=5.65/10, SD=2.35,  $p<0.01$ ). Women from a higher SES knew significantly more symptoms when unprompted (M=0.69/10, SD=0.63) than women from a mid-level SES (M=0.43/10, SD=0.71) and women from a low SES (M=0.42/10, SD=0.64) ( $F(2, 943)=13.14, p<0.001$ ). There were no other significant demographic differences in symptom awareness.

Table 6.2. Recalled and recognised ovarian cancer symptoms

	Overall sample (n=1000)		Subgroup* (n=510)	
	Recalled	Recognised	Recalled	Recognised
	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>
Persistent pain in abdomen	238 (24)	837 (84)	132 (26)	409 (80)
Persistent pain in pelvis	96 (10)	867 (87)	55 (11)	431 (84)
Persistent bloating	91 (9)	683 (68)	57 (11)	329 (65)
Extreme fatigue	35 (4)	703 (70)	17 (3)	359 (70)
Increased abdominal size	28 (3)	790 (79)	19 (4)	393 (77)
Back pain	28 (3)	706 (71)	21 (4)	368 (72)
Changes in bowel habit	24 (2)	569 (57)	16 (3)	280 (55)
Passing more urine than usual	9 (<1)	450 (45)	4 (<1)	205 (40)
Feeling full persistently	6 (<1)	450 (45)	5 (1)	253 (50)
Difficulty eating on most days	8 (<1)	247 (25)	3 (<1)	105 (21)

\*Subgroup of women aged  $\geq 45$  years

### 6.3.3 Risk factor Awareness

Risk factor recall was lower than symptom recall both in the overall sample and in the subgroup of women aged  $\geq 45$  years, with 80% ( $n=796/1000$ ) of the whole sample and 84% ( $n=427/510$ ) of the subgroup of women aged  $\geq 45$  years unable to recall any of the 12 risk factors listed in Table 6.3 ( $M=0.2/12$  for the whole sample,  $SD=0.5$  and  $M=0.2/12$ ,  $SD=0.4$  in the older subgroup). Recall was highest for the risk factor 'having a close relative with ovarian cancer' both in the overall sample and in the subgroup (15% and 14% respectively), closely followed by 'being a smoker' (recalled by 14% of the whole sample and 10% of the subgroup). Women were least aware of the risk factor 'having endometriosis' in both the overall sample and the subgroup, with no women recalling this risk factor in both.

As with knowledge of symptoms, awareness of risk factors was considerably higher when women were prompted. Almost 100% (97%,  $n=970/1000$ ) of the total sample and 96% ( $n=489/510$ ) of the subgroup of women recognised at least one of the risk factors listed in the Ovarian CAM measure. On average, women recognised just under half of the risk factors ( $M=5.1/12$ ,  $SD=2.5$  in the overall sample and  $M=4.8/12$ ,  $SD=2.5$  in the subgroup). Recognition was lowest for 'going through the menopause' (16% in the overall sample; 14% in the subgroup) and 'using talc on genitals' (16% in the overall sample; 19% in the subgroup). In both the overall sample and the subgroup, women most commonly recognised 'having a close relative with ovarian cancer' (77% and 69% respectively).

Women from a higher SES knew significantly more risk factors ( $M=0.29/12$ ,  $SD=0.55$ ) than women from a mid SES ( $M=0.19/12$ ,  $SD=0.44$ ,  $p<0.05$ ), when unprompted. There were no other significant demographic differences in risk factor awareness.

Table 6.3. Recalled and recognised ovarian cancer risk factors

	Overall sample		Subgroup*	
	(n=1000)		(n=510)	
	Recalled	Recognised	Recalled	Recognised
	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>
Having a close relative with ovarian cancer	154 (15)	771 (77)	70 (14)	3560 (69)
Being a smoker	141 (14)	661 (66)	52 (10)	320 (63)
Being overweight	37 (4)	551 (55)	16 (3)	279 (55)
Not having children	22 (2)	197 (20)	11 (2)	96 (19)
History of breast cancer	12 (1)	529 (53)	2 (<1)	265 (52)
Using HRT	8 (<1)	384 (38)	4 (<1)	183 (36)
Having ovarian cysts	5 (<1)	666 (67)	0 (0)	317 (62)
Using talc on genitals	2 (<1)	159 (16)	2 (<1)	97 (19)
Being over 50	3 (<1)	366 (37)	2 (<1)	185 (36)
Having IVF	6 (<1)	156 (16)	5 (<1)	69 (14)
Gone through the menopause	3 (<1)	287 (29)	1 (<1)	142 (28)
Having endometriosis	0 (0)	338 (34)	0 (0)	163 (32)

\*Subgroup of women aged  $\geq 45$  years

#### 6.3.4 Barriers

Respondents endorsed few barriers to help-seeking ( $M=2.2/10$ ,  $SD=2.2$  for the sample overall;  $M=1.6/10$ ,  $SD=1.8$  for the subgroup). A quarter of the overall sample (26%) anticipated no barriers, whilst the figure was higher (34%) for women aged  $\geq 45$ . The most endorsed barrier was worry about what the GP might find (34% for the sample overall; 29% for the subgroup) and the least endorsed was difficulty arranging transport to the GP (5% for the sample as a whole; 4% for the subgroup) (Table 6.4).

Table 6.4. Endorsement of barriers to seeking medical help for a symptom that might be serious

Barrier	Overall (n=1000)		Subgroup** (n=510)	
	<i>n</i>	%*	<i>n</i>	%*
<i>Emotional barriers</i>				
Worry what the GP might find	343	(34)	145	(29)
Too scared	209	(21)	77	(15)
Too embarrassed	138	(14)	38	(8)
No confidence in talking to GP about symptom	127	(13)	37	(7)
<i>Practical barriers</i>				
Too busy	296	(30)	102	(20)
Too many other things to worry about	267	(27)	116	(23)
Difficult to arrange transport to GP	48	(5)	22	(4)
<i>Service barriers</i>				
Difficult to make an appointment with GP	315	(32)	135	(27)
Wasting GP time	303	(30)	120	(24)
GP difficult to talk to	131	(13)	44	(9)

\*Respondents were able to endorse more than one barrier

\*\* Subgroup of women aged  $\geq 45$  years

### 6.3.5 Anticipated time to help-seeking

Median anticipated time to help-seeking varied by symptom. Women anticipated waiting the longest for extreme fatigue, persistent bloating, back pain, persistently feeling full and changes in bowel habit. The shortest anticipated time was for persistent abdominal

pain. Patterns were the same for the overall sample and the subgroup (Figure 6.1 shows median time to help-seeking by symptom for the sample overall).

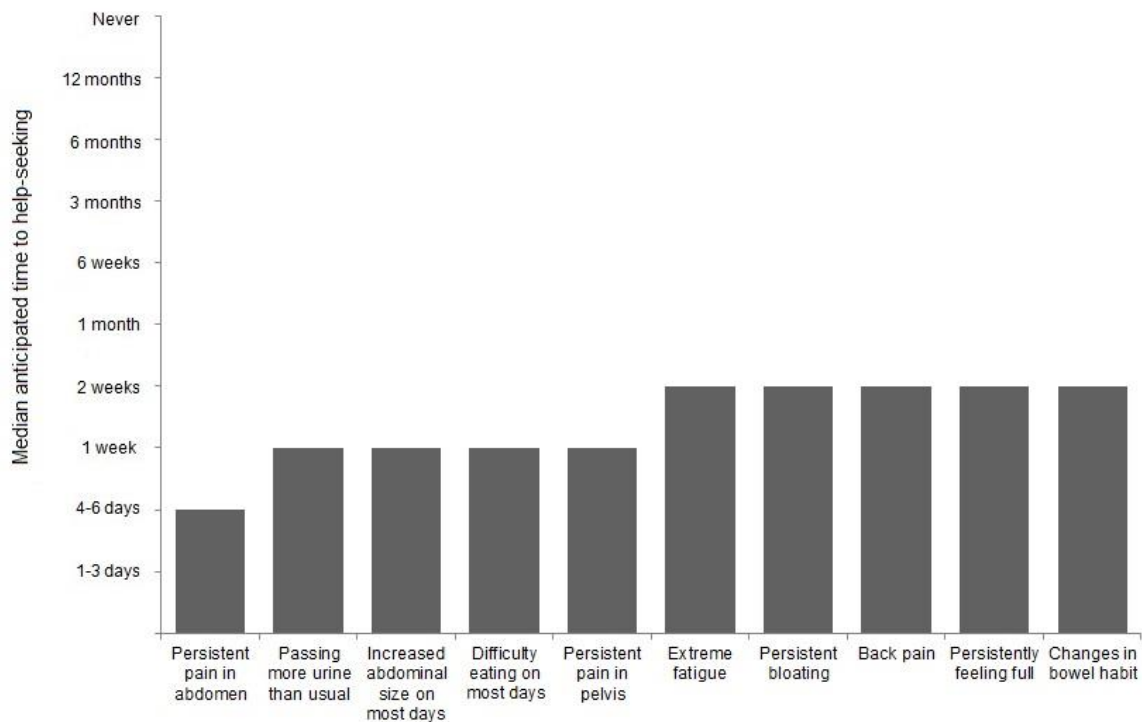


Figure 6.1 Median anticipated time to help-seeking for symptoms of ovarian cancer

In the sample as a whole, bivariate analyses showed that women from a White ethnic background anticipated taking longer to seek help for more symptoms than women from a non-White ethnicity ( $M=3.93$ ,  $SD=3.28$  versus (vs.)  $M=2.83$ ,  $SD=2.72$ ,  $p<0.01$ ). This was also true in the subgroup of older women ( $M=4.00$ ,  $SD=3.25$  vs.  $M=2.04$ ,  $SD=1.83$ ,  $p=0.001$ ). Analysis of Variance revealed that there was also significant difference in anticipated time to help-seeking ( $F(2,943)=8.55$ ,  $p<0.001$ ) between women from different SES groups. Post-hoc analysis using the Tukey HSD test showed that women from a high SES ( $M=4.28$ ,  $SD=3.32$ ) would wait longer for significantly more symptoms than women from a mid SES ( $M=3.49$ ,  $SD=3.12$ ) or a low SES ( $M=3.20$ ,  $SD=3.21$ ).

There were also significant differences between SES groups in the subgroup of women aged  $\geq 45$  years ( $F(2,462)=11.04, p<0.001$ ). The post-hoc analyses showed the same pattern, with women from a high SES anticipating waiting longer for more symptoms ( $M=4.53, SD=3.30$ ) than women from a mid SES ( $M=3.41, SD=3.00$ ) or a low SES ( $M=2.65, SD=2.99$ ).

Finally, there was a significant correlation between number of symptoms women anticipated waiting longer for and both number of service barriers ( $r(998)=.14, p<0.001$ ) and practical barriers ( $r(998)=.20, p<0.001$ ) in the sample as a whole, and between the number of service barriers ( $r(508)=.21, p<0.001$ ), practical barriers ( $r(508)=.21, p<0.001$ ) and emotional barriers ( $r(508)=.11, p<0.05$ ) in the subgroup of women aged  $\geq 45$  years. Symptom knowledge (recalled or recognised), risk factor knowledge (recalled or recognised) and cancer experience (either personal or experience with someone close) showed no association with time to help-seeking in either the sample as a whole or in the subgroup.

The regression model for the sample overall explained 6% of variance in scores on the scale of anticipated time to help-seeking ( $Adj R^2=.06, F(5,940)=13.53, p<.001$ ). Endorsing more practical and service barriers and having a higher SES were significant predictors of a higher score on the scale (i.e. longer anticipated time to help-seeking for more symptoms). The standardised beta was largest for practical barriers ( $\beta=.16, p<.001$ ) and slightly smaller for SES ( $\beta=.12, p<.001$ ) and service barriers ( $\beta=.10, p<.01$ ), suggesting that perceiving more practical barriers to help-seeking has the strongest influence on anticipated time to help-seeking.

The regression model for the subgroup explained 11% of the variance in scores on the scale of anticipated time to help-seeking ( $Adj R^2=.11, F(6,458)=10.56, p<.001$ ). Endorsing more practical and service barriers, having a higher SES and being of a White ethnicity all significantly predicted a higher score. The standardised beta was



largest for SES (beta=.22,  $p<.001$ ) and smaller for service barriers (beta=.17,  $p=.001$ ), practical barriers (beta=.13,  $p<.01$ ) and ethnicity (beta=.12,  $p<.01$ ), suggesting that, in the subgroup of women aged  $\geq 45$  years, SES has the strongest influence on anticipated time to help-seeking. See Table 6.5 for both regressions.

Table 6.5. Multiple linear regression analyses showing predictors of longer time to help-seeking

	Overall sample (n=946)*			Subgroup (n=504)*		
	Beta <sup>†</sup>	S.E.	$p$	Beta <sup>†</sup>	S.E.	$p$
Constant	-	-	.014	-	-	.529
Age	.06	.03	.064	.01	.05	.802
Ethnicity	.07	.04	.075	.12	.04	.008
SES	.12	.05	<.0001	.22	.05	.0001
Practical Barriers	.16	.04	<.0001	.13	.05	.008
Service Barriers	.10	.05	.005	.17	.05	.001
Emotional Barriers	-	-	-	.04	.05	.413

<sup>†</sup>Standardised \*Sample sizes are smaller due to missing data

Overall sample Adj  $R^2=.06$ ,  $p<.001$ , Subgroup Adj  $R^2=.11$ ,  $p<.001$ .

Note: Ethnicity is a categorical variable, coded as Non-White=0, White=1 and SES is an ordinal variable, coded as Low =0, Mid=1 and High=2.

## 6.4 Discussion

To my knowledge, this study was the first to systematically measure anticipated time to help-seeking for ovarian cancer symptoms and to identify variables associated with a longer time to help-seeking specifically for this cancer in a UK sample. In Chapter One I discussed the importance of early detection of ovarian cancer, which may be achieved through prompt help-seeking.

This is also the first study that has attempted to measure awareness of a comprehensive list of ovarian cancer symptoms and risk factors in a UK population and to identify those that are more, versus less, well-known. Given the evidence discussed in Chapter Three, which showed that misattribution of symptoms and non-recognition of symptom seriousness may play a part in a longer time to help-seeking, it is important to determine the current levels of awareness in order to identify areas for improvement in knowledge. Further, the influence of perceived risk (which may result from awareness of risk factors) can be explained by many of the models described in Chapter Two, and there is evidence for the effects of this within the literature on help-seeking for female cancers (Freidman et al., 2006). As such, it is important to also explore awareness of risk factors in order to identify areas for improvement.

Ovarian cancer symptom recall was very low (overall  $M=0.6/10$ ; subgroup  $M=0.6/10$ ), whereas recognition was considerably higher, reflecting previous findings using recall and recognition to measure gynaecological cancer symptom awareness, including the findings reported within Chapter Five and findings within other cancer groups (Robb et al., 2009; Simon, Juszczak, et al., 2012; Waller et al., 2009). Nevertheless, on average women were still only able to recognise just over half of the symptoms when prompted (overall  $M=6.3/10$ ; subgroup  $M=6.1/10$ ), a figure that does not seem to have improved considerably in the following years (Brain et al., 2014).

These findings suggest a need for interventions to increase awareness of symptoms of ovarian cancer. Moreover, as symptoms for ovarian cancer can be non-specific (Department of Health, 2009; National Institute for Health and Clinical Excellence (NICE), 2005) it might be pertinent for any interventions designed to increase awareness to focus on the characteristics of the symptoms experienced as well as their presence. For example, there is evidence that symptoms such as abdominal pain, pelvic pain, bloating, constipation, and increased abdominal size are significantly more severe and frequent in women with ovarian cancer than in women in a general clinic population (Goff, Mandel, Melancon, & Muntz, 2004).

Symptoms for which the lowest recognition was observed were frequent urination (overall=45%; subgroup=40%), feeling full (overall=45%; subgroup=40%) and difficulty eating (overall=25%; subgroup=21%). Research suggests that these symptoms (as well as abdominal and pelvic pain) are present in earlier stage ovarian cancers (Goff et al., 2007; Hamilton et al., 2009; Lataifeh, Marsden, Robertson, Gebiski, & Hacker, 2005; Olson et al., 2001) (although more recent evidence suggests that the specificity of these symptoms may be lower than originally thought (Lim et al., 2012)). Consequently consideration of these symptoms as potential ovarian cancer symptoms could aid earlier diagnoses. That awareness was lowest for these symptoms, then, is concerning. On average a GP will only see one case of ovarian cancer every five years (NHS Choices, 2012b; Office for National Statistics, 1999), which may reduce the likelihood of GP consideration of ovarian cancer in a patient presenting with such symptoms. However, if awareness were higher in women overall, this could increase the chances of the patient herself considering ovarian cancer, and therefore being able to highlight this to her GP upon presentation.

Overall risk factor awareness was also not very high in this sample, again with recall being much lower than recognition; even when prompted, women were able to identify less than half of the risk factors for ovarian cancer ( $M=5.1$ ,  $SD=2.5$  in the overall sample

and  $M=4.8$ ,  $SD=2.5$  in the subgroup). It was promising, however, that over two thirds of the overall sample and the subgroup of women recognised the relationship between having had a close relative with ovarian cancer and risk of developing the disease, and that, although a much lower proportion of women were aware of this risk factor when unprompted (14% and 15% in the overall sample and subgroup respectively), it was the most recalled risk factor. Given the evidence that around 10% of ovarian cancer cases may be attributable to an inherited genetic susceptibility to the disease (through the inherited BRCA1 and BRCA2 genes) (Claus, Schildkraut, Thompson, & Risch, 1996) , it is important that women are aware of this risk factor. The genetic, inherited risk of these genes in relation to breast cancer has been highlighted in the media recently, with a number of celebrities (notably, American film actress Angelina Jolie and UK pop star, Michelle Heaton) opting to have mastectomies due to this risk. This has no doubt raised awareness of the risk for breast cancer, however, it seems there may be more work to be done in raising awareness of the risk for ovarian cancer, although around half of the women here did recognise the association between breast and ovarian cancer.

More than half the women here also recognised the risks associated with being a smoker, being overweight and having ovarian cysts. Again, however, recall was considerably lower for these risk factors. Both smoking and weight are modifiable factors, and just under 10% of ovarian cancers have been argued to be attributable to tobacco (Parkin et al., 2011), whilst increasing weight has been shown to increase the relative risk by 1.14 for each 10 unit increase in BMI (Reeves et al., 2007). These risk factors are also applicable to most other cancers (Parkin et al., 2011). Increasing awareness of these risk factors, then may encourage women to make healthier lifestyle choices to reduce their risk of developing any cancer.

In contrast to my hypothesis, I found no association between symptom awareness and anticipated time to help-seeking. This finding does not necessarily mean that symptom awareness has no influence on time to help-seeking, however. Symptom awareness

may influence attribution or appraisal behaviour (which has been shown to be related to time to help-seeking (Macleod et al., 2009)), rather than having a direct relationship with time to help-seeking. This is evident within the MPT, described in Chapter Two. Within this model, an individual will appraise the change they have detected within their body. It is this appraisal process and the success of any self-management techniques undertaken which determines whether the individual decides to seek medical attention. Although an awareness of cancer symptoms likely plays a part in this appraisal process, it is perhaps insufficient to determine help-seeking behaviour in isolation. The complexities of this relationship should be explored further to aid understanding of help-seeking behaviour for ovarian cancer symptoms.

It was promising that women anticipated seeking help quickest for persistent abdominal pain as this is one of the three most important symptoms highlighted to health professionals in the DoH's Key Messages on ovarian cancer (Department of Health, 2009), and has been found in up to 49% of early stage (I/II) invasive epithelial ovarian cancer cases (Rossing et al., 2010) (90% of ovarian cancers are this type (Cancer Research UK, 2012c)). Previous research exploring symptom presentation in primary care found that abdominal pain was one of the most common symptoms reported (Goff et al., 2004). Further, women with abdominal pain are encouraged to seek help promptly for this symptom (Smith and Anderson, 1985). This finding, taken together with the results shown here, suggests that women may feel comfortable presenting with abdominal pain and consequently may not anticipate a reason to wait before seeking help for this symptom.

Both women in the sample overall and the subgroup at increased risk (those aged  $\geq 45$  years) anticipated waiting the longest for extreme fatigue, persistent bloating, back pain, persistently feeling full and changes in bowel habit. All of these symptoms are mentioned in the DoH's Key Messages (Department of Health, 2009), which highlight persistent bloating and persistently feeling full as two of the three most important

symptoms. Abdominal bloating and loss of appetite (represented here as persistently feeling full) have been found to have Positive Predictive Values (PPVs) for ovarian cancer of 0.3% and 0.6% respectively. When paired, these two symptoms have a PPV of 3.3%, second only to the pairing of loss of appetite and abdominal distension (PPV>5%) (Hamilton et al., 2009). Although these PPVs are not high (possibly owing to a high frequency of these symptoms in the general population (Agréus, Svärdsudd, Nyrén, & Tibblin, 1994; Pitts et al., 2011)), bloating or feeling full have been found to be present in over 44% of early stage disease (Rossing et al., 2010).

Further, Olson and colleagues (Olson et al., 2001) found that 71% of ovarian cancer patients reported experiencing bloating and/or fullness in the six to twelve months prior to diagnosis; similar results to those reported by Goff et al. three years later (Goff et al., 2004). Consequently, if a patient presents with both symptoms, it may help a GP to more accurately either diagnose or refer (particularly if the patient is aged  $\geq 45$  years, given that these symptoms are more likely to be associated with ovarian cancer with increasing age (Cancer Research UK, 2013c)). Encouraging earlier help-seeking for these two symptoms specifically, particularly in older women, may impact on diagnoses of less advanced disease.

The amount of variance explained by the regression models was relatively small, suggesting that there are other factors that are important in anticipated time to help-seeking. However I did identify some important predictor variables. In the overall sample and in the subgroup, more perceived practical barriers predicted a higher score on the scale of anticipated time to help-seeking (indicating a longer time to help-seeking for more symptoms), supporting previous research exploring help-seeking for 'generic' cancer symptoms (Simon, Waller, Robb, & Wardle, 2010). In contrast to the findings in the latter research, I also found that endorsing more perceived service barriers was a significant predictor of a higher score on the scale of anticipated time to help-seeking, whereas endorsing more emotional barriers was not. This finding may be due to the low

awareness that these symptoms could be indicative of ovarian cancer, leading women to assume that these symptoms were not significant enough to merit the difficulty of arranging a doctor's appointment. Further, previous findings in the literature discussed in Chapter Three has been inconclusive about the effects of one of the emotional barriers, 'fear'. The complex relationship between fear and help-seeking may have influenced the findings relating to emotional barriers here. Future research might explore this emotional barrier separately.

An interesting finding was that women from lower SES and non-White ethnic groups anticipated seeking help earlier for more symptoms of ovarian cancer than those from higher SES and White ethnic backgrounds. This finding reflects earlier research (Adamson, Ben-Shlomo, Chaturvedi, & Donovan, 2003; Robb et al., 2009) and there is evidence that these relationships between ethnicity and SES and help-seeking also apply to actual help-seeking behaviour (Morris et al., 2005). However, women from lower SES and non-White ethnic backgrounds are more frequently diagnosed with later stage cancer compared to those from higher SES and White backgrounds (Downing et al., 2007; Morris et al., 2010; Schwartz et al., 2003).

The disparity in primary care help-seeking and stage of diagnosis between White and non-White ethnicities may be a result of GP time to referral and diagnosis (Morris et al., 2005), which in turn may be a product of the lower ovarian cancer incidence rates observed in Asian and Black ethnicities when compared to the White ethnic group (National Cancer Intelligence Network & Cancer Research UK, 2009). Ovarian cancer cases are rare in primary care (NHS Choices, 2012b; Office for National Statistics, 1999); if few of those cases are in women of non-White ethnicities, this may lead to a much reduced possibility that a GP will even consider an ovarian cancer diagnosis in these women even if they present promptly with symptoms. In contrast, however, no such difference has been observed in incidence for ovarian cancer between SES groups

(National Cancer Intelligence Network, 2009). Consequently, the disparity in SES groups warrants further investigation.

#### **6.4.1 Strengths and limitations**

As with Chapter Five, this study was strengthened by the use of a validated tool to measure awareness and anticipated help-seeking behaviours. If this tool is utilised in future research, it will allow researchers to identify shifts or differences in patterns of help-seeking by accurately comparing these data with other time periods or other countries. Although the sample was not population representative, data were collected from a range of women from different age and demographic groups, and consequently, it is likely that the relationships found in the results in the present study would apply to the UK population.

A potential limitation of this study is the measurement of help-seeking intention for a hypothetical symptom as opposed to actual help-seeking behaviour for an existing symptom (the limitations of which I have discussed earlier). A second limitation is that questions were asked within the context of ovarian cancer and it is likely that women anticipated faster help-seeking than would occur in a real life situation where the symptom might not be appraised as a warning sign of cancer. For example, the longest median anticipated time to help-seeking was two weeks. However, I limited the impact of this issue by looking at median time to help-seeking for each symptom and thus explored the relative speed of help-seeking behaviour for each symptom, than the time period itself. Further, DoH guidelines for patients (NHS Choices, 2012b) do not give advice on how long women *should* wait before seeking medical help for symptoms potentially indicative of ovarian cancer. Although the DoH (Department of Health, 2009) and NICE (NICE, 2011) guidelines mention persistency as a key feature for health professionals to look for, for a number of symptoms (such as pelvic or abdominal pain, abdominal distension and difficulty eating or feeling full quickly), they do not define



'persistence', therefore making it difficult to say how long women should wait before seeking help for these symptoms.

A further limitation applicable to this study was the lack of data relating to the frequency, severity or novelty of hypothetical symptoms. As such, I was unable to explore the impact of these variables on intention to seek help. Doing so would have been interesting, as symptoms that are frequent, severe and novel are more likely to indicate ovarian cancer (Department of Health, 2009; Goff et al., 2007, 2004; Macleod et al., 2009; NICE, 2011). Finally, coding of the open recall items was carried out by Synovate researchers, and as some symptoms could potentially be viewed as being similar (for example 'persistent bloating' and 'increased abdominal size'), it is possible that there was some coding error. This may have resulted in the estimates of knowledge found here being too conservative.

Quota sampling was used because it is an efficient and practical method of collecting data. However, this method limits the generalisability of the findings. Despite this, the study was well-powered and novel and it provides an indication of the factors which may influence time to help-seeking, as well as an idea of the relative levels of awareness of different ovarian cancer symptoms in a UK female population.

#### **6.4.2 Conclusions**

This study suggests that there is low awareness of ovarian cancer symptoms in this population and variation in anticipated help-seeking behaviour for these symptoms. Women anticipated waiting longest for persistent bloating and persistently feeling full, symptoms which are both associated with ovarian cancer, and have been found in just under half of early stage cases.

Although barriers may be important in predicting help-seeking, there may be more important variables involved that were not measured here, or the complexity of the

relationship between individual barriers and help-seeking may need to be understood further. Consequently, there is a need for more in-depth, exploratory research to identify these factors.

In the next chapter, I have explored responses to symptoms potentially indicative of a gynaecological cancer, including ovarian cancer in women who are currently experiencing these symptoms. Building on one of the limitations in the present study, I also explored responses to symptoms which are frequent and/or severe.

## **CHAPTER SEVEN - EXPERIENCE OF SYMPTOMS INDICATIVE OF GYNAECOLOGICAL CANCERS IN UK WOMEN (STUDY 3<sup>12</sup>)**

### **7.1. Introduction**

#### **7.1. Background**

In Chapter Three I discussed the work undertaken by Cooper et al. (2013), who explored women's responses to symptoms across all five of the gynaecological cancers. Notably, there were some symptomatic women who had waited years to seek medical help or had never done so. One of the main limitations of this study was the lack of a complete distinction between women who had hypothesised having a symptom and those who actually did. Given the differences in hypothetical and actual help-seeking, it may be the case that some of the relationships found were not as applicable in real life. It is likely that in the UK, as in the US, there are also many more women who are experiencing symptoms who do not currently seek help from their GP. Although these symptoms are unlikely to be cancer, encouraging help-seeking could not only increase earlier cancer diagnoses, but also aid detection of other potentially treatable conditions.

To my knowledge, there have been no assessments of the population prevalence of symptoms encompassing all gynaecological cancers, nor responses to these symptoms in women experiencing them in a UK sample. In the studies described in Chapters Five and Six, it was made explicit to participants that they were being asked about symptoms of ovarian and cervical cancer. This is also true of previous research exploring symptom awareness and anticipated help-seeking for cancer symptoms in general (Robb et al., 2009), and research on awareness of specific cancer types (for example, Forbes et al., 2011).

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<sup>12</sup> A version of this chapter has been published elsewhere and can be found in Appendix 5 (Low, Simon, Waller, Wardle, & Menon, 2013)

### 7.1.1 'Symptom' versus bodily change'

Symptoms do not necessarily begin as 'symptoms' (i.e. associated with illness or disease (Cathcart, Wilson, & May, 2012)), rather as sensations or changes within our bodies that may come to be interpreted as such. Hay (2008) offers a clear distinction between a 'sensation' and a 'symptom', describing the former as "felt experience" and the latter as a "constructed and socially informed cognitive interpretation that indexes". As discussed, in Chapter Two, this is also the stance that the most recent models attempting to explain help-seeking ('Andersen's Model' and the MPT) take; both assume that a bodily change is first experienced, before illness is inferred.

However, only those bodily sensations or changes that are attended to may be subjected to an interpretive process, and not all sensations are attended to. As mentioned previously, bodily sensations are constantly being processed, although the vast majority are not processed consciously (Pennebaker, 1982). Even those sensations that are processed consciously may be dismissed as part of 'the everyday'. For example, Halkowski (2006) describes 'the patients' problem'; i.e. how a person, upon experiencing a new sensation or change in their body, may consider whether it is just part of the normal, everyday sensations and changes that come with having a body, or whether it is a threat to health.

In 2012, Cathcart et al. published the findings of a qualitative study exploring the transition from bodily sensation to symptom in catarrh sufferers. They concluded that, at the time of help-seeking, a person is not at the beginning of their 'symptom story'. To describe the process of how a sensation becomes a symptom, they devised a 'symptom evolution pathway for physiological body sensations' (Figure 7.1, below).

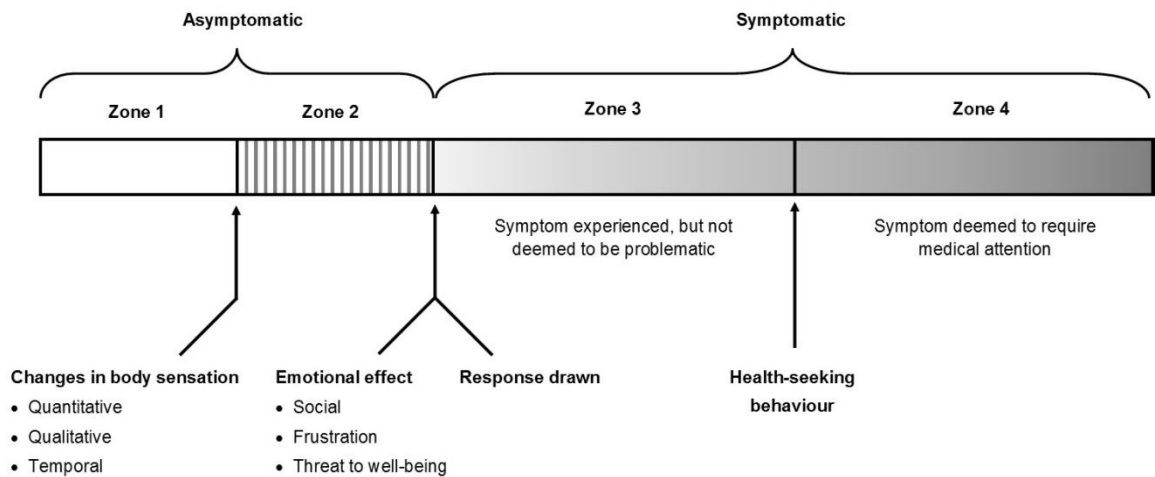


Figure 7.1 Symptom evolution pathway for physiological body sensations (Cathcart et al., 2012)

Zone one describes the existence of a bodily sensation, before a person has become consciously aware of it. Zone two describes the period when a person becomes aware of their bodily sensation because there has been, or there is a perception that there has been, a change. Cathcart described the change from Zone one to Zone two as being caused by an awareness of the bodily sensation, which had previously been present (Zone one), but inconspicuously so. In his catarrh patients, these changes were qualitative (change in the consistency of the mucus), quantitative (change in flow rate) and temporal (an increase in the length of time the sensation has persisted).

The transition from Zone two to Zone Three (when the sensation becomes a symptom, but one has decided that help is not yet required) occurs when a more sinister, deeper meaning is attributed to the changed bodily sensation, which then is perceived to be a social inconvenience, frustrating and/or a threat to well-being. Finally, a symptom will be deemed to require a response, which Cathcart et al. argue may be passive or active, negative or positive and mild, moderate or strong, allowing for individual differences in symptom response and external influences. Cathcart et al. conclude that once an individual has acknowledged a bodily sensation and deemed it to be in need of action, the sensation has become a symptom.

Given the above, it is important when exploring help-seeking (either hypothetical or real) not to frame a symptom or symptoms in the context of illness, by using the term 'symptom'. In doing so, the individual is moved along the pathway of interpretation of a bodily sensation as a symptom. The idea that a symptom does not begin as such is also reflected in the MPT (Walter et al., 2012) on page 57. The model (which is discussed in more detail in Chapter Two) describes the detection of a 'bodily change' and the subsequent evaluation that occurs to determine a) whether the change is indeed a symptom (i.e. indicative of illness or disease) and, if so, b) does it require medical attention.

In attempting to explore and understand how a bodily change or sensation comes to be perceived as a symptom (if indeed it does), it is necessary to avoid the term 'symptom'. If we consider the pathways described here, it is clear that by using the term, 'symptom', a research participant will be 'moved forward' in the pathway from bodily sensation to symptom, to symptom requiring medical attention. It then becomes impossible to explore what influences may have led to that occurrence naturally.

### **7.1.2 Frequency and Severity of symptoms**

In Chapter Six, I noted that a limitation of the Ovarian CAM was the lack of exploration of the impact of frequency and/or severity of the symptoms explored and whether asking women about a frequent or severe symptom may have affected the findings in relation to anticipated time to help-seeking. It is important to explore this, as there is evidence that symptoms which are frequent, severe and novel are more likely to indicate ovarian cancer (Department of Health, 2009; Goff et al., 2007, 2004; Macleod et al., 2009; NICE, 2011). Further, generically, it is advised that, for some symptoms, frequency or severity may indicate an increased chance of cancer (Cancer Research UK, 2009). However, to my knowledge, there is no published research that has explored the relationship between frequency and severity of symptoms and help-seeking behaviour for symptoms of gynaecological cancers.

### **7.1.3 The current study**

This is the first study to assess the prevalence of symptoms potentially indicative of a gynaecological cancer, the frequency and severity of symptoms, and current help-seeking behaviour in response to symptoms. Therefore no specific hypotheses were made for this study.

## **7.2. Methods**

### **7.2.1 Recruitment**

As part of their omnibus survey (which included modules from different contributors, on a range of non-health topics) I commissioned the market research agency, TNS Global<sup>13</sup> (London) to approach 2173 women (aged  $\geq 16$  years) using stratified random location sampling. Women were invited to complete my survey module using Computer Assisted Personal Interviewing (CAPI) in the presence of trained interviewers in their own homes, in July 2011. Before deciding whether to participate, potential respondents were given written information about the study due to the sensitive nature of the questions (see appendix 6). The information explained that the survey contained questions about bodily changes experienced in the last three months, including changes in the reproductive system. It made clear that the module was anonymous and confidential and that respondents who decided to take part were free to withdraw at any time. The interview was conducted in English and therefore any women who were not fluent in English were excluded. The study was approved by the UCL Research Ethics Committee (ref: 1122/005, see appendix 7).

### **7.2.2 Measures**

#### **7.2.2.1 *Participant characteristics***

Respondents were classed as higher or lower SES (A, B, C1 vs. C2, D, E categories) using the National Readership Survey social grading system (National Readership

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<sup>13</sup> [www.tns-ri.co.uk](http://www.tns-ri.co.uk)

Survey, 2007, described in detail in Chapter Five) as is the convention in the literature (for example, Waller et al., 2009). Further, by dichotomising the sample in this way, I was able to analyse data from participants in manual and non-manual occupations separately. Ethnicity was dichotomised into 'White' or 'non-White', with White, non-British women included in the 'White' category. It was a requirement of participation that women must possess a level of English adequate to understand the survey. I collected data on exact age at the time of completing the survey, and dichotomised age at 45 years, because 85% of all new cases of gynaecological cancers in the UK are in women aged  $\geq 45$  years (Cancer Research UK, 2012g, 2013b, 2013c, 2013d, 2013e).

#### **7.2.2.2 Symptom reporting**

Women were presented with a list of 13 symptoms (see Table 7.2 in the 'Results' section for the full list) potentially indicative of a gynaecological cancer (sourced from NHS Choices (NHS Choices, 2013c)), and asked, "*In the past three months, have you experienced any of the following [symptoms]? (please answer each item with 'yes', or 'no'. If you are not sure, or if the item does not apply to you, answer 'no')*". A three month reporting time-frame was selected as some symptoms could only be detected following at least two menstrual cycles (for example inter-menstrual bleeding). In the analyses, it was not possible to stratify symptoms by gynaecological cancer type as many of the symptoms of these five gynaecological cancers overlap.

#### **7.2.2.3 Symptom frequency and severity**

Respondents reporting a symptom were asked, "*Please tell us (as far as you remember) how often you experienced [symptom] in the past three months*". Response options included, 'Once', 'twice' (both recoded as 'infrequent') 'several times' and 'all the time' (both recoded as 'frequent'). They were then asked: "*Using the 5-point scale below, please tell us how bad the [endorsed symptom] was on the worst day you had it. If it was as bad as you could imagine it could be, score 5. If it was not bad at all, score 1.*"



*Please remember you can score any number from 1 to 5*". Responses were recoded into 'not severe' (scores 1-3) or 'severe' (score 4 or 5). The frequency and severity questions were repeated for each symptom the respondent reported. For some analyses, I divided respondents into two groups: i) with a symptom that was severe (score 4 or 5), frequent ('several times' or 'all the time') or both, and ii) with a symptom that was neither frequent nor severe (see Figure 7.2). These questions were similar to those used in other studies exploring frequency and severity of symptoms potentially indicative of a cancer (for example, Goff et al., 2004).

Figure 7.2 Participant groups by frequency and severity of symptoms

	Not severe	Severe	Infrequent	Frequent
Not severe	-	-	Group I	Group II
Severe	-	-	Group II	Group II
Infrequent	Group I	Group II	-	-
Frequent	Group II	Group II	-	-

#### **7.2.2.4 Help-seeking**

To measure help-seeking, I asked, *"Please tell us from the following what, if anything, you did about your [symptom]"*. Response options were: seeking advice from a pharmacist (chemist); a practice nurse; a GP; going to A&E (the hospital emergency department); asking for advice from a friend/relative; looking for advice on the internet; asking/looking for advice somewhere else; using an own remedy/treating it themselves; and waiting to see if it went away/got worse. For each response option, respondents answered 'Yes' or 'No'. Women were only asked about help-seeking for one randomly computer system-selected symptom, referred to here as the 'index symptom'. The study

was designed in this way to avoid the survey becoming so time-consuming that it would be off-putting to participants. A copy of the full survey can be seen in Appendix 6.

### **7.2.3 Analyses**

Data were analysed using SPSS version 18 (IBM Corporation, 2009). To assess demographic differences between survey responders and non-responders, I used t-tests and  $\chi^2$  tests. I used  $\chi^2$  tests to identify significant demographic differences in symptom reporting and group differences in help-seeking behaviour. I did not perform any regression analyses on the help-seeking data in this study as the small group sizes would mean that these analyses would likely be underpowered (Field, 2009).

#### **7.2.3.1 Weighting**

Weights for the data were provided by TNS. Data were weighted through an interlocking matrix by region (North/Midlands/South), age (16-24; 25-44; 45-64;  $\geq 65$  years) and social grade (ABC1/C2/DE) to achieve a nationally representative sample of women in the UK. Weighting had the biggest effect on SES (48% fell into the ABC1 group in the unweighted data, whereas 60% did in the weighted data) and on symptom reporting, with 55% reporting at least one symptom in the unweighted data, compared to 44% in the weighted sample. The differences observed are likely to have been a result of a weighting applied to all of the participants who completed the whole survey, and not just those who completed my module. See Table 7.1 for a comparison of the weighted and unweighted data.

#### **7.2.3.2 Missing data**

There were no missing data in the demographic, symptom reporting (including frequency and severity) or help-seeking data in those women who had a symptom and had agreed to participate in the survey module.

### **7.2.3.3 Parametric assumptions**

As in the previous data chapters, data were tested for normality and homogeneity of variance to be certain that any significant results were down to genuine group differences in means. I also repeated these tests with the demographic data here. As the variables were outside of normal distribution ranges (-1 – 1+) when testing skewness and kurtosis, non-parametric  $\chi^2$  tests were used.

## **7.3. Results**

### **7.3.1 Sample characteristics**

Of the 2173 women who took part in the overall TNS omnibus survey, 911 (42%) completed my survey module. Although this is not a true response rate (as TNS do not record how many addresses they attempt to recruit from), it at least provides an indication of a response rate to my survey. Respondents were aged 16-98, with a mean age of 45 years, SD=17.09). When age was dichotomised, 442 women were aged  $\geq 45$  years and 469 were aged  $< 45$  years. Most women were White (93%) and had a high SES (60%). Only a very small number of women (7%) reported minority ethnicities, so they were grouped together and the sample was categorised as 'White' or 'non-White', as discussed in the methods section. Responders to the symptom survey module were significantly younger, had a higher SES, were more likely to have a White ethnicity and were more likely to be married or living as a couple than those who refused to complete the module (see Table 7.2).

Table 7.1 Sample Characteristics (Weighted/Unweighted  $n=911/ n=882$ )

	Unweighted		Weighted	
	<i>N</i>	(%*)	<i>N</i>	(%*)
<i>Age (mean (SD))</i>	45	(17.2)	45	(17.1)
<i>Socioeconomic status</i>				
ABC1 (higher)	424	(48)	543	(60)
C2DE (lower)	459	(52)	368	(40)
<i>Ethnicity</i>				
White	823	(93)	848	(93)
Non-white	59	(7)	62	(7)
<i>Marital Status</i>				
Single	219	(25)	204	(22)
Married/living as a couple	502	(57)	558	(61)
Widowed/divorced/separated	161	(18)	149	(16)
<i>Reported Symptoms</i>				
At least one	395	(55)	398	(44)
None	488	(45)	513	(56)

Table 7.2. Socio-demographic characteristics of responders and non-responders to the symptom module (weighted data, overall n=2173)

	Responders (n=911)		Non-responders <sup>a</sup> (n=1262)		$\chi^2$ (df)
	n	%	n	%	
Age (mean (SD), t-test)	45	(17)	49	(20)	5.61**
Socioeconomic status					
ABC1 (higher)	543	(60)	674	(53)	8.25 (1)*
C2DE (lower)	368	(40)	588	(47)	
Ethnicity					
White	848	(93)	1097	(88)	17.69 (1)**
Non-white	62	(7)	154	(12)	
Marital status					
Single	204	(22)	294	(23)	15.10 (2)**
Widowed/divorced/separated	149	(16)	283	(22)	
Married/living as a couple	558	(61)	676	(54)	
Reported symptoms					
At least one	398	(44)	-	-	-
None	513	(56)	-	-	-

\*Significant at the .01 level, \*\*significant at the .001 level

<sup>a</sup>These women took part in the omnibus survey but opted out of the symptom module

### 7.3.2 Symptom reporting

Just under half the respondents (44%, 398/911) reported at least one of the 13 symptoms in the survey ( $M=1.2$ , range=0-9), with 'pain in the abdomen, lower back or pelvis' (19%, n=173), 'increased abdominal size' (17%, n=154) and 'increased need to go to the toilet' (15%, n=138) being the most common (Table 7.3). The median number of symptoms endorsed was 0 (56%, n=513), with 11% reporting one symptom (n=103), 12% reporting two symptoms (n=108) and 21% reporting three symptoms or more (n=187). The highest number of symptoms experienced was nine, reported by five women (0.5%). Of those women who reported a symptom (n=398), the majority had between one and three (72.4%, n=288). Overall, women were more likely to report a

symptom indicative of a gynaecological cancer if they were younger (50% of those under 45 vs. 37% of those aged 45 and over,  $\chi^2(1,910)=14.87, p<0.001$ ), lower SES (49% vs. 40% in the higher SES group,  $\chi^2(1,911)=7.58, p<0.01$ ) and non-White (58% vs. 43% in White participants,  $\chi^2(1,910)=5.64, p<0.05$ ).

### **7.3.3 Frequency and severity of symptoms**

Overall, 35% (n=317/911) of respondents reported a symptom that was frequent and/or severe, and 9% (78/911) had a symptom that was neither frequent nor severe. Less than a third (132/442, 30%) of women aged  $\geq 45$  reported a frequent and/or severe symptom; 14% of the total sample (n=132/911) (Table 7.4). Individual symptom endorsements by age and frequency and/or severity of symptom are reported in Table 7.3.

As stated above, women were only asked about their response to one index symptom in order to keep the survey to reasonable length. As the symptoms were randomly selected, it is possible that women may have been asked about a mild, infrequent symptom, when they also had a frequent, severe symptom, which they may have responded differently to. To assess how many women this applied to, I calculated the proportion of women who had an index symptom which was mild and infrequent and the proportion of these women who also had a non-index symptom that was frequent and/or severe. These calculations showed that just 7% of the total sample (n=911) had a mild or infrequent index symptom, as well as a frequent and/or severe non-index symptom.

Table 7.3 Gynaecological symptoms reported by all respondents (n=911), and by age and frequency and severity

Symptoms endorsed	Whole sample (n=911)		<45 years (n=469)				≥45 years (n=442)			
			Frequent and/or severe		Not frequent or severe		Frequent and/or severe		Not frequent or severe	
	N	(%)*	n	(%)*	N	(%)*	n	(%)*	n	(%)*
Pain in abdomen/lower back/pelvis	173	(19)	81	(17)	27	(6)	55	(12)	10	(2)
Increased abdominal size	154	(17)	62	(13)	26	(6)	45	(10)	21	(5)
Increased need to go to the toilet	138	(15)	60	(13)	13	(3)	51	(12)	13	(3)
Increased wind or constipation	121	(13)	42	(9)	15	(3)	46	(10)	17	(4)
Difficulty eating/feeling full quickly	116	(13)	53	(11)	14	(3)	40	(9)	7	(2)
Heavier/longer periods	107	(12)	52	(11)	24	(5)	23	(5)	7	(2)
Pain/discomfort during sex	83	(9)	39	(8)	26	(6)	11	(3)	5	(1)
Itching, pain or soreness of vulva	64	(7)	24	(5)	17	(4)	18	(4)	4	(<1)
Bleeding between periods	49	(5)	17	(4)	20	(4)	7	(2)	4	(<1)
Discharge that smells unpleasant or is blood stained	44	(5)	22	(5)	15	(3)	7	(2)	1	(<1)
Bleeding during/after sex	31	(3)	10	(2)	13	(3)	1	(<1)	6	(1)
Growth/lump/sore/ulcer on skin of vulva	26	(3)	5	(1)	11	(2)	1	(<1)	8	(2)
Bleeding after menopause	10	(1)	1	(<1)	3	(<1)	0	(0)	6	(<1)

\*Respondents were able to select more than one symptom, hence the total percentage will exceed 100%.

Table 7.4. Symptoms reported by age group (n=911)

	Total sample (n=911)		Women aged <45 (n=469)		Women aged ≥45 (n=442)	
	N	(%)	N	(%)	n	(%)
Did not report symptoms	513	(56)	235	(50)	278	(63)
Reported at least one symptom	398	(44)	234	(50)	164	(37)
At least one frequent and/or severe symptom	317	(35)	186	(40)	132	(30)
No frequent or severe symptoms	78	(9)	46	(10)	32	(7)

### 7.3.4 Help-seeking behaviour

Respondents were asked about help-seeking for a single index symptom. The selection rate for each symptom (expressed as the number of times the symptom was selected as a proportion of the number of times that symptom was endorsed) was fairly similar across symptoms (see Table 7.5), and consequently, all endorsed symptoms were equally likely to be endorsed as the index symptom. Just over a third (36%, 142/398) of respondents who reported a symptom had seen a health care professional (HCP) (pharmacist, GP, practice nurse, A&E) about their index symptom, with most (30%, 120/398) having seen a GP. Of the subset of women aged 15-29 (n=111/398, 28%), 21% reported having seen a GP for their index symptom. In symptomatic women, the most common response to the index symptom was to monitor it (54%, 216/398) and the least common response was to go to A&E (6%, 24/398). In the sample as a whole, 16% (n=142/911) of women had seen a HCP about at least one of the symptoms under investigation and 13% had seen a GP (n=120/911).



Table 7.5. Chance of selection as an index symptom for all symptoms

Symptoms endorsed	(n=398)	
	Chance of selection over number of endorsements	
	N	(%)*
Pain in abdomen/lower back/pelvis	64/173	(37)
Increased abdominal size	63/154	(41)
Increased need to go to the toilet	46/138	(33)
Increased wind or constipation	44/121	(36)
Difficulty eating/feeling full quickly	49/116	(42)
Heavier/longer periods	34/107	(32)
Pain/discomfort during sex	23/83	(28)
Itching, pain or soreness of vulva	23/64	(36)
Bleeding between periods	17/49	(35)
Discharge that smells unpleasant or is blood stained	9/44	(20)
Bleeding during/after sex	13/31	(42)
Growth/lump/sore/ulcer on skin of vulva	11/26	(42)
Bleeding after menopause	2/10	(20)

\*Respondents were able to select more than one symptom, hence the total percentage will exceed 100%.

Of the older ( $\geq 45$  years) symptomatic women, 37% (n=60/164) had seen a HCP and 33% (54/164) had seen a GP. The most common response to a symptom was to monitor it (49%, 81/164) and the least common response was to visit the A&E department (2%, 4/164). Older women were significantly less likely to have asked a friend or relative for advice (14% vs. 28%,  $\chi^2(1,399)=11.36, p=0.001$ ) or to have gone to A&E (2% vs. 9%,  $\chi^2(1,398)=6.47, p<0.05$ ) than younger women. The behaviour patterns remained the same for women with a frequent and severe symptom, although more women had sought medical help, with 42% having seen a HCP (135/317).

Table 7.6. Help-seeking for one index symptom among respondents who reported a symptom by risk group (n=397)

Response to symptom	Higher risk women (n=132)		Lower risk women (n=265)		$\chi^2$ (df)
	N	(%)	n	(%)	
Monitored symptom	69	(53)	147	(55)	0.28 (1)
Used own remedy/self-treatment	59	(45)	104	(39)	1.08 (1)
Sought help from GP	50	(38)	71	(27)	5.11 (1)*
Sought help from internet	32	(25)	79	(30)	1.26 (1)
Sought help from friend or relative	21	(16)	67	(25)	4.34 (1)*
Sought help from pharmacist	21	(16)	33	(12)	0.90 (1)
Sought help from practice nurse	18	(14)	35	(13)	0.02 (1)
Sought help from somewhere else	14	(11)	30	(11)	0.05 (1)
Sought help from A&E	4	(3)	20	(8)	3.17 (1)

Higher risk = women aged  $\geq 45$  years with a frequent and/or severe symptom. Lower risk = women aged  $< 45$  years and women with no frequent or severe symptoms.

\*Significant at the .05 level

\*Respondents were able to select more than one response, so total % sometimes exceeds 100%.

Among the older women ( $\geq 45$  years) with an index symptom that was frequent and/or severe (i.e. the most high-risk group), 43% (n=56/132) had seen a HCP and 38% (n=50/132) had seen a GP. These women were most likely to have monitored their symptom (53%, 69/132) and least likely to have visited A&E (3%, 4/132). Older women with frequent and/or severe symptoms were significantly more likely to have seen a GP (38% vs. 27%,  $\chi^2$  (1,397)=5.11,  $p < 0.05$ ), but significantly less likely to have asked a friend or relative for advice (16% vs. 25%,  $\chi^2$  (1,396)=4.34,  $p < 0.05$ ) than women who did not fall into this group (see Table 7.6).

#### 7.4. Discussion

Just under half (44%) the women in my sample reported a symptom that may indicate a gynaecological cancer, and for a third (35%), the symptom was frequent and/or severe. The rates of GP consultation for potential gynaecological cancer symptoms found here

(13% of the women in the total sample, n=120/911) are somewhat lower than have been found in a previous study exploring primary care consultation rates for gynaecological symptoms (Stapley & Hamilton, 2011) (20%). However, Stapley and Hamilton only explored consultation rates in women aged 15-29, and when I explored consultation rates in a sub-sample of the participants in my study aged 16-29, I found similar rates (21%).

Interestingly, previous research exploring *intention* to seek help for some of these symptoms in a UK population found that 65-89% of women said that they would go to their GP within two weeks if they had one of these symptoms (Target Ovarian Cancer, 2013). This again highlights the differences in exploring hypothetical symptoms and intention to seek help and actual responses to real symptoms. The current survey suggests that, although just under half of British women may currently have a symptom potentially indicative of a gynaecological cancer (n=398/911, 44%), only around a third of these (n=120/398, 30%) have sought advice from a GP. This percentage is considerably lower than the percentage of women who said that they would seek help promptly for similar symptoms. This suggests that actual help-seeking may be much lower than anticipated help-seeking and adds weight to evidence that intention may not be translated into behaviour (Sheeran, 2002), as discussed as a limitation of the TPB, in Chapter Two.

This disparity between intention and behaviour in help-seeking may be due to the influences on help-seeking behaviour in response to an actual symptom (Andersen et al., 2009) that participants may not consider in a hypothetical situation. For example, in Chapter Three, I explored the influences on intention to seek help and actual help-seeking for gynaecological and breast cancers. Although there were some similarities, not all of the influences on intention to seek help were applicable in a real life situation (see Chapter Three).

The findings described here suggest that many more women in the UK have symptoms potentially indicative of a gynaecological cancer than seek help for them. Any successful intervention which encourages women with these symptoms to seek help at primary care level could lead to a considerably increased pressure on the primary care system, and there is evidence that GPs may be concerned about the impact of such interventions (Evans et al., 2014). However, evidence from other campaigns aimed at increasing awareness of cancer symptoms and encouraging prompt help-seeking have demonstrated that the increased work load may be manageable. For example, a report published in 2011 explored the impact on primary care presentations for lung cancer in the Midlands area of the UK, following a campaign in the local area to promote awareness and early diagnosis of lung cancer. The report reveals that, although presentations for a cough that has lasted for three weeks or more increased by 23%, this equated to less than three additional presentations per practice, per week (Mayden, 2012). Further, in Evans et al.'s (2014) study, a quarter of the GPs had already implemented systems to encourage women to seek help promptly for potential symptoms of a gynaecological cancer, suggesting that the impact may be smaller still, as it may only apply to those practices who have not yet done so.

Moreover, it may not be appropriate to encourage all women with these symptoms to seek help immediately; for some women it may be advisable to monitor the symptom in the first instance. It is likely that the majority of symptomatic women in the current sample did not have a gynaecological cancer, based on incidence rates for these cancers in the UK population. In the highest risk age groups for cervical cancer (30-34 and 35-39) only one case in every 5650 and 6173 women respectively would be expected. In the highest risk age groups for uterine, ovarian, vulval and vaginal cancers (70-74, 80-84, 85+ and 85+ respectively) one would only expect to see one case in every 1101, 1437, 4082 and 23,810 women in the UK respectively (Office for National Statistics, 2012b). These incidence rates mean that, statistically, I would expect to find less than one case of a gynaecological cancer in this sample of 911 women.

Encouraging all of the women in the current sample to seek help then may not be appropriate, and an alternative course of action may be to target higher risk groups in any intervention aimed at encouraging women with symptoms to seek help. However, encouraging all women with a symptom they report as frequent and/or severe to seek medical help (whether this symptom indicates cancer or a more benign condition) is likely to be of benefit to the patient in terms of receiving treatment and ameliorating discomfort.

Just over a third of the women in this study (35%) reported a symptom potentially indicative of a gynaecological cancer that was frequent and/or severe. As some of the symptoms explored here are more likely to indicate a gynaecological cancer if they have such characteristics (Goff et al., 2004; Olson et al., 2001), women with these types of symptoms may be at higher risk of a gynaecological cancer. Furthermore, younger women were more likely to report a symptom, whereas most symptoms are more likely to be indicative of cancer in older women (Cancer Research UK, 2012g, 2013e; Office for National Statistics, 2012b). For example, abdominal distension, loss of appetite, abdominal pain and urinary frequency all have higher positive predictive values (PPVs) for ovarian cancer in women aged  $\geq 55$ , compared to younger women (Rossing et al., 2010).

If interventions are not only targeted at women with a frequent and/or severe symptom, but also at those who are older, the increase in consultations could be minimised. For example, my data showed that only 14% of the women surveyed ( $n=132/911$ ) were both older ( $\geq 45$  years) and had a frequent and/or severe symptom, but 5% ( $n=50/911$ ) had already seen a GP, so around 9% ( $82/911$ ) of the total sample could be characterised as needing to see their GP urgently. Targeting interventions in this way should ensure that consultations occurring as a result of encouraging earlier help-seeking would be more likely to lead to a cancer diagnosis. In terms of trying to increase earlier stage diagnoses

of gynaecological cancers, this relatively modest increase in consultations as a result of any successful intervention could potentially be worthwhile.

#### **7.4.1 Limitations**

Over half (58%) the women who completed the overall omnibus survey did not agree to complete the questions; which raises the issue of whether the results reflect the true prevalence of possible gynaecological cancer symptoms in the population. However, the final sample was broadly representative of the British female population in terms of ethnicity and SES (Ipsos MediaCT, 2009; Population, Ethnicity, Religion and Migration (PERM), 2009), despite demographic differences between respondents and non-respondents. Feedback from the interviewers indicated that the reason women gave for refusing or withdrawing was often being embarrassed by the survey content, despite the assured anonymity and the ability to self-complete the survey, suggesting that the data may not be missing at random. It would be difficult to overcome this limitation in any self-report survey with similar content.

Because it is not clear whether embarrassment would be more or less common in women with symptoms, I am unable to speculate about the direction of any possible bias. However, to estimate the impact of the missing data on my findings, I extrapolated the number of women with at least one symptom from my sample (n=911) to a sample including my sample and the non-responders (n=2173) using the demographic information I had for the non-responders (age, SES and ethnicity). This showed that the number of women that I would expect to report at least one symptom, (based on the demographic structure of the sample including the non-responders) ranged from 43% to 45%; very similar to the findings in the final sample (44%, n=398/911). Of course, these estimations do not take into account alternative reasons for non-response, such as having a symptom and feeling too embarrassed to talk about it.

Due to the small numbers of women endorsing each symptom, I analysed all the symptoms together, rather than individually or by cancer type. This meant that I did not report findings on help-seeking for individual symptoms or by gynaecological cancer. However, any frequent or severe symptom would be of concern, and it was therefore important to explore help-seeking responses to all symptoms combined.

The exploration of help-seeking for only one randomly selected index symptom was necessary to reduce the overall length of the survey, but may have meant that help-seeking was explored for a symptom that was neither frequent nor severe, when that participant may also have had a symptom that was either frequent, severe or both. However, I determined that this only applied to a very small proportion of the total sample.

I felt that it was important to explore the help-seeking behaviour for all symptom types, including the seemingly less serious symptoms, as this helps to provide a picture of whether people seek help appropriately. However, I acknowledge that it would have been interesting to have had help-seeking data for all of the symptoms endorsed. This could be a consideration for future research.

Finally, the survey did not go through any rigorous reliability and validity testing. Wherever possible the items drew on previous published work. For example, the frequency and severity questions are similar to those used in a previously published study exploring ovarian cancer symptoms (Goff et al., 2004). However, future studies using similar measurements may benefit from carrying out psychometric testing prior to use.

#### **7.4.2 Conclusions**

There is a clear indication that the occurrence of gynaecological symptoms potentially indicative of cancer in women in England is substantially higher than recorded in primary

care. The findings presented here suggest that the most likely alternative to help-seeking may be to monitor the symptom. However, it may not be appropriate to encourage all women with symptoms to seek help at the primary care level immediately.

Older women were less likely to report a symptom than younger women. Evidence that symptoms are more likely to be indicative of a gynaecological cancer if frequent and/or severe and that gynaecological cancers are more common at older ages, suggests that targeting interventions towards older women who have a symptom that is frequent or severe could promote appropriate help-seeking without increasing consultations with the 'worried well'.

The results in the present study are helpful in understanding how many women may have a symptom potentially indicative of a gynaecological cancer, and how most women may respond to such symptoms. However, the questionnaire design did not allow for an in-depth exploration of why the women who may be in most need of medical advice had not sought it out. In the next chapter I aim to explore symptom interpretations and responses using a qualitative methodology to attempt to understand these processes in more depth.



## **CHAPTER EIGHT – WOMEN'S DETECTION OF BODILY CHANGES, INTERPRETATION AND RESPONSE TO SYMPTOMS POTENTIALLY INDICATIVE OF A GYNAECOLOGICAL CANCER**

### **8.1 Introduction**

#### **8.1.1 Background**

In the preceding chapters I established that intention to seek help was high in women who anticipated having a symptom of a gynaecological cancer (see Chapter Six), but actual help-seeking was lower in women with symptoms that may indicate a gynaecological cancer (see Chapter Seven). Further, my findings in the previous chapter showed that there are potentially many more women in the population with symptoms than are seeking help for them, although only a small percentage of those women might be classed as needing to see their GP urgently. I concluded that interventions may be most effective if they are focused upon these higher-risk women. However, the research in Chapter Seven did not explore how and why women respond to bodily changes. An exploration of this kind could help understand why so many symptomatic women do not seek help and, as such, be informative in determining the content of any intervention.

In both the previous chapter and in Chapter Three, I described a qualitative focus group study published in 2013 by Cooper, Polonec, Stewart and Gelb. This study was novel in its exploration of both hypothetical and actual help-seeking across all five gynaecological cancers, outside of the context of illness or cancer. The majority of research in this area has focused on just one gynaecological cancer type, and has tended to be retrospective or just hypothetical (see Chapter Three). However, the study does have some limitations; the authors did not always clearly differentiate between women who had anticipated help-seeking for a hypothetical symptom and those who had experienced actual symptoms (nor did the authors provide information about how many symptoms were hypothetical and how many were real). This makes it difficult to isolate how women with real symptoms felt about their symptom, what they attributed it

to and how they responded to it. Moreover, the study was conducted in the US, which has a different healthcare system to the UK and perhaps other cultural differences in attitudes to help-seeking. Consequently, not all of Cooper et al.'s findings may be applicable here.

### **8.1.3 The Model of Pathways to Treatment**

With appropriate help-seeking for symptoms that may indicate a gynaecological cancer at a low level, it is necessary to identify the processes and influences involved in a help-seeking response. In doing so, it may be possible to identify areas where interventions to encourage appropriate help-seeking could be most effective. The use of a model to underpin research exploring time to help-seeking has also been recommended by the Aarhus Statement (Weller et al., 2012).

The MPT, (Walter et al., 2012, see page 57), which was discussed in detail in Chapter Two, is novel amongst help-seeking models as it includes the process of detecting a change in one's body, deciding that the change is a symptom and then deciding upon a response to the symptom. As mentioned in Chapter Two, the help-seeking process is complex and not necessarily linear.

### **8.1.4 The present study**

This study was undertaken to further investigate the process of detection of a bodily change, interpretation of the bodily change as a symptom, attributions and responses to the symptom. I focused the topic guide around the first two intervals (appraisal and help-seeking) of the MPT (Walter et al., 2012), avoiding the terms 'cancer' and 'symptom' in order to achieve a level of ecological validity, in line with previous research (Cooper et al., 2013) and the study described in Chapter Seven.

The present study was novel in its exploration of current symptom and response experiences, only in women who were currently or had recently experienced a symptom that may indicate a gynaecological cancer using a qualitative methodology. Exploring

current or recent symptom experiences in these women eliminated any recall bias associated with retrospective studies. Further, as with Cooper et al.'s (2013) study, there was no context of illness or cancer (achieved through avoiding the terms 'symptom' and 'cancer'), which reduced any reporting bias that may have occurred if participants had been aware that I was concerned with potential cancer symptoms. In order to achieve the above, I used in-depth interviews to explore symptom experiences and responses to symptoms. The rationale for adopting a qualitative methodology in this study is explained below.

### **8.1.5 Qualitative research methods**

The previous chapters within this thesis have explored help-seeking and symptom awareness using quantitative methodologies. These methods, which are concerned with hypothesis testing through collection and statistical analysis of numerical data (Clark-Carter, 1999), are useful in determining awareness of symptoms indicative of gynaecological cancers and anticipated help-seeking in a large group of women and for determining where statistical differences lie.

Conversely, qualitative research is concerned with the study of phenomena in a naturalistic setting using an interpretive approach and focusing on the meanings that participants assign to these phenomena (Fossey, Harvey, Mcdermott, and Davidson, 2002). Qualitative data are non-numerical and are usually collected via participant observation, interviews, document analyses or focus group. Qualitative research has been steadily growing in popularity within health research (Pope and Mays, 2009), as the value of such research in terms of understanding the complex area of health beliefs or exploring research areas for which there is little knowledge (Pope and Mays, 1995) has become more widely recognised.

As discussed, the vast majority of research exploring delay for help-seeking for symptoms potentially indicative of female cancers has explored hypothetical symptoms, rather than actual experienced symptoms. In Chapter Seven I aimed to explore the level

of symptoms potentially indicative of a gynaecological cancer and responses to these symptoms in women with actual symptoms. However, although it is important that we have an idea of how many women may be experiencing these symptoms and what the most common responses are, the study in the previous chapter did not capture the lived experiences of these women. Women's actual experiences of these symptoms and real world responses to them are likely to be complex and potentially influenced by a number of different factors; some of which may not have been considered when using quantitative research designs. For example, perceived barriers, low awareness or knowledge of symptoms and demographic variables are all thought to play a part in seeking help for symptoms of cancer, however, I found evidence in Chapter Six that help-seeking for symptoms that may be indicative of a gynaecological cancer cannot entirely be explained by these variables.

A qualitative methodology allowed me to explore the intricacies of meanings, thoughts and feelings that are part of this potentially sensitive experience. Quantitative methodologies such as questionnaires and surveys may not be sensitive enough to capture this level of detail. This deeper exploration enabled me to develop a much richer understanding of how women experience a symptom potentially indicative of a gynaecological cancer in the context of their lives, and to truly understand the lived experience of these women.

#### **8.1.6 Aims of this chapter**

- a) To understand the processes involved in the detection of a bodily change and how that change comes to be perceived as a symptom in women with symptoms that may indicate a gynaecological cancer
  
- b) To understand the processes involved in deciding to seek help or take alternative action in response to a symptom that may indicate a gynaecological cancer

- c) To explore help-seeking responses to a symptom which may be indicative of a gynaecological cancer, outside of the context of cancer

## **8.2 Methodology**

### **8.2.1 Study design**

The current study consisted of in-depth telephone and face-to-face interviews with 26 women aged thirty years and over. The interviews were carried out during June and November 2012. The study was approved by the UCL Research Ethics Committee (reference: 2734/001, see appendix 8 for the approval letter).

### **8.2.2 Sampling**

I aimed to use a purposive method of sampling to guide recruitment in the present study in order to achieve a demographically diverse sample. The original target sample was 40 women aged over thirty who had experienced a symptom that may indicate a gynaecological cancer in the three months prior to their recruitment. I chose this age cut-off as women below this age are far less likely to be at risk of a gynaecological cancer (Cancer Research UK, 2011, 2012d, 2012e, 2012f, 2013a). As in Chapter Seven, a three month cut-off for symptom experience was chosen so that symptoms and responses would still be fresh in participants' minds, but enough time had passed to allow a symptom to be detected (for example, heavier or longer periods might only be detected after two or more menstrual cycles).

I aimed to recruit women to four different groups, each consisting of 10 participants. Group 1 was to include women who reported a frequent symptom(s) and who sought help; Group 2 was to include women with a frequent symptom(s) who hadn't sought help; Group 3 was to include women who had an infrequent symptom(s) who had not sought help and finally, Group 4 was to include women who had an infrequent symptom(s) who had sought help. These groups were selected to enable me to identify factors involved in appropriate help-seeking (Groups 1 and 3) and inappropriate help-seeking (Groups 2 and 4). These groups were based on the results in Chapter Seven,

which showed that women with a frequent and/or severe symptom responded differently to those with a mild and infrequent symptom. I did not ask about severity in the screening questionnaire as, although both frequency and severity are important (for example, Goff et al., 2004; Olson et al., 2001), I wanted to avoid a lengthy screening questionnaire in case participants decided that they did not want to be interviewed or they were ineligible, which would make their data redundant. I did, however, explore both frequency and severity in-depth in the interviews (described below). I aimed to recruit women from a range of ethnic and socioeconomic backgrounds (using education, home ownership and car ownership as markers), and also asked women whether they were registered with a GP or not, as I wanted to interview only women who would have the option of seeing a GP.

### **8.2.3 Recruitment**

To achieve my purposive sample, I developed a screening questionnaire. The screening questionnaire (appendix 9) asked women for demographic information (age, ethnicity, education, car ownership and housing tenure), which symptoms they had experienced in the prior three months (they were provided with a list of symptoms, all of which could indicate a gynaecological cancer, which was the same list of symptoms that was used in Chapter Seven), how often they had experienced each symptom reported (once or twice, several times or all the time) and whether they had sought help or not. I used several methods to recruit women to my study in order to increase the chances of filling each of the quotas that I had set (discussed above). These methods are described below.

#### **8.2.3.1 Online recruitment**

An electronic version of the screening questionnaire was developed to be used online, via the website SurveyMonkey<sup>14</sup>. An advertisement explaining the study, along with the link to the screening questionnaire was published on a number of websites in June

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<sup>14</sup> [www.surveymonkey.com](http://www.surveymonkey.com)

2012, including the National Federation of Women's Institutes online edition newsletter<sup>15</sup>, Hillingdon Women's Centre<sup>16</sup>, Harringayonline<sup>17</sup>, Mumsnet<sup>18</sup> and Streetlife.com<sup>19</sup>. Further, information regarding the study and the link to the screening questionnaire were emailed to all employees at Santander in the Bluewater shopping centre in Kent and Citywire Financial Publishers, based in Vauxhall, London via the branch manager and the online producer respectively. The online advertisement and text used in the emails can be seen in appendices 10 and 11.

### **8.2.3.2 Offline recruitment**

In addition to the online advertisements directing women to the web-based version of the screening questionnaire, I also created posters advertising the study, with removable tabs. The web address for the screening questionnaire was printed on these removable tabs, so that interested women were able to take the tabs home and access the screening questionnaire at a convenient time. These posters were placed in various locations around London, including the Job Centre in Angel, Regent's Park Library, the West London Community Association, Hopscotch Asian Women's Centre, Curves Gym in Bromley and the HPod centre.

Potential participants were asked to complete the online screening questionnaire, and were told that they would be asked questions about their current health. At the end of the questionnaire, participants were asked whether they would like to be contacted about an interview, which would involve discussing their recent health in more detail. They were informed that they would be reimbursed for their time and any expenses incurred to attend an interview. If women indicated that they would be interested and

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<sup>15</sup> [www.thewi.org.uk/become-a-member/structure-of-the-wi/england/nottinghamshire/news/federation-newsletter](http://www.thewi.org.uk/become-a-member/structure-of-the-wi/england/nottinghamshire/news/federation-newsletter)

<sup>16</sup> [www.hillingdonwomenscentre.org.uk](http://www.hillingdonwomenscentre.org.uk)

<sup>17</sup> [www.harringayonline.com/](http://www.harringayonline.com/)

<sup>18</sup> [www.mumsnet.com](http://www.mumsnet.com)

<sup>19</sup> [www.streetlife.com](http://www.streetlife.com)

met the quotas discussed above, they were asked for their contact details and to specify a convenient time at which to contact them. I called or emailed these women to confirm interest and arranged a time for interview, if relevant. Women were offered either a telephone or face-to-face interview at UCL premises (1-19 Torrington Place, London), depending upon their preference.

#### **8.2.4 Interview topic guide**

The interview topic guide was underpinned by the MPT (Walter et al., 2012, page 57), as discussed above. I developed a semi-structured topic guide that allowed women to deviate from the structure and discuss their experiences, which may be outside of the context of the MPT. I structured the guide so that women were first asked about what bodily changes they had experienced, then about their responses to these changes and finally whether they had any other conditions or illnesses or were worried about or felt at risk of any. The topic guide was structured in this way to avoid mentioning illness until after the participant had discussed their own attributions and responses to the bodily change. Once a first draft had been written, this was then reviewed by one of the researchers involved in the development of the MPT (Dr. Suzanne Scott), and feedback was provided. I amended the interview topic guide following feedback and a final draft was drawn up (see appendix 12).

#### **8.3.5 Analysis**

All interviews were recorded using an electronic recorder. An external company (Devon Transcription<sup>20</sup>) transcribed 23 of the 26 interviews verbatim. To ensure that I was fully immersed in the data, I interviewed all participants, coded all of the resulting transcripts and transcribed 10% of the transcripts (three interviews). Once transcription was finished, I also read and re-read the transcriptions of the interviews.

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<sup>20</sup> <http://www.devontranscription.co.uk>



I analysed the interviews using framework analysis; a widely used method of qualitative analysis which uses a matrix to allow classification and organisation of data according to overarching and sub-themes (Ritchie & Spencer, 1994)). This analysis was aided by the NVivo software package (version 10, a software package designed to aid qualitative data analysis) (QSR International Pty Ltd., 2012). The transcripts were uploaded into the software in preparation for coding.

To code the interviews, following my initial reading and re-reading, I identified potential themes, and developed an initial thematic framework within which these initial themes were placed. Once the initial framework had been developed, I tested it against a subset of transcripts. As this was an initial framework, a number of additional themes emerged following my initial testing, and the framework was adapted accordingly.

Using the initial, revised framework, I carried out an initial coding of all of the transcripts. This involved selecting parts of the text within the transcripts and assigning codes to them. More than one code could be assigned to the same piece of text if applicable. This initial coding was at a very detailed level, to allow me to identify all of the relevant information. During coding of the later interviews, some codes emerged that had not been noted in earlier interviews. In order to ensure that all interviews were coded with all of the identified codes, all interviews were recoded after the initial coding was completed.

After this second round of coding, I identified 10 main themes (appendix 13), all of which had sub-themes. Once an initial coding frame had been identified, a second researcher (MS) coded two un-coded transcripts (OL01<sup>21</sup> and OL43) using the themes already

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<sup>21</sup> Initially, I had aimed to recruit some women online and some women through visiting some of the locations described in the recruitment section (section 8.2.3). As such, I had anticipated that some women may complete paper-based versions of the screening questionnaire (see Appendix 9) (and would have an ID prefix of 'PB') and some women would complete an online version of the screening questionnaire (and would have an ID prefix of 'OL'). However, all of the women were recruited online, and as such, all had the prefix 'OL'.

identified. Once this was completed, the coding for the two transcripts by MS and myself were compared in NVivo using Kappa, which revealed a range of agreement between 82.97% and 99.97%. Although this methodology of coding validation could be argued to simply show how well the second coder has learned the coding frame developed by the first coder, I attempted to overcome this limitation by asking MS to identify any additional codes that she felt did not fall within the coding frame I had developed. MS did identify 20 additional codes, however, upon further discussion with MS, it was agreed that all of these codes would actually come under the existing coding frame, and so no novel codes were added.

This framework was refined a total of eight times. Many of the themes, while interesting, were not relevant to the specific area of interest; they did not add to my understanding of the processes involved in the detection of a bodily change and how a bodily change comes to be perceived as a symptom in the group of women under investigation, nor did they aid understanding of the processes involved in deciding to seek help or take alternative action in response to a symptom that may indicate a gynaecological cancer. As these themes were not useful within the context of this research study, they were not included in the analyses reported here. Further, during the refinement process, it became clear that some of the overarching themes and sub-themes were similar; as such, these were merged.

During the refinement process, advice was sought from two other researchers (JW and GB). Once no more themes could be merged and I was left with themes that were all relevant to the focus of the research, I created the final framework. Within this framework, three broad themes were identified: 'detection and interpretation of bodily changes', 'symptom attributions', and 'responses to symptoms'. Within these broad themes, a number of sub-themes were identified, which can be seen in Figure 8.1.

Following identification of the final thematic framework, I began analysing relationships and links between themes, which enabled me to look for explanations of the variations in responses to symptoms across the women in my sample. To do this, I initially read through all the quotes that were coded within each theme. This process allowed me to identify where links between themes may lie, and allowed me to immerse myself in each theme. Once I had identified where relationships between themes may lie, I used the query function within NVivo to explore those relationships in more depth. The query function allows quotes which lie across one or more themes to be identified, which in turn can reveal how one or more themes may influence another. For example, I was able to explore the relationship between a number of different variables (such as family history of illness and experiences of, or advice from, others) and responses to symptoms (such as the decision to self-manage, learn to live with their symptoms, ignore the symptom or decide that nothing can be done). This process allowed a deeper level of analysis.

## **8.3 Results**

### **8.3.1 Sample of women for interview**

As described above, I aimed to recruit 40 women, which comprised four groups of ten women representing inappropriate and appropriate help-seeking. I also aimed to achieve a sample of women from a range of socioeconomic and ethnic backgrounds. This sampling method was designed to capture the experiences of a range of women and experiences.

The final sample consisted of 26 women. Although over 120 women responded to the screening questionnaire (n=123), the majority (n=97) of respondents fitted a quota that was already filled (most women who responded were educated to a mid- or high-level, (i.e. 'A' Level or Scottish Highers and above and were White British) or were ineligible (for example they did not have one of the symptoms of interest or did not give their consent to be contacted for interview). All of the women interviewed were registered with a GP. Please see Table 8.1 for demographic information relating to the women who

responded to the screening questionnaire (including both those who were interviewed and those who were not). Upon recruitment, I found that it was not possible to achieve the distinct 'symptom frequency' groups I had aimed to, as almost all (n=22, 85%) of the eligible women interviewed (n=26) had more than one symptom.

Table 8.1 Demographic information of women who were interviewed (n=26) and those who responded to the screening questionnaire, but were not interviewed (n=44\*).

	Women interviewed		Women not interviewed	
	n	%**	N	%**
Age group				
30-39	9	35	18	19
40-49	6	23	13	13
50-59	5	19	6	6
60-69	6	23	7	7
Ethnicity				
White British	22	85	33	34
White Other	4	15	7	7
Non-White	0	0	4	4
Education level				
Degree or higher degree	16	61	25	26
Higher education qualification below degree level	2	8	7	7
A-levels or Highers	2	8	3	3
ONC/BTEC	2	8	0	0
O Level or GCSE equivalent	3	11	8	8
No formal qualifications	0	0	0	0
Other	1	4	1	1
Car ownership				
None	7	27	12	12
One or more	19	73	32	33
Home ownership				
Own outright	7	27	12	12
Own with mortgage	12	46	16	17
Rent from Local Authority/Housing Association	2	8	3	3
Rent privately	4	15	12	12
Other (e.g. living with family/friends/squatting)	1	4	1	1
Symptoms reported***				
Pain in abdomen/lower back/pelvis	14	54	11	11
Increased abdominal size	12	46	21	22
Increased need to empty bladder more often/urgently	13	50	18	19
Increased wind or constipation	12	46	19	20
Difficulty eating/feeling full quickly	6	23	8	8
Heavier/longer periods	11	42	12	12
Changes in bowel habit	10	38	11	11
Pain/discomfort during sex	7	27	17	18
Itching, pain or soreness of vulva	7	27	21	22
Bleeding between periods	6	23	9	9
Discharge that smells unpleasant or is blood stained	7	27	7	7
Bleeding during/after sex	6	23	7	7
Growth/lump/sore/ulcer on skin of vulva	7	27	7	7
Bleeding after menopause†	0	0	0	0

\*53 women responded to the questionnaire, but declined to divulge any demographic information either because they were ineligible, and as such were not asked to provide this information or they declined to be contacted for interview and did not want their information recorded. Therefore no data for these women are provided here.

\*\*Most participants had more than one symptom and consequently the % for symptoms will be >100%

\*\*\*Symptom data were taken from the interviews for those women who participated, as this was the most up-to-date information at the time. Symptom data for women who responded to the screening questionnaire, but who were not interviewed were taken from the screening questionnaire.

†Despite inclusion in the survey, none of the women interviewed reported this symptom.

For women with more than one symptom, the frequency of each symptom often varied, as did the response to the symptom, meaning that each woman would fit into more than one, if not all groups, depending upon the symptom under discussion. Instead, I explored frequency itself as a variable that may influence the process of detecting a bodily change, attribution, and the response. This is discussed in the thematic framework below.

Further, although I aimed to recruit women from a variety of socioeconomic backgrounds using car and home ownership and education as markers, I was unable to recruit any eligible women with no formal qualifications. However, I did recruit women with a range of housing situations, including some women who owned their houses outright and some who were renting from their local authority, and women who either had one or more cars or none at all. Consequently this indicates that there was some variation in the SES of the women interviewed. Similarly, I was unable to recruit any women who were not from a White ethnic background. Although four of the women who responded to the survey were not White (see Table 8.1), none consented to being contacted for an interview.

None of the women interviewed reported post-menopausal bleeding, although five women reported being post-menopausal during the interview process. Many women reported more than one symptom in the screening questionnaire although specific symptoms reported sometimes varied from the screening questionnaire to those reported in the interview (possibly due to the time passing between completing the questionnaire and completing the interview). Despite this, a range of symptom experiences were achieved, with at least six participants reporting each symptom, bar post-menopausal bleeding (see Table 8.1).

### **8.3.2 Thematic framework**

#### **8.3.2.1 Theme One: 'Detection and interpretation of bodily changes'**

The sub-themes discussed below fit within the 'detection of bodily change(s)' event in the MPT (Walter et al., 2012) and act to help understand how women detect changes within their bodies and how they interpret those changes.

##### **8.3.2.1.1 Prompts to detection and interpretation**

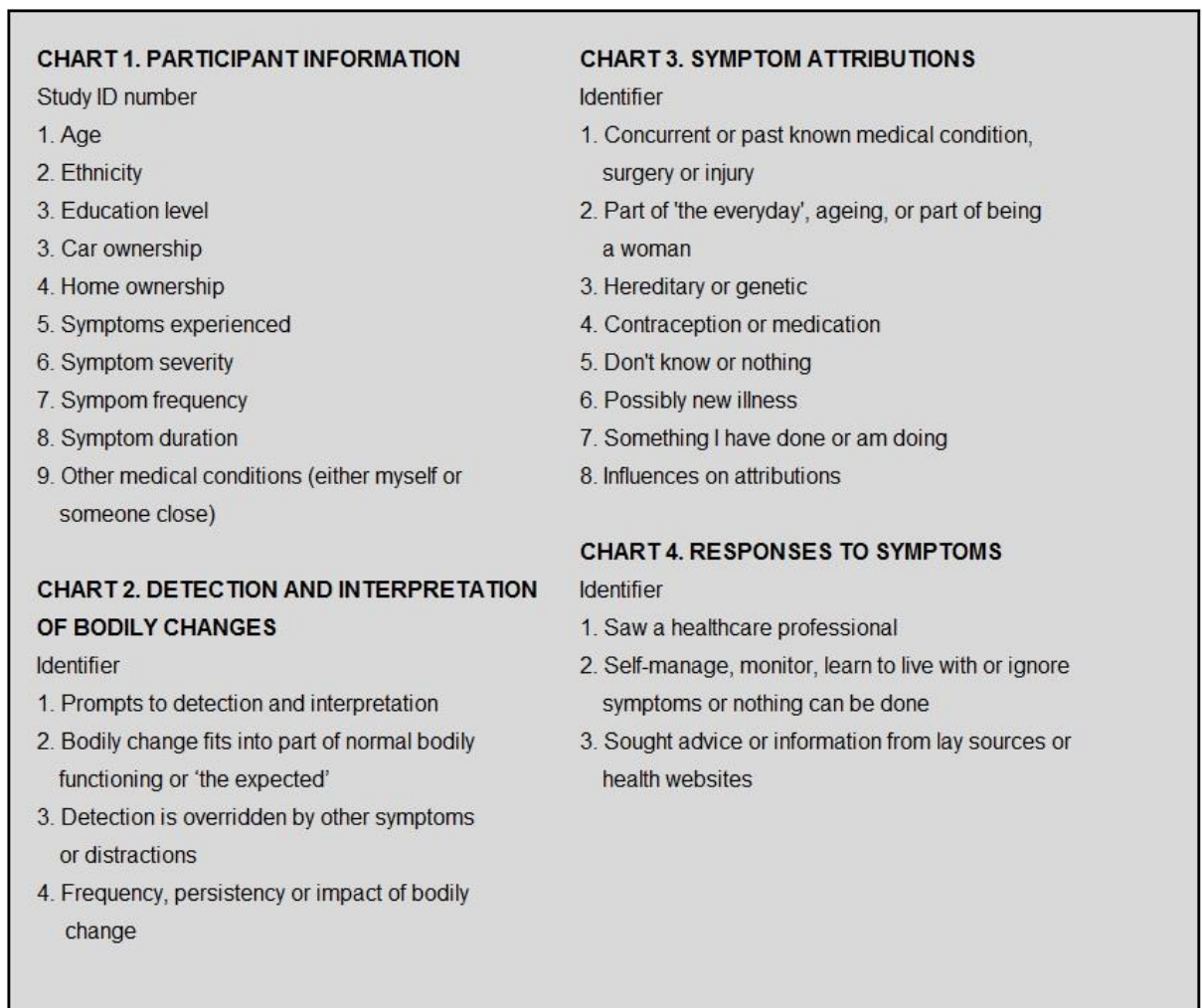
This sub-theme comprises women's experiences of perceiving a change in their bodies, including how that might occur, how they interpret these changes and influences on the detection of a bodily change. This broad theme in particular was difficult to draw out, as the act of asking women whether they had experienced the bodily changes within the study led to some women noticing a change for the first time, when they may not have otherwise noticed it. However, there was evidence that bodily changes may remain outside of conscious detection until attention is drawn to them by another person in real life situations as well. For example, one woman mentioned that she had only noticed the change in her body after her sister mentioned that she had also been experiencing the same change.

*"I think, well, my sister said that she noticed that and I, kind of, thought, oh, actually, so have I."* (OL10, unpleasant smelling vaginal discharge, age 39, White British, High SES)

##### **8.3.2.1.2 Bodily change fits into part of normal bodily functioning or 'the expected'**

For other women, although they appeared to be aware of the change in their bodies on some level, they did not pay it much attention as, for them, it fitted into their normal life or their expectations of what was normal.

*"It's not something I have particularly paid attention to; it's just one of those things that, you know, are there."* (OL31, increased abdominal size, age 62, White British, High SES)



**Figure 8.1 Final thematic framework for analysis**

### **8.3.2.1.3 Detection is overridden by other symptoms or distractions**

A few of the women interviewed mentioned that they had not paid attention to a bodily change or had not noticed it because they either were distracted by other things happening in their lives or by another, more severe symptom.

*"I had a really catastrophic back injury, so I was in so much pain in general anyway, I mean ... you can't tell?"* (OL01, pain during sex, age 50, White British, Mid SES)



#### **8.3.2.1.4 Frequency, persistency or impact of bodily change**

For some women, although they had detected their bodily change when it was happening, its behaviour, (for example frequency, persistency or having a minimal impact on their life), meant that they did not pay any attention to it, or their detection did not go further than a brief awareness.

*“To be honest, I have not particularly noticed. I mean, it’s just not something I have thought about, really. They are not things you dwell on unless it’s really, really affecting your life, do you?”* (OL31, changes in bowel habit, age 62, White British, High SES)

#### **8.3.2.2 Theme Two: ‘Symptom attributions’**

##### **8.3.2.2.1 Concurrent or past known medical condition, surgery or injury**

Most women, across symptoms, attributed their symptom to an existing or past condition, illness, disease, surgery or injury. These attributions suggest that women will attempt to ‘fit’ arising symptoms to existing illness heuristics, or explain them within that context; at least in the first instance.

*“I probably blame the fibroids ... These things are, kind of, crowding me out, I can’t eat, I can’t hold my urine, I can’t do anything, I’m heavy, I’m bloated. So I guess the fibroids are what I would, kind of, blame logically first”* (OL04, heavier or longer periods than normal, increased abdominal size, discomfort in the abdomen, increased need to empty bladder more often or urgently and difficulty eating, age 46, White British, High SES)

For some women, fitting their symptom to an existing condition required them to make assumptions. For example, one woman mentioned that she had sensitive skin on the outside of her body, and consequently reasoned that she would have sensitive skin elsewhere on her body, including the skin in her vaginal wall, which could have led to vaginal bleeding during sex. The woman added further weight to her attribution when she later explained that she often bled from her nose when irritating it (for example, by blowing it).

*“I think skin sensitivity, I honestly do. I feel that this is minor bleeding on the inside of the vagina. I ... have excessively sensitive skin on the outside and also in my nose and I know that sounds weird but it seems to me that if you’re kind of sensitive on the outside, why might you not be on the inside?”*

*“You know, if I blow my nose here, it will bleed. I mean, I often get blood there. Not nose bleeds, but just blood. It’s, so going back to vaginal bleeding, you can see why it’s not something that would disturb me unduly.”* (OL01, bleeding during sex, age 50, White British, Mid SES)

#### **8.3.2.2.2 Part of ‘the everyday’, ageing, or part of being a woman**

A number of women attributed their symptoms to something that is part of who they are, or ‘how their body works’. For some women, the pattern of the bodily change or symptom acted to confirm their attribution. If the bodily change acted in a way that fitted with how they expected their body to work, or with their idea of their own natural rhythms, or even with simply being female, women were able to attribute the changes in the body to something expected or normal for them.

*“that’s probably, again, linked to my periods because it’s worse at certain times of the month ... I’ve just always thought that maybe it’s, kind of, diet and, kind of, linked with my periods. A lot of my friends ... complain a bit as well so I just, kind of, think that it’s something that’s fairly common ... It was just, kind of, one of those things that you just think, well, that’s part of being a woman, really.”* (OL02, abdominal bloating, age 46, White British, High SES)

However, if that view was challenged by experience or new information, attributions could change. For example, one woman described believing that her vaginal discharge was normal until her sister mentioned that she had sought medical attention and been given treatment for the same symptom. This new information caused her to reassess her own attribution.

*“I just ... ignored it ... thinking it was normal and then she said, “Oh, I’ve gone to the doctor and got a medicine for this,” and I, kind of, thought, well if you’ve got a medicine for that, does that mean it’s not normal? Whereas before I think I’d just assumed it was normal”.* (OL10, vaginal discharge that smells unpleasant, age 39, White British, High SES)

Another common attribution was for women to put the changes in their bodies or their symptom down to ageing or to part of the ageing process, such as the menopause. Given that over 40% of the women interviewed were at an age where they would be expected to be peri-menopausal, menopausal or post-menopausal (the average age for

menopause is 52 in the UK, (NHS Choices, 2013d), it is not surprising that the menopause was one of the attributions women made here, and it is quite probable that this attribution was correct. For some women, that they were going through a big change in their bodies anyway, made it difficult for them to isolate their symptom, in much the same way as women who had another symptom found it difficult, as discussed above.

*"I'm right in the process of kind of menopause ... periods are getting less and less and less and less. So I think they're sort of departing. They may even have gone by now, I may actually have had the last one. So it's a very.. it's actually really difficult to discern kind of what's bleeding and what's period residue."* (OL01, bleeding after sex, age 50, White British, Mid SES)

#### **8.3.2.2.3 Hereditary or genetic**

Another common attribution for symptoms was that they were caused by something that was a hereditary or genetic condition. This attribution was often accompanied by an explanation that there was a family history of this condition.

*"I think it's hereditary, you see, because my mother had this problem as well"* (OL01, Increased need to empty bladder, age 50, White British, Mid SES)

For some women, although they did not disclose that a diagnosis had ever been made medically, the symptom had been experienced by many women within their family and subsequently a sophisticated explanation had been developed. For example, one woman who reported pelvic pain around the time of her period disclosed that dizygotic twins ran in her family. In this context, she believed that the pain was caused by the release of two eggs during ovulation. This attribution was then further cemented by information from her grandmother.

*"my nan reckons that eggs are released from both sides or a double egg comes from one side every other month ... She says that's why twins run in the family ... everybody was really surprised when I was pregnant that I ... didn't have twins because ... I had got those pains ... That's why I have been told that I get those pains, because I get a bad pain on my left-hand side every other month."* (OL26, pelvic pain, age 34, White British, Mid SES)

Some women argued that, although the symptom had never been attributed to a specific medical cause, this was not a problem as their family members who had the same symptom had lived with it without any complications.

*“Just like my mum and my auntie, we are all a bit of a likeness that way. My auntie is not known as Windy Wendy for no good reason ... But it’s also one of those things that ... because members of your family have experienced the same sort of problem as they have got older and it hasn’t meant anything, you know, there’s been no problem associated with it, you think, oh I’m just getting older and it’s a family thing and I don’t worry about it.”* (OL33, Increased wind, age 60, White British, Mid SES)

#### **8.3.2.2.4 Contraception or medication**

For many women, their symptom occurred alongside taking medication or being on contraception (including the contraceptive pill or the coil). They therefore attributed their symptom to that issue.

*“I guess I have experienced ... heavier periods and bleeding between periods in the last three months, more than what I would consider to be normal for me. And I have definitely attributed both of those things to the fact that I have been doing fertility treatment and having exciting fake hormones.”* (OL07, heavier or longer periods than normal and bleeding between periods, age 33, White other, Mid SES)

One explanation for this attribution may have been that these women applied parsimony; the taking of medication or being on contraception was a change in their life that they could easily attribute the change in their bodies to. One woman even talked about how the symptoms she experienced were obviously caused by the medication or contraception.

*“I have a contraceptive implant which can cause irregular bleeding and I have had it since April. It never caused me any trouble and suddenly all this. So that could be one of the reasons. That would be the obvious reason.”* (OL37, heavier or longer periods than normal, age 30, White Other, Low SES)

In these cases a number of women had already been warned that their symptom may be a side effect of the medication they were taking. Therefore, when they did experience that symptom, it was logical for them to attribute it to the medication.

*“I suppose the word on the street really was that if you have a normal coil put in ... the non-hormonal one, that there is a tendency for your periods to be heavier and so I just assumed that that was.”* (OL16, heavier or longer periods than normal, age 41, White British, Low SES)

#### **8.3.2.2.5 Don't know or nothing**

Not all women had made an attribution for their symptom, and there were a number of reasons for this. For many women, the symptom seemed to resolve itself, which led them to believe that it had not been indicative of anything serious. These women also expressed a lack of concern about their symptoms (for example, see OL06's quote below, in section 8.3.2.2.6), which may have influenced their lack of attribution.

*“So I just thought to myself I'll give it a couple of weeks, it doesn't feel as though it's anything... it feels literally just under the skin. So I thought I'd give it a couple of weeks or so and see if it went, and it did. So that was it really, nothing particularly exciting.”* (OL06, lump on vulva, age 34, White British, Mid SES)

Other women appeared to have just questioned why their symptom was happening, without coming to a conclusion. They had considered reasons for the symptom, but, as the reasons did not fit with their idea of how their body worked, they could not decide upon an attribution. For example, one woman talked about how the bloating and abdominal pain she was experiencing did not fit with what she may have otherwise attributed her symptom to (her menstrual cycle), because it did not happen when she might have expected it to.

*“My stomach was completely bloated and I was just, like, not due to get my period right then, so that didn't make any sense and anyway it wasn't the right, kind of, cramping. I was constipated and I was just, like, why is this happening? I still haven't worked it out, no.”* (OL07, Increased wind, constipation, increased abdominal size and abdominal pain, age 33, White British, Mid SES)

For some women, the perceived normality or low impact of the symptom meant that they had not considered what might have caused it.

*“It happens. Ooh, it’s happened. It’s not offensive, it’s not a particular... it’s just a little blow-off of wind. Now, I’ve never sat and thought, is this associated with what I am doing, what I’m eating, what I’m drinking. I’ve never really considered it.”* (OL33, Increased wind, age 60, White British, Mid SES)

#### **8.3.2.2.6 Possibly new illness**

Although I attempted to avoid the context of cancer and illness, some women did mention that they had thought about illness, including cancer when they had attempted to attribute their symptoms. However, despite the consideration of cancer, women did not appear to have been overly concerned or to truly believe that the symptom could indicate a cancer. For example, the woman below mentions that perhaps she should have seen a doctor, but she wasn’t sure, despite considering stomach cancer. This woman appears to dismiss the idea of stomach cancer partly because her symptom seems to have improved, leading her to consider other, benign causes, and partly because she does not want to see her GP more than she deems is necessary.

*“I don’t know, if I have stomach cancer or, I don’t know, anything like that, because everything seemed to be getting better and I, kind of, thought it was probably to do with the uterus and the fibroids. Whether I should have gone and spoken to the doctor about things as well? I don’t know. I don’t like going to the doctor more than I need to.”* (OL04, increased abdominal size, discomfort in the abdomen, age 46, White British, High SES)

In the example below, the participant has considered cervical cancer, but again, almost seems to dismiss this as over-reaction to her symptoms, referring to herself as a ‘worrywart’.

*“I am either going through the menopause or I have got cervical cancer. And then, for some reason, I decided that I could possibly have chlamydia, not that that’s got anything to do with your periods or the fact that I was at risk of getting it but I’m just, erm, a bit of a worrywart, really.”* (OL16, heavier or longer periods than normal, age 41, White British, Low SES)

A lump is often described in the literature as a classic sign of cancer (for example, Robb et al., 2009; Smith, Pope, and Botha, 2005), and there is evidence to support the idea that this is by far the most well-known symptom (Robb et al., 2009). However, only

a couple of the six women<sup>22</sup> who reported a lump even considered cancer as a possible cause. Most believed that their lump was something benign, such as a cyst, ingrown hair or blocked gland. The lack of serious consideration of cancer in these women may have been a result of the location of the lump, as illustrated by the woman below.

*“I wasn’t particularly concerned about it ... if I find a lump in my breast, then alarm bells start ringing and you start going, oh my gosh, I’ve got to see the doctor straight away... it maybe fleetingly went through my mind that it would be something that ... needed investigation, yeah, a bad lump, a cancerous lump or something like that ... it’s not causing any problems ... it hadn’t made alarm bells ring in my mind so I just want to see what happens to it, rather than rushing to the doctor and freaking out.”* (OL06, lump on vulva, 34, White British, Mid SES).

Believing symptoms were caused by thrush seems to be a common attribution amongst women who reported unpleasant smelling vaginal discharge or itching or soreness of the vulva. For the woman below, this attribution was made following a conversation with her friend, who offered a simple explanation.

*“It’s quite funny really. I phoned up my friend and I said, “I’ve got some stuff, I don’t know what it is,” and she said, “What is it?” and I told her and she went, “You have got thrush, love.”* (OL26, unpleasant smelling vaginal discharge, age 34, White British, Mid SES)

#### **8.3.2.2.7 Something I have done or I am doing**

A number of women attributed their symptom or bodily change to something they were doing, such as drinking alcohol or eating certain foods, or to something that they had done, including causing themselves an injury or damage. For example, the woman below attributed her increased frequency and urgency to urinate to damage she believed that she had caused by holding her urine for long periods of time during a busy time at work. Her language suggests that she had to search quite hard for this attribution (*“if I really, really thought about it”*).

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<sup>22</sup> In Table 8.1, seven women are reported as having a growth, lump, sore or ulcer on skin of vulva, including six women who reported a lump and one woman who reported an ulcer.

*"I was working on this ... project last year and I literally maybe got to pee, maybe, maybe once a day as a special treat to myself ... I was working for, like, 60 or 70 hour weeks and it was just mental. And if I really, really thought about it, I would probably say it was probably that I did some sort of damage during that period ... which eventually will probably work itself out."* (OL7, Frequent and urgent urination, age 33, White Other, Mid SES)

Another woman attributed her bleeding during and after sex to her rigorous sex life.

*"The last three months, on one occasion there was bleeding during or after sex but, as I said, that's down to what we are doing."* (OL14, bleeding during or after sex, age 40, White British, Mid SES)

#### **8.3.2.2.8 Influences on symptom attributions**

The women in this study described a number of ways in which the attributions they made for their symptoms were influenced. One of the most common influences on attributions was a previous experience of the symptom or of something else (such as a surgery or problems in a similar physiological area). For example, the woman below describes how the somatic information she received when she had pelvic inflammatory disease was similar to that which she was receiving at the point of interview. It was therefore easy for her to attribute her current bodily change to a previously experienced condition.

*"I was pretty convinced it was gynaecological because in the past I had pelvic inflammatory disease when I was a lot younger ... the feeling that I had reminded me of the feeling when I had that many years ago. So that's what I thought."* (OL06, abdominal pain, age 34, White British, Mid SES)

Women also talked about seeking help via what has been described as the 'lay system of care' (Pescosolido & Boyer, 1999), which includes family, friends and others that an individual may come into contact with, such as colleagues. Some women described how the experiences of others influenced their appraisals. For example, the woman below had suspected that her irregular bleeding was caused by the contraceptive implant she had had fitted, and described seeking advice from a friend who also had this contraceptive device fitted.



*"I spoke to my friend who had it as well and she said, "Oh, just take [the contraceptive implant] out, it will stop." So it has, hopefully." (OL37, heavier or longer periods than normal, age 30, White other, low SES)*

Although the 'lay system of care' described above describes help sought from social connections, I did find evidence that women may use the information they obtain through this system of care differently, depending upon whose advice is sought. For example, although women talked about incorporating the experiences of others into the appraisal of their own symptoms, this was particularly useful when the advice was sought from a relative. This type of advice perhaps gives more depth to the appraisal and potential consequences of a bodily change or symptom over and above experiences of non-relatives because of the shared genes between close relatives. For example the woman below talked about the importance of seeking advice from close relatives so as to gauge the level of threat to health that her bodily change poses.

*"I talked to my mum and my sister about it and my mum said, oh yeah, it's cystitis, cystitis. And I said, it's not ... I think it's hereditary ... I just tend to think that it's always worth asking your mother and your sister about these things because a lot of these things are quite similar within families and if they appear to have the same thing and they're still alive, why should I not be?" (OL01, Increased need to empty bladder, age 50, White British, Mid SES)*

Another common influence on attributions was how the symptom behaved. For many women, the symptom appeared to occur in patterns around their menstrual cycle, or around pre-held beliefs of what illness is, which then made it easy for them to attribute the symptom to part of that. This attribution then reduced any worry they might have, had the symptom behaved differently.

*"you know, if I had had it and then it didn't turn into a period then I'd be worried but, you know, I'd, sort of, have it for a day and then my period comes and then it tails off and I suppose it's just the tail end and the beginning, I suppose." (OL02, blood stained vaginal discharge, White British, Mid SES)*

One woman interviewed talked about how having a lump on her vulva influenced a consideration that she may have cancer, because of the association between a lump and cancer. However, interestingly, for most of the other women with the same symptom, cancer was not a consideration (as described above).

*“I didn’t believe it was cancer ... It’s really weird but that didn’t worry me at all. Whereas I think when you do have a little lump, you think, oh is that... [cancer]? Yes, I think there’s an element of that... I hope I haven’t got it. I haven’t had it checked. But it’s in the back of your mind, of course. Cancer is the thing, whether it’s breast or whatever.”* (OL28, lump on skin of vulva, age 57, Mid SES)

For other women, when the symptom did not behave in a way that they thought it should to fit with an attribution, they then considered alternatives. For example, one woman had increased wind and constipation, which she usually put down to an intolerance of raw onions. However, when an occasion arose where she experienced those symptoms when she had not had raw onions, she came up with an alternative attribution.

*“nothing else was out of the ordinary; you know, everything else was completely like something I would normally eat. So then I just, kind of, thought, well that’s just weird, presumably this could just be stress related.”* (OL07, increased wind and constipation, age 33, White Other, Mid SES)

### **8.3.2.3 Theme Three: ‘Responses to symptoms’**

Women reported a number of different responses to their symptoms, including monitoring them or waiting to see what happened, seeing a healthcare professional or a non-medical professional.

#### **8.3.2.3.1 Saw a healthcare professional**

Almost all of the women interviewed reported having visited at least one healthcare professional (HCP) (a GP, a Genitourinary Medicine (GUM) clinic, a pharmacist, an osteopath, the hospital accident and emergency (A&E) department, a consultant or a specialist) for at least one of the symptoms I asked about.

Women identified a number of different issues which influenced their decision to seek medical help for their symptom(s). The most common influences on help-seeking were related to the behaviour of the symptom itself. Almost all of the women in the study stated that they had sought help, or would seek help if their symptom(s) worsened, recurred, or changed. For example, women would be prompted to seek help if a new symptom appeared alongside the original symptom or if the symptom persisted.

*“maybe if it was associated with the sores or if the skin was broken, if it was like there was a possibility of infection ... or if it was persistent, you know, and lasted for longer. All of those things, yeah ... if it did actually combine with, you know, more severe, more time and maybe other symptoms.”* (OL31, vulval soreness, age 62, White British, High SES)

One woman, who was only in her late thirties described waiting until her need to frequently and urgently urinate were really quite debilitating before she would seek help.

*“It would have to go on for a lot longer and be a lot more urgent ... And if I was wetting myself or, you know, partially wetting myself then I would be conscious of smelling or things like that. I wouldn’t, sort of, suffer in silence but perhaps having to get up every hour in the night or ... if it’s twice a night then I can put up with it.”* (OL10, increased need to urinate more frequently and urgently, age 39, White British, High SES).

Another woman had a tipping point of frequency for her symptom; she determined that if her symptom occurred a third time, then she would seek help.

*“Once the pain has gone, you just tend to think, well, okay, there’s not really any point. If I get it again, the third time will definitely be the cut-off and I will go and see if they can refer me on.”* (OL02, lower back pain, age 46, White British, Mid SES)

Other women who had initially decided to self-manage, or would initially consider self-management, revealed that if their management of the symptom(s) did not work, they would then go, or would consider going to their GP.

*“I know my own body much better now so if it goes over three days then I would eat lots of liquorish, eat some prunes and drink lots of water and if that didn’t work then I would probably go to see my GP.”* (OL35, constipation, age 64, White British, Low SES)

Another, perhaps unsurprising influence on help-seeking was fear, concern or worry about what the symptom may indicate. For some women this fear or worry was related to an attribution that the symptom was indicative of something serious, which was related to an awareness of a family history of illness.

*“I had read that if you get bloating and it doesn’t go away, that is usually a sign maybe that’s cancer. If it went down, which happens to me, it probably isn’t ... There is quite a history of cancer in my family ... I was frightened so it prompted me... I think I am probably like a lot of people who think, oh it will go away, it will be fine, don’t worry, but it didn’t and ... I got scared.”* (OL43, persistent bloating, age 64, White British, Low SES)

Another common influence on medical help-seeking was being in pain or discomfort, with almost half of the women interviewed mentioning that this would prompt them to seek help. The woman below emphasised just how bad the symptom would need to be before she would seek help (*“If it was painful or really, really bad”*).

*“it depends how bad it was. If it was painful or really, really bad, then yes, obviously, but if it was just a bit of an odour, then, no, I probably would just wait and see.”* (OL10, vaginal discharge that smells unpleasant, age 39, White British, High SES).

A number of women talked about feeling justified in seeking help. This feeling of justification came in a number of different forms. For some women, the simple presence of the symptom was sufficient justification. One woman reasoned that she would go to her GP if her symptom occurred again because, *“you are getting that for a reason”* (OL02, lower back pain, age 46, White British, Mid SES). For others, however, the presence of the symptom was not enough to prompt them to seek medical attention, and they needed further justification. For example, in the quote above from participant OL43, this woman describes how her family history, along with the behaviour of the symptom and the fear this caused led her to seek help. This need for further justification is possibly linked to a concern that the symptoms weren’t serious enough, and that there was a possibility of wasting the doctor’s time. This is illustrated in the quote below.

*“I felt, silly enough, it justified me going to the GP because I’d had the background. ... it’s quite old-school thinking - you don’t bother a doctor until you are nearly dying. But that justified... yes, there is... it didn’t need justification but that made me think I can go now, which is stupid ... Yeah, it was stupid that I thought oh now I’ve got that they won’t think that I am just... which is stupid.”* (OL43, persistent bloating, age 64, White British, Low SES)

A couple of women talked about initially believing that their symptoms were something that every woman experienced. However, after investigating their symptoms online, and reading about the experiences of other women, they realised that perhaps their symptom wasn’t normal, and consequently they felt justified in seeking medical attention.

*“I ... saw other people’s experiences and that ... persuaded me that mine was bad enough to actually do something about it and that I wasn’t just making a fuss about nothing ... I, sort of, realised yes, it probably is quite bad ... that was probably a factor in doing something about it as well.”* (OL03, heavier or longer periods than normal, age 34, White British, Mid SES).

Women perceived a number of different barriers to help-seeking. Two of the most common reasons were a lack of worry about the symptom or perceiving the symptom to be minor or not serious enough and believing that there was no point, or not enough justification (see above) to seek medical attention. Some women believed that there was no point in seeking help because they felt that what they were experiencing was just something that ‘happens’.

*“I guess I have not thought enough to be able to actually go and get it sorted out or, you know, speak to anybody about it, I just, kind of, assumed, you know, that might be what happens.”* (OL24, bleeding between periods, age 35, White British, High SES).

For one woman, her lack of concern about her symptom led to her feeling that she was not bothered enough to seek medical attention.

*“I’d say not [severe] enough to bother to do anything about it. “* (OL27, pain and discomfort during sex, age 52, White British, high SES)

Other common reasons for avoiding seeking help included not prioritising help-seeking or putting it off. One woman talked about having help-seeking 'in the back of her mind', and her language is quite flippant, suggesting a lack of real concern, despite considering that she may have either cervical or ovarian cancer.

*"I mean in the back of my mind ... is, I really must do something about it to make sure I haven't got cervical cancer. And there was a minor ovarian cancer scare for a few days."* (OL01, vaginal bleeding after sex, age 50, White British, Mid SES)

Other reasons for putting off seeking medical attention or for putting it off included having other illnesses or more urgent health needs, needing or wanting to put others first, having a holiday booked, believing that the symptom was a one-off, or judging the symptom by previous experiences. For example, one woman had previously experienced severe pancreatitis. This previous experience of a very painful and severe illness coloured her judgement of later symptoms, whether they were similar or not.

*"I have been with the pancreatitis, that was drastic ... obviously, that's immediate. Whereas this isn't quite immediate and I think, actually, that's a bad thing for me because I tend to judge everything by that previous experience, say, well if it's not like that, it's not as urgent, it's not as important, which isn't a good thing ... I have been blowing it off a bit."* (OL14, heavier or longer periods than normal, age 40, White British, Mid SES).

A few women described previous bad experiences with a doctor, which then put them off considering going in the future. For one woman, her negative experiences with her GP led to her decision to seek private medical health care in the future.

*"So that's the end of it, really. I don't know, I don't think I will bother going to NHS doctors, really, with this again. I'm thinking of going private. Private costs but at least they will actually listen to you."* (OL37, bleeding after sex and pain during sex, age 30, White other, low SES)

A number of women reported service barriers to seeking help, namely a difficulty in getting an appointment, or not having enough time with the GP once an appointment was made.

*"It would have to be easier to get an appointment with the GP. It really is that, that is such a bloody drama. And you get you know, thirty seconds with you GP and you're allowed to talk about one thing."* (OL01, vaginal bleeding after sex, age 50, White British, Mid SES)

Another service barrier that women mentioned in the present study was a concern about wasting GP time. For most of these women this seemed to stem from a belief that perhaps their symptoms weren't serious enough, or there wasn't adequate justification to 'bother the doctor'.

*"I would do. I'm sensible. I'm not going to be stupid about it, but, on the other hand, I don't want to bother people because there are people who are really ill."* (OL28, itching, pain or soreness of vulva, age 57, Mid SES).

In much the same way that persistency or frequency of a symptom would influence help-seeking, a lack of persistency or frequency for some women acted as a barrier to help-seeking, although again, this did seem to be linked with a concern about bothering the GP unnecessarily, or wasting their time.

*"I think it would have to be more persistent and last for longer for me to think it was worthwhile to bother the GP. You always feel apologetic when you see a GP."* (OL31, constipation, age 62, White British, High SES)

For a number of women, the gender of their GP acted as a barrier to help-seeking. Most of these women said that they would prefer a female GP as they would feel embarrassed about talking to a male GP about the symptoms in this study.

*"I think it would have to become really bad. Because he's the male GP as well and I would feel a bit embarrassed talking to him in a way."* (OL36, increased wind, age 53, White British, Mid SES)

Finally, one woman talked about a lack of trust as a reason why she would not want to go to her GP with intimate female health issues.

*“I think there is a real problem with clinics, that there’s nobody... you go into your GP, there’s nobody specific who knows who you are, or cares, you are just a number, and I know it may be more efficient but I think for female health and particularly things about, you know, vagina or sex or this stuff, you need to have somebody that you trust and you can go to.”* (OL28, Pain/discomfort during sex, Itching, pain or soreness of vulva, Growth/lump/sore/ulcer on skin of vulva, age 57, Mid SES).

#### **8.3.2.3.2 Self-manage, monitor, learn to live with or ignore symptoms or nothing can be done**

The majority of women interviewed reported having at least one symptom that they decided to live with or self-manage, rather than seek medical help, although the reasons or justifications they gave for these decisions varied. The language used by some women suggested that they viewed their symptoms with a ‘stiff upper lip’, deciding that they shouldn’t let it interfere with their lives, even if it was causing them discomfort or concern.

*“I would say in my mid-40s it started to bother me. I mean, it is a bother but, you know, you just put up with it, don’t you?”* (OL21, increased wind, age 62, White British, Mid SES)

Other women described self-management as a way of ruling things out, or deciding whether medical attention was needed.

*“I took some motilium and, kind of, moved on with my life and, sort of, figured if it went on for any longer then I probably would go and see my GP because that would be worrying.”* (OL07, increased abdominal size that does not go away (including bloating), age 33, White other, Mid SES)

Some of the women who used self-management as a way of ruling things out or deciding whether medical attention was needed had an idea about what might have caused their symptoms, which appeared to influence their response to it.



*"I think I'd probably try and sort myself out first with eating and say, right, okay, that's enough of dairy ... and then I'd see how it went from there and then if I thought I needed to go to my GP, I'd head off there."* (OL27, increased abdominal size, age 52, White British, high SES)

For a few women, their decision to put up with their symptom or ignore it seemed to be related to the impact it had on their lives.

*"it's not frequent enough, it doesn't give me any trouble, so, as I say, I'm inclined just to ignore it."* (OL33, increased wind, age 60, White British, Mid SES)

One of the most common non-medical self-management techniques that women mentioned was to manage their symptoms with food or drink remedies, including avoiding certain foods or drinks or introducing others into their diets. Women who reported using these self-management techniques mostly reported experiencing changes in their bowel habits, including constipation and a persistently increased abdominal size, including bloating. This suggests that women believed that their symptoms were related to their digestive system, and that they could be resolved by altering their eating or drinking habits. For a couple of women, using food or drink remedies was preferable to using medication.

*"I don't take laxatives or anything like that. I try to do it through what I eat, through roughage. I don't know whether it's a lazy gut or whatever because sometimes it can be violent."* (OL43, changes in bowel habit, including constipation, age 64, White British, Low SES)

Although this form of self-management was mostly reported by women who had changes in their bowel habits or an increased abdominal size, some women with other symptoms also reported using food or drink remedies to manage their symptoms. Three women with difficulty eating or feeling full quickly also mentioned attempting to make changes to their diets, including reducing their portion sizes, eating a variety of foods and eating higher fat foods for energy.

*“in order to really make sure that I've eaten lots of good solid food that's going to keep me strong and keep me moving around, cos I walk and .. I do a lot of stuff. I really do rely on fairly kind of high fat stuff.”* (OL01, difficulty eating, age 50, White British, Mid SES).

Some women mentioned using remedies involving food or drink for symptoms that aren't directly related to the digestive system. For example, one woman mentioned eating probiotic yoghurts to combat the unpleasant smelling vaginal discharge that she was experiencing, whilst another considered drinking nettle tea to help stop the heavy periods she was experiencing, as she believed that this would be effective for her.

*“I was considering ... nettle tea, it's a very effective blood-stopping herb... it's not very tasty but I believe if it doesn't stop I'll have to start drinking it. But that's what I considered. I didn't actually have to do it in the end.”* (OL37, heavier or longer periods than normal, age 30, White other, low SES)

Women who were experiencing an increased need to empty their bladders managed their symptoms in a number of ways. Some mentioned ensuring that they always went to the toilet just before they left their homes. Other management methods included avoiding drinking too much or at all before leaving the house or at night.

*“I cannot have a drink before I come out. I've got an hour ... train journey. It's the inconvenience. Because you want to go ... I know every toilet in every shop. You are gearing where are the loos, that's the first thing you do and it's just peeing me off, to be quite honest.”* (OL43, increased need to empty bladder, age 64, White British, Low SES)

Three of the women experiencing pain during sex reported managing their symptom by either avoiding penetrative sex, either altogether or during certain times of the month, when the pain increased or by using lubricant and 'taking things slowly'.

*“So it's just managing it and, sort of, finding the time in the month when it's going to be okay. But I appreciate that that will probably get worse and then we'll have to think about other ways of lubrication and stuff. I'm not quite there yet.”* (OL02, pain during sex, age 46, White British, Mid SES).

Two women who were experiencing pain in the lower back managed their symptom by making changes to their lifestyle or surroundings. For example, one woman mentioned that she had been a keen runner, but had read that running was bad for her, so she stopped running and found that her back pain improved. Another woman found that walking around, rather than lying down was the best way to manage her back pain.

*“The best thing I can do when I have got a bad back is... don’t stay in bed, you get up and you walk. That was just a natural thing that I felt that I had to do because I think if I’d have stayed in bed I would never have got up again.”* (OL35, lower back pain, age 64, White British, Low SES)

Finally, some women reported self-medicating with over the counter medications; again, the medications used varied by symptom. One woman reporting constipation mentioned that, although she preferred to use non-pharmaceutical methods to manage her symptoms, she would also use laxatives when she felt that her symptoms might worsen.

*“sometimes I buy a laxative when I feel like I will blow up and I have tried liquorish, sometimes different things. So if I change my diet it can help. And I was given loads of fibre something, a laxative you make up into a drink by my GP and I really, really don’t like it; I’d much rather take a tablet. But I would rather not do anything.”* (OL35, constipation, age 64, White British, Low SES)

Half of the women interviewed said that they would monitor or wait and see what happens with at least one of the symptoms they reported. This behaviour either seemed to be influenced by a concern over seeking help prematurely, when the symptom may resolve itself or not being particularly worried about the symptom, or a hope that the symptom would resolve itself and not require medical attention.

*“Then I had a little feel, I thought, oh s\*\*t, I’ve got a lump. And then you think [gasps], there’s always a moment of [gasps] oh gosh, oh gosh, and then I take a deep breath and think, well it will probably go away and if it doesn’t then I’ll do something. That’s my psychological, kind of, pattern.”* (OL28, lump on vulva, age 57, Mid SES).

Some women again wanted to gather information before seeking medical help, which involved monitoring the symptom.

*“I like the wait and see approach because then, you know, you are gathering more data, so to speak, so if it does actually really become a problem, you can go to the GP and say, look, this has been going on for x amount of time, this has happened, that’s happened, this is happening, I’m not happy there is something wrong. Rather than rushing off and going, oh, I’ve Googled it, I’m dying, kind of thing, which is wrong.”* (OL14, heavier or longer periods than normal, age 46, White British, High SES)

Two women talked about having time limits for how long they would wait and watch their symptom for, or limits on how many times the symptom had occurred before they would stop monitoring their symptom and seek medical help.

*“actually, my behaviour would be that if it was something that I thought, oh my God, it’s something really bad, and then to calm down for a bit and think, oh no, it’s not, it’s just one of those things. And then just to see how things went and after a week or two if it was still going on, to actually go and see the GP.”* (OL05, heavier or longer periods than normal, itching, pain or soreness of the vulva, changes in bowel habit, age 46, White British, Mid SES).

Other women believed that their symptoms were not indicative of anything serious, and therefore felt that monitoring them was the best thing to do.

*“I wasn’t particularly concerned about it. I mean, I suppose, if I find a lump in my breast, then alarm bells start ringing and you start going, oh my gosh, I’ve got to see the doctor straight away. So I just thought to myself I’ll give it a couple of weeks, it doesn’t feel as though it’s anything.”* (OL06, lump on vulva, age 34, White British, Mid SES)

#### **8.3.2.3.3 Sought advice or information from lay sources or health websites**

Some women opted to seek advice from a source other than a healthcare professional, including looking for information online, usually on sites such as NHS Direct<sup>23</sup>. Other women sought advice or information from lay sources, including their friends, family or colleagues and online, on non-medical sites, including Mumsnet<sup>24</sup>.

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<sup>23</sup> [www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)

<sup>24</sup> [www.mumsnet.com](http://www.mumsnet.com)

A few women saw searching online for information as a precursor to seeing the doctor. One woman discussed how this enabled her to try to 'suss out' what was going on before she saw her GP. Another described being proactive about seeing her doctor, but stated that she sought information from the internet and NHS Direct before doing so.

*"The first port of call is usually the internet, the second port of call would be NHS Direct, the third port of call would be go and see the GP."* (OL30, constipation, age 32, White Irish, Low SES)

For other women, however, the internet was used as the sole manner of diagnosis, rather than in addition to, or before seeking medical help. Using the information or advice they received online, women then self-diagnosed and took action accordingly to the diagnosis they had made.

*"I tried to stick to the NHS sites actually when I was looking because I thought I could trust the advice on those. The one thing that... kept seeming to come up? ... [Endometriosis] ... that's come up a few times and that slightly concerned me, and that's why I probably felt I best leave that for now because I can think about that another time."* (OL24, heavier or longer periods than normal and bleeding between periods, age 35, White British, High SES).

For one woman, the internet was a place to obtain additional information, alongside that given by a doctor.

*"Then I went to see the doctor and she said she didn't think I was peri-menopausal but referred me for a scan and then I just Googled what that would all mean and what the implications were."* (OL05, heavier or longer periods than normal, age 46, White British, Mid SES).

Although these women may have felt that the internet was a useful tool when arming themselves with information or ruling things out before visiting the GP, some women found looking on the internet unhelpful because they felt that they would always be told that they were seriously ill.

*"I do remember Googling these things, and they always come out, you know, with all this terrible melodramatic stuff and you think, I'm going to drop dead tomorrow."* (OL01, difficulty eating or feeling full quickly, age 50, White British, Mid SES)

Although many women did seek advice on the internet, some also sought advice or information from those around them. For some, this then influenced whether they would go on to seek medical help or not.

*"A friend of mine ... is a doctor and I, sort of, said, "Oh, it's all been a bit horrible," and he was just like, "You are fine," ... I find the thing that if you have a lot of friends who are doctors and you do, sort of, say, "I feel a bit ugh," and they are like, "Yeah?" ... What do you want me to do about it? ... It gives you a slightly ... robust approach to whether or not I am actually going to go to the doctor."* (OL07, constipation, increased abdominal size and abdominal pain, age 33, White other, Mid SES)

## **8.4 Discussion**

### **8.4.1 Overview of findings**

This study is, to my knowledge, the first to explore how British women attribute changes in their bodies potentially indicative of a gynaecological cancer and responses to them in women with real symptoms, using a qualitative methodology. Building on the previous chapters, I aimed to explore the processes involved in the detection and interpretation of bodily changes. I also explored influences on interpretation, attributions and responses to symptoms through semi-structured interviewing.

The design of the study was underpinned by reference to the first two intervals ('Appraisal' and 'Help-seeking') of the MPT (Walter et al., 2012, see Figure 2.5 on page 57), and the events and processes that surround transition from one interval to the other. Overall, my findings map broadly onto the MPT, as I found evidence for the influence of patient factors in the appraisal process (such as having a previous experience of a symptom or something similar) and disease factors (such as having preconceptions about what a cancer symptom is) (see Figure 8.2). I did not find evidence for the influence of healthcare provider or system factors on appraisal, which is unsurprising as women may not have considered seeking help at the appraisal interval. I

also identified a number of patient factors which influence help-seeking (such as feeling justified or worrying that a symptom might be serious) and some that acted as barriers to help-seeking (such as experiencing other, more pressing health issues or social conflicts). Being able to see a female was one of the healthcare provider and system factors which acted to encourage help-seeking, whereas concern about wasting GP time acted as a barrier. Further, I also found evidence for the influence of disease factors, such as a worsening, change or recurrence of a symptom which acted to encourage help-seeking and having an infrequent or non-severe symptom, which acted as a barrier.

I found evidence that women may not always choose to seek medical attention, and will sometimes seek advice elsewhere, such as on the internet or through engagement in the 'lay system of care' (Pescosolido & Boyer, 1999). As such, I added this option to the processes within the appraisal interval in Figure 8.2, below. My findings are discussed in more detail below, with my discussion broadly organised in relation to the MPT.

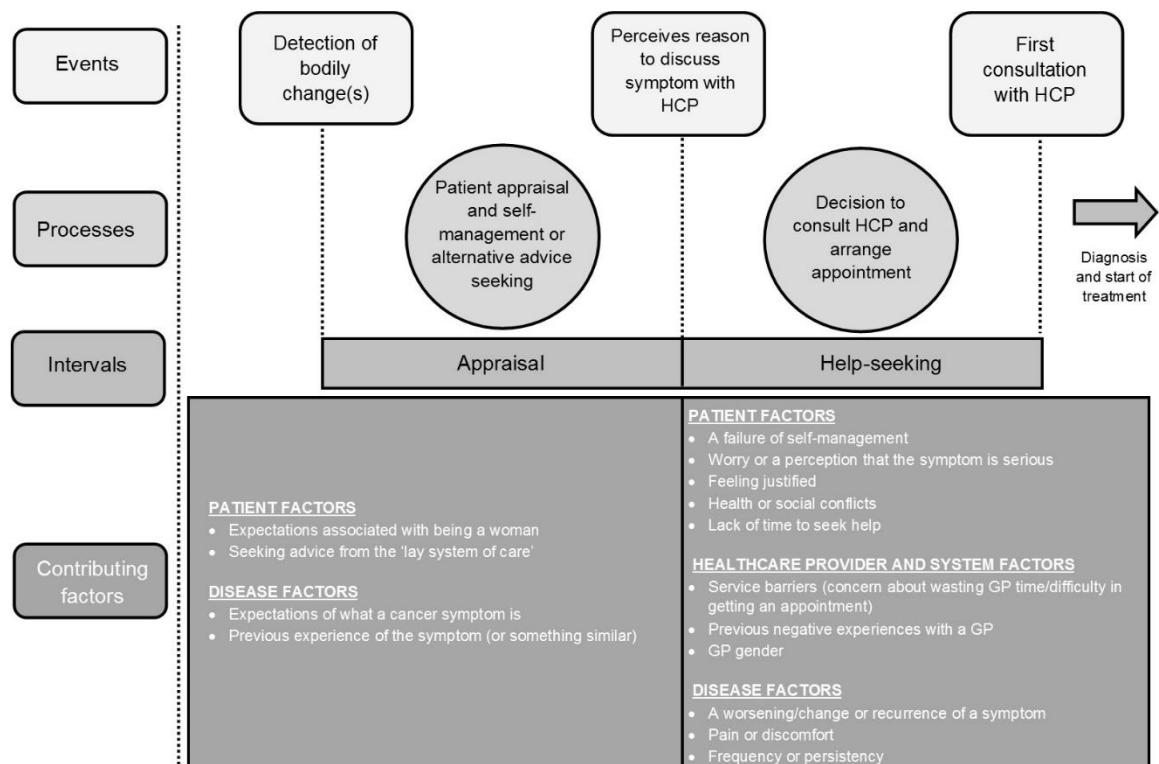


Figure 8.2 Mapping of influences on appraisal and help-seeking found in the present study onto the MPT

#### **8.4.2 Detection of a bodily change**

During the interview process, I found that it was difficult to truly explore the natural process of the detection of a bodily change. The action of asking women about their bodily changes prompted some women to pay attention to changes that they may not have previously or otherwise noticed. I also found evidence in this study (both in the artificial interview situation and from real life) that some bodily changes remain in the background, outside of explicit detection (and therefore the interpretive and appraisal process) until attention is drawn to them. Given that our bodies are constantly processing sensations at the most basic level (for example, internal processes) it is understandable that not all can, or should, be attended to.

#### **8.4.3 Appraisal**

Once bodily changes have been attended to, they will then be subject to an interpretive process, resulting in a belief that the bodily change is either a symptom or threat to health, or it is not (Halkowski, 2006; Walter et al., 2012). The majority of 'delay' in a diagnosis of cancer is attributed to the appraisal stage (for example, Andersen et al., 1995; de Nooijer et al., 2001; Walter et al., 2012). As such, it is of vital importance that we are able to develop a solid understanding of the appraisal process in women with bodily changes that may be indicative of a symptom of a gynaecological cancer.

Evidence from the present study suggests that bodily changes may be appraised on different levels, and that a lower level (or lack of) processing and interpretive work is linked to the context within which the change was experienced or the behaviour of the bodily change. If bodily sensations were congruent with what they expected to happen, or they were not very different to what may be expected to happen as part of being a woman, or of 'the everyday' (such as vaginal bleeding), they were not interpreted as symptoms. For example, bodily changes that occurred during the menopause (or for one woman, the In Vitro Fertilisation process) were easily attributed to that, when a higher level of cognitive processing may have occurred outside of that context. Further, I found evidence that if a symptom is not in an 'expected' location (i.e. the breast), even the



'classic' cancer symptom of a lump (for which there is evidence of high levels of awareness, (Robb et al., 2009)) can be dismissed as being something benign. This process fits with the 'location' heuristic, described in the CSM (Leventhal et al., 1980) (see Chapter Two, and Table 2.1), which was used in the development of the MPT (Walter et al., 2012).

This finding also fits with previous research showing that women with atypical symptoms take longer to seek help, suggesting that they are less likely to be appraised as cancer, (Ramirez et al., 1999). Further, this can also be explained within the context of the CSM, described in Chapter Two. The CSM describes an 'identity' domain (i.e. symptoms and labels), which may influence the coping response (i.e. whether one seeks help or not), as an individual who believes that the symptom is indicative of something serious may be more inclined to seek medical attention. Evidence from the breast cancer literature shows that an inability to correctly identify a range of symptoms, measured on an 'identity scale' significantly predicts an intention to wait longer before seeking help (Grunfeld et al., 2003).

The findings around the influence of the behaviour of a bodily change and the context within which it occurs are supported by Pennebaker and Epstein's (1983) research, which posits that we hold beliefs about the way in which we expect our bodies to function and other research that asserts that symptoms (or bodily changes) will be interpreted within an individual's social (Ajzen, 1985, 1991; Diefenbach & Leventhal, 1996; Dingwall, 1976; Pescosolido & Boyer, 1999) and cultural context (Andersen et al., 2010). As many of the symptoms in the study are not occurrences that would be far removed from those women might expect as part of their normal lives (for example, every woman of child-bearing age will be used to vaginal bleeding as part of their monthly periods, and it may be the case that, on occasion, those periods are heavier or longer with no sinister cause), this tendency towards an attribution to 'the everyday' is not surprising.

I found evidence that women seek out lay advice within their lay system of care here, with women describing seeking advice from friends and family members, as described in the IAM (IAM, Dingwall, 1976), discussed in Chapter Two. However, my findings suggest that social influence may be more complex than simply seeking advice from one's friends. For example, some of the women in the present study discussed seeking advice from family members, but in doing so were also given information about their family history that may have explained their symptoms; in turn this may have influenced attributions. It may be important for future research to distinguish the difference between lay advice from friends and family, as the experiences of close relatives may hold more weight than the experiences of friends due to the possibility of an inherited predisposition shared with a family member.

#### **8.4.4 Responses to bodily changes and symptoms**

A common response to the symptoms experienced in the present study was to self-manage or put up with a symptom, rather than to seek medical advice. This was consistent with my finding in Chapter Seven that the most common response to a symptom was to monitor it, and also consistent with Cooper et al.'s (2013) findings, reported earlier. For some women this response was borne out of a decision that they did not want the symptom to interfere with their lives, even if it was worrying or causing discomfort. That a 'stiff upper lip' attitude may influence help-seeking for symptoms of cancer has been previously explored (for example, Forbes et al., 2013). However, often this stoicism is thought to be a male trait, rather than a female one (for example Barsky, Peekna, and Borus, 2001), and has been explored in the literature on male cancers as a possible reason for a delay in seeking medical attention (Mason and Strauss, 2004). The findings in the present study suggest that this is not an exclusively male trait, and perhaps warrants further exploration as an influence on female help-seeking for potential cancer symptoms in the literature.

For other women here, the decision to put up with or self-manage their symptom was the result of a belief that they knew what had caused it. These women wanted to rule out benign causes or felt that their symptom did not have a large enough impact on their lives; as such, they felt that they could either manage the symptom themselves or put up with it (again consistent with the findings reported by Cooper et al. (2013)). However, a number of women did mention a 'tipping point' at which they could no longer manage or put up with their symptom, or at which their initial attribution had been ruled out and they would consider seeking medical attention. For some women this tipping point was quite concrete and specific. For other women, however, the tipping point wasn't specific or concrete, and was influenced by an increase in persistency, severity or a change in the symptom (including the addition of new symptoms). Some of the literature and media campaigns encouraging help-seeking for symptoms potentially indicative of cancer (including ovarian) do highlight time-points at which one should seek help (NHS Choices, 2013a), and it seems that this may be beneficial in encouraging help-seeking for symptoms of gynaecological cancers. Further, Leventhal's CSM (Leventhal et al., 1980) posits that symptoms which last longer are more likely to be perceived as serious than those that last for shorter periods of time (see Table 2.1), which in turn may lead to an increased likelihood for seeking medical attention.

Fear of what a symptom might mean (including whether it may indicate a cancer) is often cited as a barrier to seeking medical attention (Smith et al, 2005; and Chapter Six). My findings in the present study, however, suggest that the relationship between fear and help-seeking may be more complex than this. Reflecting my summary of the literature on help-seeking for female cancers in Chapter Three, in the present study I found evidence that, for some women, when a consideration of cancer was coupled with fear, it acted to *prompt* help-seeking, whereas a consideration of cancer without fear (mainly because the consideration was not a serious one) seemed to act as a *barrier* to help-seeking. The discrepancy between my findings here and those in Chapter Six and in some of the literature on help-seeking for symptoms of gynaecological cancers (for example, Smith and Anderson (1985) may be due to the methods used in these

previous studies. For example, in Chapter Six, women were asked about their intended response to hypothetical cancer symptoms, and as previously discussed, intention does not always predict behaviour. Further, although some of the literature does involve patients who have had a diagnosis of cancer, these accounts are retrospective (the limitations of this type of literature is discussed earlier in the thesis, see Chapter Three).

A number of the women in the present study described seeking help only when they felt justified in doing so. This may be linked to the 'stiff upper lip' attitude and a subjective, perceived 'tipping point'. Women may continue to put up with their symptoms, even when they are quite severe up until the point that they feel justified in seeking help, which may be linked to a worry about wasting the doctor's time. A couple of women mentioned feeling justified because they had heard of other women with similar symptoms who had sought help, or perhaps had a diagnosis of illness, or because they had a family history of an illness, which added weight to an attribution of illness for their current symptoms. In their qualitative synthesis of studies reporting help-seeking for symptoms of cancer, Smith et al. (2005) also found that sanctioning of help-seeking (sometimes by friends and family members) added legitimacy to the decision to seek help, encouraging symptomatic individuals to do so. Taib et al., (2011) described the importance of others in the need to be sanctioned as sick or ill in order to interpret symptoms of breast cancer as serious. Moreover, there is evidence in the literature that marital dissatisfaction and a lack of emotional support may contribute to a longer time to help-seeking for symptoms of a gynaecological cancer (Cochran et al., 1986), suggesting that a lack of individuals who may help to sanction the decision to seek help may reduce the likelihood of doing so. Finally, the effects of sanctioning in seeking medical help can be described within the IAM (Dingwall, 1976) and the NEM (Pescosolido & Boyer, 1999) (see Chapter Two). The IAM assumes that interpretive work will be undertaken not only by the individual, but also by others within their social networks, which may lead to a belief that a symptom is normal or abnormal, and consequently may lead to help-seeking or not. Within the NEM, again, help-seeking is

placed within the context of social networks and influences. The model posits that an individual may be encouraged or discouraged from interpreting a bodily change as a symptom or help-seeking, depending upon the interactions they have had with others within their social network.

Women also mentioned some of the service barriers (including not being able to get an appointment with a GP and a concern about wasting the GP's time) and practical barriers (such as not having time to see a GP or having too many other things to worry about) explored in Chapter Six and in other literature exploring help-seeking for symptoms of cancer (for example, Robb et al. (2009); Waller et al. (2009)).

Unsurprisingly, given the nature of the symptoms explored in the current study, some women expressed a preference for a female GP, and suggested that the lack of availability of a female GP may contribute to a longer time to help-seeking. One woman also mentioned the need for a trust-based relationship with a GP for intimate female health problems.

#### **8.4.5 Strengths and Limitations**

This qualitative study was the first to explore the experiences of British women with symptoms that may indicate one of the five gynaecological cancers, and to do this outside of the context of cancer. The qualitative approach proved to be successful at examining influences on attributions and interpretations, as well as responses to symptoms on a deeper level than may have been achievable using a quantitative methodology.

Two of the main limitations within the present study relate to the sampling and the exploration of how women detect a bodily change. I attempted to achieve a diverse sample in terms of ethnicity, education and SES by recruiting from a number of different companies and agencies. Although there was some variation in housing situations and car ownership, my final sample was not as diverse as I had aimed for, as all of the

women were from a White ethnic background (although not all were British) and all had a formal education. The aim of qualitative research is not to generalise to a larger population, and as such does not need to achieve a population representative sample. However, my findings in Chapters Five, Six and Seven showed that there were differences in symptom and risk factor awareness, anticipated time to help-seeking and symptom reporting between different ethnic and SES groups. It may be the case that some of the themes identified here may not be applicable to women with a lower SES or those from non-White ethnic background. Moreover, had my sample been more heterogeneous, additional themes may have emerged, that were not identified here, although I did reach data saturation within my relatively homogenous sample. Nonetheless, similar research focusing on these groups of women may be beneficial.

Similarly, I initially aimed to purposively sample four groups of women to represent those who may have been more likely to have engaged in appropriate help-seeking and those who may have engaged in inappropriate help-seeking. This was not achievable as the majority of women had a number of symptoms that may have spanned a number of different groups. However, my final sample included women with a range of symptom and help-seeking experiences. As such, it is not anticipated that the findings here will have been influenced by the lack of these four distinct groups.

#### **8.4.6 Conclusions**

I found evidence here that, once bodily changes have been attended to, they are not always subject to the same level of processing. The level at which a bodily change or symptom is processed may be influenced by the socio-cultural context within which it is experienced. It seems that if a symptom or bodily change is congruent with what is expected, or can be attributed to part of the normal bodily processes one experiences, individuals will apply a lower level of appraisal.

In particular, it should be noted that women hold a number of expectations about what it means to be a woman, such as experiencing vaginal bleeding or going through the

menopause. These anticipated processes may not always be very different to symptoms that may indicate a gynaecological cancer, which may make it difficult to make an attribution outside of these boundaries, and easier for women to normalise or minimise their symptoms.

Women in the present study mentioned a concern about wasting GP time and about needing to feel justified in seeking help, or reaching a 'tipping point'. Part of this seemed to be influenced by a tendency towards a 'stiff upper lip', which may not always be seen as a female trait, and a need for their decision to seek help to be sanctioned by others either directly or indirectly (through learning of the experiences of others or by learning of a potential genetic predisposition to certain conditions). This 'stiff upper lip' seems to be under-explored in the current literature on help-seeking for symptoms of female cancers, and should be considered when developing interventions encouraging women to seek help.

Women specifically mentioned a need for trust, and for some, a female GP, when they did decide to seek help. This is understandable given the intimacy of the symptoms explored in the current study. Having the availability of a female GP may encourage help-seeking in this group of women, as well as being able to seek help in an empathetic and trusting environment.

Finally, I demonstrated that there are a number of patient, disease and healthcare provider and system factors that influence the appraisal and help-seeking interval within the MPT. Future studies might test the predictive power of these variables in relation to the first two intervals of the MPT.

## **CHAPTER NINE – GENERAL DISCUSSION AND CONCLUSIONS**

### **9.1 Summary of thesis rationale**

The research in this thesis was undertaken in response to an increased effort to improve survival rates for cancers in the UK (Department of Health, 2011b; NHS Scotland, 2008; Northern Ireland Cancer Network, 2008; Welsh Government, 2012), an effort likely to have been driven by evidence in recent years that the survival rates for many cancers are falling behind those observed in other European countries (Coleman et al., 2011; De Angelis et al., 2014; Sant et al., 2009; Thomson & Forman, 2009). In particular, I focused on gynaecological cancers, as this group of cancers poses a significant threat to women (see Chapter One), and yet, are under-represented in the early diagnosis and help-seeking literature, as demonstrated in Chapter Three. Consequently, gynaecological cancers are worthy of a research focus aimed at encouraging prompt help-seeking for symptoms.

### **9.2 Thesis aims and research questions**

The overarching aims of this thesis were to understand current levels of awareness of gynaecological cancers and the processes involved in help-seeking behaviour (including which variables may be most influential on help-seeking behaviour), and to explore, using the MPT, *when* these variables may be most influential. In Chapter Four, I laid out four research questions that I aimed to answer in my thesis. Below I have summarised my findings in relation to these questions.

#### **9.2.1 How much do women in the United Kingdom currently know about gynaecological cancer symptoms and risk factors?**

In studies one and two (presented in Chapters Five and Six) I explored awareness of symptoms and risk factors for cervical and ovarian cancer in women in England using the Cervical CAM and the Ovarian CAM, respectively (Simon, Wardle, et al., 2012).

Although I measured both recalled (unprompted) and recognised (prompted) awareness



levels, in Chapter Five I argued that measures of recognition may be more appropriate in the area of research under investigation in this thesis.

#### **9.2.1.1 Study one findings**

Study one (presented in Chapter Five) explored awareness of risk factors and symptoms of cervical cancer in a population-based sample of 1392 English women. On average, there was evidence for a need to increase awareness, as women were only able to recognise around half of the risk factors and symptoms presented, even when prompted (50% and 55%, respectively).

Knowledge of some risk factors (smoking and infection with chlamydia) appears to have improved in recent years, but knowledge of the biggest risk factor, HPV, has largely remained the same, compared to previous findings (Philips et al., 2005; Waller et al., 2004a). Also in line with previous research, my findings suggest that few women are aware of the mechanism for the link between sexual activity and cervical cancer (i.e. HPV infection), despite the launch of the HPV vaccination and associated publicity.

Women were most aware of the two most common symptoms of cervical cancer (unusual vaginal bleeding and persistent, abnormal or unusual vaginal discharge), although awareness was still low even for these (29% and 15%, respectively).

However, these data were collected just prior to the launch of the Department of Health's key messages on cervical cancer in 2010 (NHS Choices, 2011), which includes information about risk factors and symptoms. As such, it is possible that awareness may now be higher, and future research might measure the impact of these key messages using the Cervical CAM for comparison.

#### **9.2.1.1 Study two findings**

Study two (presented in Chapter Six) also demonstrated a low awareness of risk factors and symptoms for ovarian cancer in a population-based sample of 1000 English women.

On average, women recognised 63% of the ovarian cancer symptoms (reflecting findings from a more recent study exploring symptom awareness, Brain et al., 2014). Awareness of risk factors was lower, with women recognising less than half of the symptoms (43%).

Campaigns focusing on increasing survival rates and reducing incidence of ovarian and cervical cancer tend to focus on symptoms and risk factors respectively (for example, the NHS 'Be Clear on Cancer: ovarian cancer' campaign (NHS Choices, 2013b) and a campaign run for the NHS raising awareness of HPV in 2011 (Behance, 2011)). This is likely to be a result of the lower survival rates and lack of screening programme for ovarian cancer increasing the importance of symptom recognition and prompt medical presentation and existence of the cervical screening programme which has reduced symptomatic presentation of this disease, as well as the discovery that almost all cervical cancers result from HPV infection (Walboomers et al., 1999).

As discussed in Chapter One, there are still nearly 1000 deaths attributable to cervical cancer each year (Office for National Statistics, 2012a), and there is evidence that attendance in higher risk age groups may be falling (Health & Social Care Information Centre, 2012). Further, those who do not attend screening may be diagnosed at a later stage (Castanon et al., 2013). These women, may benefit from awareness of the symptoms of cervical cancer in order to present to a health care professional in a timely manner. This, coupled with the findings from study one suggest that there is a need to educate women about the symptoms of cervical cancer, as well as the risk factors.

It is also suggested that women would benefit from efforts to increase awareness of ovarian cancer risk factors. The findings in this thesis show that awareness is low, and the models of help-seeking described in Chapter Two highlight the importance of an awareness of risk for disease. Both the CSM and the IAM can describe how new information can increase an individual's perception of risk for a disease. For example, within the CSM, new information (such as that obtained from a media campaign about risk factors), can lead to a bodily change that was previously dismissed as not serious,

being reassessed as serious. Within the IAM, symptom interpretation can also be influenced by external knowledge, such as an increase in the prevalence of a disease. If women are able to identify that they are at risk of ovarian cancer, this may then increase the likelihood of prompt help-seeking.

### **9.2.2 What variables predict time to hypothetical help-seeking for symptoms for ovarian cancer?**

In study two, as mentioned above, I also reported data on anticipated time to help-seeking for symptoms of ovarian cancer. This built on the findings reported in study one, exploring not only awareness of risk factors and symptoms, but also whether this and other demographic variables might predict time to help-seeking for a gynaecological cancer. Further, I also analysed a subgroup of the overall sample, who were at higher risk of ovarian cancer due to their age ( $\geq 45$ ) (Cancer Research UK, 2013c).

The findings showed that there were a number of predictors of hypothetical time to help-seeking for ovarian cancer, including endorsing more service and practical barriers, and having a higher SES in the overall sample as well as in the subgroup, along with having a White ethnicity. These findings are similar to those reported by Brain et al. (2014), who also found that being educated to degree level (which may be indicative of a higher SES) and endorsing more practical barriers were significantly associated with anticipated delay for symptoms of ovarian cancer. However, my full model only predicted 6% of the variance in anticipating a longer time to help-seeking in the overall sample and 11% in the subgroup, suggesting that there are other variables associated with a longer time to help-seeking which were not measured here.

The findings from study two highlight subgroups within the population who may be at risk of delaying help-seeking for symptoms indicative of ovarian cancer, and as such may allow interventions to be focused on addressing those groups who may be most

likely to wait longer before seeking help. In particular, the predictors of time to help-seeking in women aged  $\geq 45$  years may be important, given that these women are more at risk of ovarian cancer. Future campaigns or programmes to encourage earlier diagnosis for ovarian cancer might focus more on this group of women,

### **9.2.3 How do women respond both behaviourally and emotionally to symptoms which may indicate a gynaecological cancer?**

In study two I explored predictors of hypothetical help-seeking, and identified some variables which may predict hypothetical help-seeking. Building on this, in study three, I explored responses to symptoms in 911 English women, and broadened my research to explore this in all five gynaecological cancers. Further, I wanted to explore whether responses to symptoms may be different when outside of the context of cancer, and as such I avoided using the term, 'cancer' within this study.

As with study two, in order to investigate symptom reporting and help-seeking in women who may be at higher risk of developing a gynaecological cancer, I created a sub-sample of women whose symptoms may have been more likely to indicate a gynaecological cancer, as they were both aged  $\geq 45$  years and had a symptom which was frequent and/or severe (which may be more indicative of a gynaecological cancer, for example, Department of Health, 2009; Goff et al., 2007, 2004; Macleod et al., 2009; NICE, 2011).

The most common response to a symptom in the overall group and the subgroup to a symptom was to monitor it (54% and 53%, respectively). Reassuringly, given their higher risk, a higher proportion of the women in the subgroup had seen a healthcare professional (HCP) (pharmacist, GP, practice nurse or A&E) than in the overall sample (43% versus 36%), with the majority having seen a GP (38% and 30%, respectively).

The higher risk women were significantly more likely to have seen a GP, but significantly

less likely to have asked a friend or relative for advice than women who did not fall into this group. This suggests that higher risk women may be more likely to seek medical attention, rather than ask their friends or family for advice, whereas women with less severe and frequent symptoms are happy to seek advice from the latter. Given the increased likelihood that frequent and/or severe symptoms may be indicative of a malignancy in older women, these findings suggest that at least 43% of women may be acting appropriately, which is reassuring. It still remains, however, that the majority of these women are not help-seeking appropriately. My findings also suggest that there are many more women in the UK with symptoms than are seeking help for them.

#### **9.2.4 What factors explain the different behavioural and emotional responses women may have to an experienced symptom of a gynaecological cancer?**

In study three, I explored responses to symptoms, and identified groups of women in which responses such as medical help-seeking or an alternative may be more likely. However, I did not explore the processes which may lead to one response or another. Although I did explore predictors of anticipated help-seeking in study two, as mentioned above, my findings suggested that there are other factors which may be more influential on time to help-seeking, which were not measured.

To build on the findings in study three and to explore the factors which influence help-seeking behaviour in women who have symptoms which may be indicative of a gynaecological cancer, in study four I interviewed 26 women about their experiences, using a semi-structured interview guide. Again, I avoided the words 'cancer' or 'symptom' during the interview. As with study three, study four was also underpinned by the MPT.

I found evidence that the level at which women process their bodily changes or symptoms is influenced by the socio-cultural context within which bodily changes are

experienced; if bodily changes are congruent with what is expected or can be attributed to normal bodily processes, they may be subject to a lower level of appraisal. This may be particularly important for female cancers, as women hold a number of expectations about what it means to be a woman, including experiencing vaginal bleeding as part of their regular bodily processes, which may make distinguishing a symptom from these difficult.

The non-specific nature of gynaecological cancers symptoms has been noted (Department of Health, 2009; National Institute for Health and Clinical Excellence (NICE), 2005), and there is evidence that the number of non-specific symptoms experienced initially is significantly associated with a longer time taken to appraise gynaecological cancer symptoms (Andersen et al., 1995). However, there is also evidence that symptoms indicative of a gynaecological cancer may be significantly different from those which are benign or part of normal bodily functioning (for example, (Hamilton et al., 2009), and that combinations of symptoms may be more likely to be indicative of disease (for example, (Goff et al., 2004; Olson et al., 2001). As such, there may be an opportunity to educate women about the differences between serious and less serious symptoms.

Many women described feeling worried about wasting GP time, a barrier to help-seeking for symptoms of cancer which is frequently cited in the literature (for example, Johnson et al., 2011), and which was found to influence time to anticipated help-seeking in study two. Perhaps linked to this, was a need for help-seeking to be sanctioned, described by many women and a 'stiff upper lip' attitude to help-seeking. Interestingly, this does not seem to be a trait often reported in females (for example Barsky, Peekna, and Borus, 2001), rather, it is seen as a barrier to help-seeking for male cancers (Mason and Strauss, 2004). Women also mentioned a need for trust, which may translate as a requirement for access to a female GP when presenting with an intimate symptom. Reflecting the findings in study three, which demonstrated a higher level of medical

help-seeking for women with a frequent and/or severe symptom, the women here also described seeking help if their symptom had occurred a number of times or if it was painful.

Overall, study four demonstrated that there are specific patient, healthcare provider and system, and disease factors which may influence both the appraisal and the help-seeking process, including the time taken in both of these intervals of the MPT (presented graphically in Chapter Two, page 57). However, although I attempted to explore influence on detection of a bodily change, I acknowledge that truly measuring how women detect symptoms is difficult, as the act of asking women about these symptoms may have caused them to attend to them.

### **9.3 Contribution to the Literature**

Prior to the research undertaken in this thesis, there had been no literature published that had explored symptom awareness for cervical cancer. Although a body of research existed that had explored risk factor awareness, hardly any of the previously published research had done so in a population-based sample of women. Instead, awareness was tested in women who may be likely to have a higher level of awareness, as they were recruited via academic institutions or healthcare settings.

Again, prior to the research undertaken here, there was very little literature exploring symptom awareness for ovarian cancer, and none that had been conducted in a UK population of women. I could only find one study that had explored awareness of risk factors for ovarian cancer, despite the clear evidence for a number of factors which increase risks for the disease. However, as with the literature exploring cervical cancer risk factors, this study was undertaken in a group of women who were likely to have a higher level of awareness by virtue of their participation in a trial testing the feasibility of ovarian cancer screening.

The research undertaken here, then, enables not only current levels of awareness for symptoms and risk factors for ovarian and cervical cancer in UK women to be understood, it also identifies areas of knowledge that require further investigation. This information may be important when designing interventions or campaigns to increase awareness, which may in turn reduce the chances of misattribution, non-recognition of symptom seriousness and increase awareness of personal risk for these cancers.

The research undertaken in study three was completely novel for a number of reasons. Firstly, I found no literature that had attempted to explore the prevalence, frequency and severity of symptoms potentially indicative of a gynaecological cancer in the UK, nor women's responses to these symptoms when actually experienced. Further, this study explored responses to symptoms outside of the context of cancer, which may have consequently reflected real life responses. Understanding how common these symptoms are is important when considering future campaigns to encourage help-seeking, as these data provide an idea of the likely impact of any such campaigns on the primary care workload. Moreover, by exploring frequency and severity of symptoms, it was possible to explore when help-seeking or not may have been less or more appropriate in this population, given the evidence that frequent and/or severe symptoms may be more indicative of a gynaecological cancer.

Although one qualitative study had been published exploring responses to gynaecological cancer symptoms (Cooper et al., 2013), this was published in the US, which has a different healthcare system to the UK. Further, Cooper et al.'s study explored both hypothetical and actual responses to symptoms, but did not always differentiate between the two, and the study design and analysis was not underpinned by any theoretical models. The study described in Chapter Eight was the first to explore attributions for and responses to symptoms in UK women with actual symptoms, and to map these findings on to a model (the MPT (Walter et al., 2012)), as recommended by



the Aarhus statement for improving the design and reporting of studies on early cancer diagnosis (Weller et al., 2012).

#### **9.4 Overview**

When considering my research findings presented in this thesis as a whole, it is possible to begin to unravel the intricate processes and decisions involved in a response to a symptom which may indicate a gynaecological cancer. It is clear that levels of awareness of symptoms of gynaecological cancers in UK women are low. There is some evidence that symptom awareness may play a part in time to help-seeking, although it may not be simply a process of informing women what the symptoms are. My qualitative research demonstrates that the appraisal process is complex, and that other variables, such as the socio-cultural context in which a symptom is experienced, play a role, above and beyond symptom awareness. Further, the non-specific nature of symptoms, and in some cases, the similarity to normal processes (Department of Health, 2009; National Institute for Health and Clinical Excellence (NICE), 2005) makes symptom interpretation difficult, which may lead to a failure to recognise the seriousness of the symptom. Educating women about the subtle differences between normal bodily function and potential symptoms, and about the increased likelihood of gynaecologic malignancy with certain combinations of symptoms may help women to distinguish between the two.

Although there may be concerns about the increases in primary care workload following awareness campaigns and interventions designed to encourage prompt help-seeking for gynaecological cancers (Evans et al., 2014), evidence from other campaigns aiming to achieve this in lung cancer have shown that these fears may be unfounded (Mayden, 2012). Further, if interventions are aimed at those women who are most likely to be at risk from developing a gynaecological cancer, these increases may be further minimised, as study three showed that this group of women may be very small.

The findings presented in this thesis begin to aid our understanding of how women appraise symptoms and respond to them, and our understanding of those variables which are influential on these processes in women who have experienced symptoms. This information may be used to inform interventions aimed at increasing prompt help-seeking, which ultimately may help to increase earlier stage or lower volume disease, which in turn may positively influence survival rates.

### **9.5 The Model of pathways to Treatment**

The aim of Chapter Three was to discuss and summarise the existing literature on factors associated with a prompt time to help-seeking for symptoms of female cancers, and to explore how these variables may fit into the MPT (Walter et al., 2012). Although the literature exploring factors associated with time to help-seeking for symptoms of gynaecological cancers is sparse, I was able to identify a number of factors which may influence help-seeking at the appraisal interval, including patient factors and disease factors and factors which may influence the help-seeking interval, including patient factors, healthcare provider factors and disease factors.

In study four I explored the appraisal and help-seeking intervals of the model, and identified a number of different variables which may influence the total time taken to seek help from symptom onset. In Figure 8.2, I expanded the MPT to show those variables which may be influential in the first two intervals.

I found evidence that expectations associated with being a woman (such as the familiarity of vaginal bleeding) may influence the appraisal process, and this would be a unique process in the appraisal of female cancer symptoms. Some of the other influences may be more likely in women (such as a concern about the GP gender), but are not exclusive, and may apply to other cancers. However, it is likely that most of the variables I found (such as the frequency or severity of a symptom or expectations of what a cancer symptom is) would apply across a number of different cancers.

## 9.6 Strengths and limitations

The main limitations applicable to studies five and six were related to the exploration of hypothetical help-seeking, rather than actual help-seeking. However, retrospective research with women diagnosed with cancers also has its limitations, and a prospective study (following women who had symptoms to note their responses) would have ethical and cost implications, making such a design impossible within the time and funding limitations of my PhD. Further, study two placed help-seeking in the context of ovarian cancer, which may have influenced the times women reported intending to seek help in. In fact, most of the women did report that they would seek help very soon after symptom onset. These findings may not therefore reflect real responses to symptoms. In order to overcome this limitation, in study three I explored responses to symptoms in women who had recent experience of actual symptoms.

It would have been interesting to explore predictors of help-seeking for symptoms of cervical cancer, as well as for the other gynaecological cancers. Future work could build on this research, exploring levels of awareness for uterine, vaginal and vulval cancers. A further limitation applicable to studies one and two was the small amount of variance explained within the regression models, suggesting that there were more influential variables that were not measured. I attempted to explore what these may be in study four. Future research could use this information to explore the influence of these variables in a larger sample of women, to determine those that are statistically significant predictors of help-seeking behaviour for gynaecological cancers.

In study two, my sample was not population representative, and the use of quota sampling may have limited the generalisability of my findings. However, data were collected from a range of women from different socio-demographic groups, and consequently it is likely that the relationships observed would be the same as those observed in a population representative sample. Studies one and two both had a proportion of missing data, which is common in these types of surveys. However, the amount of missing data was low in both studies (less than 1% for each variable

measured in study one and less than 4% for any variable in study two), meaning that it was unlikely that my findings would have been different if these data had been included.

I was unable to calculate the response rates in studies one and two, as the companies who collected the data used in these studies do not record the number of addresses they attempt to recruit from. This is a common limitation associated with outsourced data collection. Future researchers might liaise with these companies before data collection to see whether the number of individuals approached could be recorded, or could select a research agency that does record these data. Alternatively, a proxy measure of response rate could be determined when a survey module is part of a larger survey, by measuring the number of respondents to the whole survey, and to the individual module, as demonstrated in study three.

In study three, only 42% of the women who completed the whole also completed my module, which raises questions regarding generalisability of my findings. Extrapolation of the number of women with at least one symptom from my sample to a sample including my sample and the non-responders using the demographic information I had for the non-responders showed that my findings would have been similar had this group of women been included. Further, the sample was broadly representative of the UK population in terms of ethnicity and SES, and so this may not have affected my findings by a huge degree.

The main strength of study four was the novelty of the research. Study two indicated that a large part of what influences women to wait longer before seeking help for a symptom of a gynaecological cancer was unexplained. Using a qualitative methodology in study four was appropriate, as it allowed novel factors to be identified, and the complexity of the help-seeking process for these cancers to be understood at a higher level than was previously possible.

Sampling issues were also experienced in this study, as I did not achieve the diversity within the sample which I had aimed to. However, there was some variation in some of the socio-demographic variables, and the aim of qualitative research is not to be generalisable.

### **9.7 Secondary analysis of data within this thesis**

The studies presented in Chapters Five and Six were designed prior to the commencement of my PhD, and the data were collected in 2009, again, prior to the commencement of my PhD. As such, I was not involved in the design of these studies nor the data collection process. However, the raw data were made available to me, and I undertook data cleaning, recoding, all analyses and interpretation of the findings for these two studies within this thesis. I designed the remaining studies presented as part of this thesis, with guidance from my supervisors, Dr Jo Waller and Dr Alice Simon and from Dr Suzanne Scott.

Although there were some limitations to the design of these studies and the data produced (as described above), some of these were only clear after the data had been analysed, and in fact, identifying these limitations allowed me to avoid the same limitations in the studies that I did design. Designing and collecting data for these studies would have taken a considerable amount of time, and the use of these data in this thesis meant that I had the time and resources available to build on the findings from these studies, and attempt to overcome some of the limitations in my subsequent studies. However, as I was not involved in the design and collection of data for these studies, it was still necessary for me to become very familiar with both prior to, and during analysis, with support from my supervisors, Alice Simon and Jo Waller, who were both involved in these studies from conception. Further, the fact that these studies were not designed as part of this PhD meant that, while they provided interesting data, they were of limited use in exploring the MPT.

## **9.8 Future research suggestions**

### **9.8.1 The influence of different variables on the appraisal and help-seeking intervals of the MPT**

My qualitative work in study four identified a number of factors which may influence the appraisal and help-seeking processes. It would be interesting to explore the complexities of these relationships in a larger quantitative study, to determine the strongest predictors of appraising a symptom as a cancer and medical help-seeking. Initially this research may be retrospective, in women who have experienced symptoms, or would explore hypothetical help-seeking via a survey, in a larger sample of women.

### **9.8.2 Development of an intervention to increase awareness of symptoms and risk factors and encourage both accurate appraisal and timely help-seeking for symptoms potentially indicative of a gynaecological cancer**

Studies one and two demonstrated a need for education on risk factors and symptoms for cervical and ovarian cancers, which in turn, may aid accurate appraisal. In particular, there may be a need for more information about those symptoms which may be more likely to indicate a serious illness. Any intervention aiming to increase awareness of these cancers could also be broadened to include the remaining gynaecological cancers, in order to ensure that women who may be at higher risk are aware of what may be normal and what may not be within their reproductive system, and can act accordingly. Study three demonstrated that there may be many more women with symptoms than are seeking help. Although it may not always be appropriate to seek help immediately for some of these symptoms, there is a clear need for those women with higher risk symptoms, who are not seeking help, to be brought into primary care.

Finally, using the results from study four, I extended the MPT to show specific factors that may affect appraisal and time to help-seeking, some more likely to occur in women. Future campaigns might address these factors when encouraging women to seek

medical attention for a symptom potentially indicative of a gynaecological cancer, and might target those women who have higher risk symptoms and are less likely to seek help promptly.

As described above, the work undertaken within this thesis provides an evidence base to support the need for interventions which may improve outcomes for women with symptoms of a gynaecological cancer. As such, it would sit within the 'Development' stage of the complex intervention development-evaluation-implementation process in the updated Medical Research Council's guidance for developing and evaluating complex interventions (Craig et al., 2008), which involves identifying the evidence base and identifying/developing theory.

### **9.8.3 Study to identify the true prevalence of symptoms potentially indicative of a gynaecological cancer**

The research described in Chapter Seven made an attempt to explore prevalence of symptoms potentially indicative of a gynaecological cancer in a UK population. However, almost 60% of the women approached did not respond. It would be difficult to overcome this limitation, as feedback from the interviewees suggested that women felt too embarrassed to answer the questions. Another way of measuring prevalence may be to access GP READ codes and measure symptoms which may indicate a gynaecological cancer.

### **9.9 Final comments**

Gynaecological cancers as a group are a significant threat to female health, and for most of these cancers, incidence levels are rising, suggesting that the threat may increase over time without intervention. Lower one-year survival levels in the UK compared to countries with comparable health systems suggest that improvements are possible. By increasing prompt help-seeking in symptomatic women, it is believed that survival rates can improve, through earlier clinical diagnosis.

The research in this thesis demonstrates that symptoms potentially indicative of a gynaecological cancer are common, and that differentiating them from those bodily processes which are part of being a woman is difficult. I identified a number of factors that may encourage help-seeking or act as barriers, and which influence the appraisal process, which adds to our understanding of the complexity of the help-seeking process. It is clear that there is a strong need for interventions aimed at increasing not only awareness, but understanding of the symptoms and risk factors for gynaecological cancers, and that those women who are clinically most at risk should be targeted.



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## APPENDICES

# Cervical Cancer Awareness Measure (Cervical CAM)

## Toolkit

This survey instrument (the Cervical CAM) was developed by the UCL Health Behaviour Research Centre, in collaboration with the Department of Health Cancer Team and The Eve Appeal, with funding from The Eve Appeal. It forms part of the Cervical Cancer Awareness and Symptoms Initiative (CCASI). It is based on a generic CAM developed by Cancer Research UK, University College London, King's College London and Oxford University in 2007-08.



Working in partnership with





1. There are many warning signs and symptoms of cervical cancer. Please name as many as you can think of:

2. The following may or may not be warning signs for cervical cancer. We are interested in your opinion:			
	Yes	No	Don't know
Do you think vaginal bleeding between periods could be a sign of cervical cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think persistent lower back pain could be a sign of cervical cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think a persistent vaginal discharge that smells unpleasant could be a sign of cervical cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think discomfort or pain during sex could be a sign of cervical cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think menstrual periods that are heavier or longer than usual could be a sign of cervical cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think persistent diarrhoea could be a sign of cervical cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think vaginal bleeding after the menopause could be a sign of cervical cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think persistent pelvic pain could be a sign of cervical cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think vaginal bleeding during or after sex could be a sign of cervical cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think blood in the stool or urine could be a sign of cervical cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think unexplained weight loss could be a sign of cervical cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

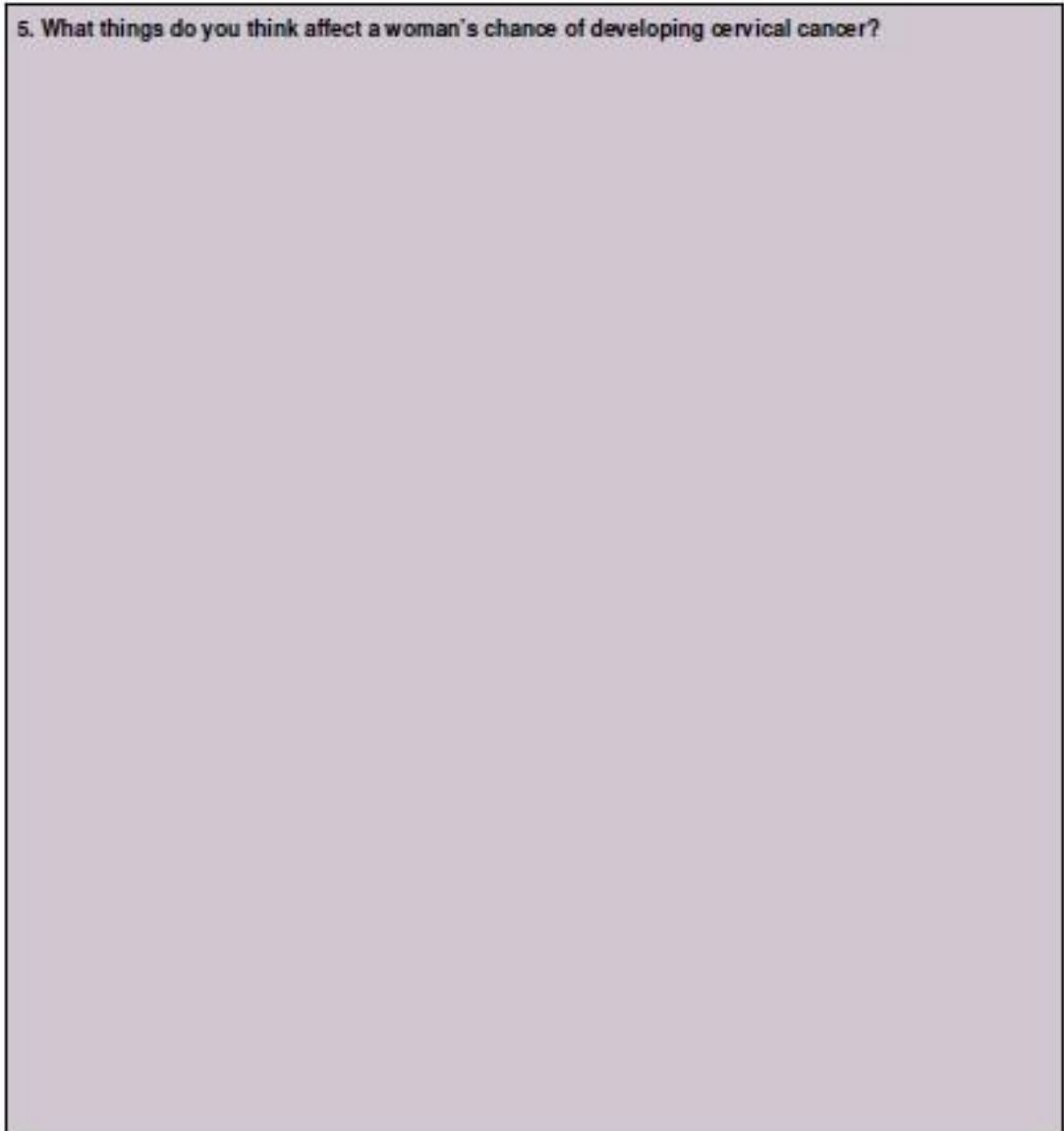
3. If you had a symptom that you thought might be a sign of cervical cancer how soon would you contact your doctor to make an appointment to discuss it?

--

4. In the next year, who is most likely to develop cervical cancer in the UK?

a) A woman aged 20 to 29 years	<input type="checkbox"/>
b) A woman aged 30 to 49 years	<input type="checkbox"/>
c) A woman aged 50 to 69 years	<input type="checkbox"/>
d) A woman aged 70 or over	<input type="checkbox"/>
e) Cervical cancer is unrelated to age	<input type="checkbox"/>

5. What things do you think affect a woman's chance of developing cervical cancer?



6. The following may or may not increase a woman's chance of developing cervical cancer. How much do you agree that each of these can increase a woman's chance of developing cervical cancer?					
	Strongly disagree	Disagree	Not sure	Agree	Strongly agree
Infection with HPV (human papillomavirus)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Smoking any cigarettes at all	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having a weakened immune system (e.g. because of HIV/AIDS, immunosuppressant drugs or having a transplant)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Long term use of the contraceptive pill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Infection with Chlamydia (a sexually transmitted infection)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having a sexual partner who is not circumcised	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Starting to have sex at a young age (before age 17)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having many sexual partners	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having many children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having a sexual partner with many previous partners	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not going for regular smear (Pap) tests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. How confident are you that you would notice a cervical cancer symptom?			
Not at all confident	Not very confident	Fairly confident	Very confident
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

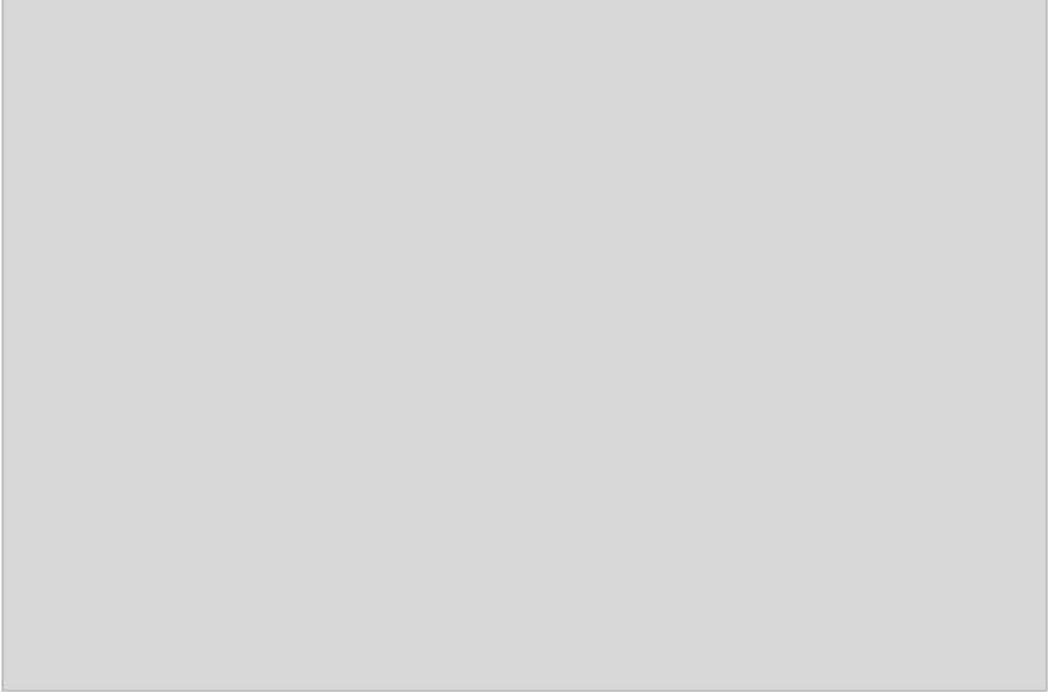
	Yes	No	Don't know
8a. As far as you are aware, is there an NHS cervical cancer screening programme?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8b. If yes, at what age are women first invited for cervical cancer screening in England? _____			<input type="checkbox"/>

	Yes	No	Don't know
9a. As far as you are aware, is there an NHS vaccination to protect against <b>cervical cancer</b> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9b. If yes, at what age is this offered? _____			<input type="checkbox"/>

# **Ovarian Cancer Awareness Measure (Ovarian CAM)**

This survey instrument (Ovarian CAM) was developed by Ovarian Cancer Action, The Eve Appeal, Ovacome and Target Ovarian Cancer. It is based on a generic CAM developed by Cancer Research UK, University College London, Kings College London and Oxford University in 2007-08.

**1. There are several warning signs and symptoms of ovarian cancer. Please name as many as you can think of:**





**2. The following may or may not be warning signs for ovarian cancer. We are interested in your opinion:**

	Yes	No	Don't know
Do you think a persistent pain in your abdomen could be a sign of ovarian cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think a persistent pain in your pelvis could be a sign of ovarian cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think persistent bloating could be a sign of ovarian cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think increased abdominal size on most days could be a sign of ovarian cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think feeling full persistently could be a sign of ovarian cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think difficulty eating on most days could be a sign of ovarian cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think passing more urine than usual could be a sign of ovarian cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think changes in bowel habit could be a sign of ovarian cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think that extreme fatigue could be a sign of ovarian cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think that back pain could be a sign of ovarian cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**3. If you had a symptom that you thought might be a sign of ovarian cancer how soon would you contact your doctor to make an appointment to discuss it?**

**4. In the next year, who is most likely to develop ovarian cancer?**

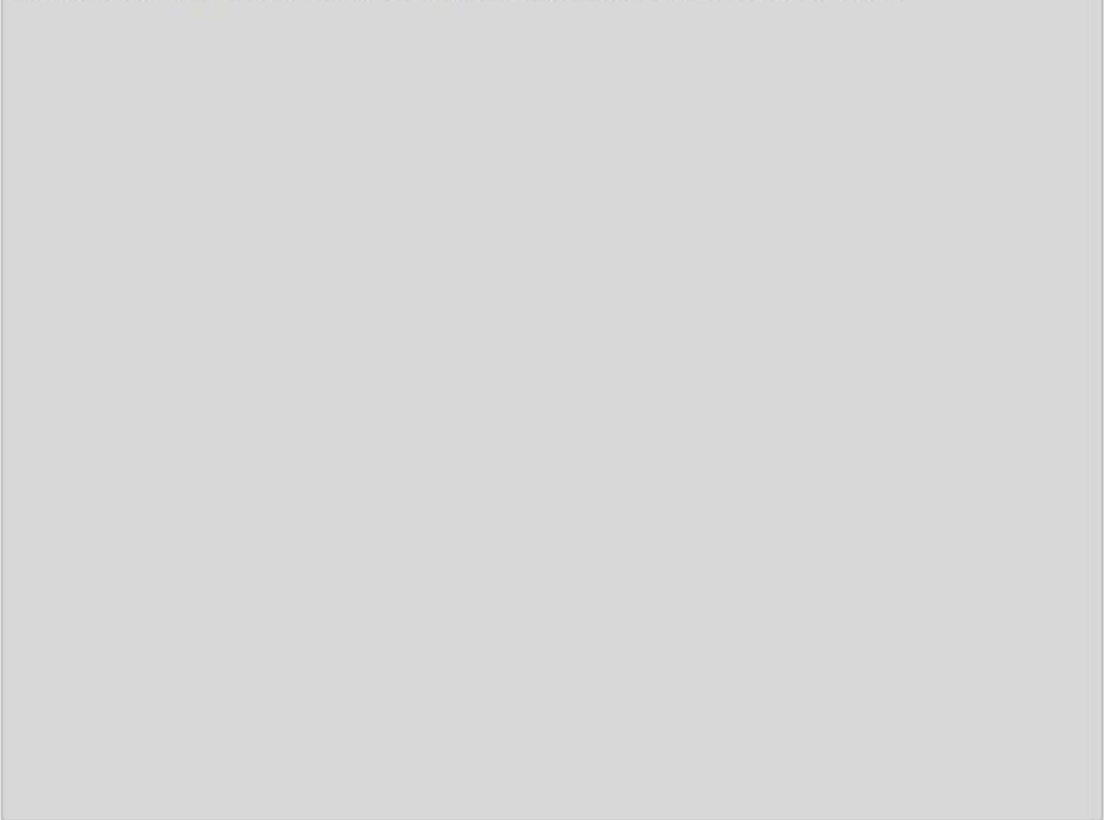
A 30 year old woman

A 50 year old woman

A 70 year old woman

Ovarian cancer is unrelated to age

**5. What things do you think affect a woman's chance of developing ovarian cancer?**



**6. These are some things that can increase a woman's chance of developing ovarian cancer. How much do you agree that each of these can increase the chance of developing ovarian cancer?**

	Strongly disagree	Disagree	Not sure	Agree	Strongly agree
Having a close relative with ovarian cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having a past history of breast cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Using HRT (Hormone Replacement Therapy)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being overweight (BMI over 25)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having endometriosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having ovarian cysts	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Using talcum powder in the genital area	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being over 50 years old	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having IVF treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not having children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having gone through the menopause	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being a smoker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Keywords: gynaecological cancer symptoms; help-seeking; symptom survey

## Experience of symptoms indicative of gynaecological cancers in UK women

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**Background:** Gynaecological cancers account for ~12% of female cancer incidence in the United Kingdom. Encouraging prompt help-seeking for potential symptoms could help improve outcomes. However, before developing help-seeking interventions, it is important to estimate the number of women with symptoms potentially indicative of a gynaecological cancer to help estimate the impact of such interventions on primary care.

**Methods:** As part of a face-to-face, population-based survey, women aged  $\geq 16$  ( $n=911$ ) were shown a list of symptoms potentially indicative of a gynaecological cancer and were asked to indicate any experienced in the last 3 months. Those who reported symptoms were asked about their responses to one randomly selected index symptom.

**Results:** Just under half (44%) of the respondents reported a symptom, with 35% reporting a frequent and/or severe symptom. Younger ( $P<0.001$ ), lower socioeconomic status ( $P<0.01$ ) and non-White women ( $P<0.05$ ) were significantly more likely to report symptoms. Few (14%) respondents were both older ( $\geq 45$  years) and had a frequent and/or severe symptom. Of these women, 38% had seen a GP.

**Conclusion:** Symptoms that potentially indicate a gynaecological cancer, even if limited to those that are frequent and/or severe, appear to be common. Consequently, encouraging prompt help-seeking may increase the burden on primary care. However, targeting those at increased risk (older women with frequent or severe symptoms) should avoid unmanageable increases in primary care consultations for gynaecological conditions.

Gynaecological cancers (uterine, vaginal, cervical, ovarian and vulval cancers) account for around 12% of new female cancer diagnoses per year in the United Kingdom (UK); (Cancer Research UK, 2012a, 2012b; Office for National Statistics, 2012a) equalling lung cancer and second only to breast cancer diagnoses. One-year survival rates have been argued to be a proxy for late-stage diagnoses (Department of Health, 2007), and there is evidence that 1-year survival rates for gynaecological cancers are significantly lower in England compared with other European countries (Sant *et al*, 2009; Thomson and Forman, 2009). Recent data from the International Cancer Benchmarking Partnership have also demonstrated lower 1-year survival rates for some cancers (including ovarian) in the UK compared with other countries with similar cancer plans (Coleman *et al*, 2011).

Data on stage distribution could confirm the hypothesis that these poorer 1-year survival rates are due to higher rates of late-stage diagnoses. However, these data are not readily available for all gynaecological cancers in the UK due to the general lack of accurate recording of staging data (Department of Health, 2012). For vaginal and vulval cancers, there are no UK figures on stage distribution, probably due to the relative rarity of these cancers compared with the other three (Cancer Research UK, 2013a). Specific stage-distribution figures for uterine cancer in the UK are also not immediately available, although most cases are diagnosed in the early stages. This could be because of the appearance of easily recognisable symptoms (i.e., post-menopausal bleeding) early in disease progression (Amant *et al*, 2005). Despite this, given that the difference in survival rate between early- and late-stage

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cancers is wide (85% for Stage I and 29% for Stage IV (Cancer Research UK, 2013b)), it is argued that any increase in earlier diagnoses may be beneficial.

For cervical cancer, the stage distribution favours early-stage diagnosis, with 75% of women in the UK diagnosed at FIGO stage I. This is likely to be attributable to the organised population-based screening programme through which the majority of stage I cervical cancers in women aged <49 years are diagnosed (NHS Cancer Screening Programmes, 2012). However, around a quarter of women (26%) in the highest incidence age group (30–39 (Cancer Research UK, 2013c)) are not up to date with screening (Health & Social Care Information Centre, 2012), and the majority of unscreened women in the age groups 20–34 and 35–49 are diagnosed with a later stage of cervical cancer (FIGO stage IB+) (NHS Cancer Screening Programmes, 2012). As with uterine cancer, given the differences in survival rates between early- and late-stage cervical cancers (over 99% at stage Ia1 and 46% at stage IVb) (Benedet *et al.*, 2003), reducing the number of later-stage diagnoses in unscreened women is likely to improve outcomes.

Recent data for ovarian cancer show that despite poorer 1-year survival rates, the proportion of early-stage diagnoses in the UK is comparable to other countries (Maringe *et al.*, 2012). Therefore, it is argued that the lower observed 1-year survival rates are more likely to be a result of poorer management of the women diagnosed at more advanced stages than higher numbers of late diagnoses. Nevertheless, early diagnosis could still improve outcomes for ovarian cancer. For example, the majority of high-grade serous ovarian cancers (HGSCs) (which are included in type II epithelial ovarian cancers; responsible for the majority of all ovarian cancer mortality (Brown and Palmer, 2009)) originate outside the ovaries, spreading to the ovaries as they progress (Gilbert *et al.*, 2012). This results in these tumours becoming advanced-stage early in their development (Cho and Shih, 2009). For type II ovarian cancers, prognosis is influenced by tumour volume, not stage (Kurman *et al.*, 2008), and moving the focus of early diagnosis for ovarian cancer from early stage to detection of low-volume disease in type II cancers, or early diagnosis of HGSCs, could substantially improve outcomes (Gilbert *et al.*, 2012).

There are currently no screening programmes for any gynaecological cancers except cervical, although results of a large randomised controlled trial testing population screening for ovarian cancer are awaited (Menon *et al.*, 2009). Meanwhile, encouraging women with symptoms to consult their general practitioner (GP) promptly is important, particularly, when considering the proportions of women diagnosed with a gynaecological cancer through emergency presentation or by death certificate only (30% of ovarian, 8% of uterine and 12% of cervical cancer diagnoses (National Cancer Intelligence Network, 2010)). Encouragement to seek help could bring these groups into primary care.

However, encouraging prompt symptom presentation and increasing consultation rates might have a significant impact on the primary care workload. Although there is some evidence on which to base estimates of GP consultation levels for gynaecological conditions (Stapley and Hamilton, 2011), it is likely that there is a wider group of women with symptoms who do not currently seek help from their GP. Although these symptoms are unlikely to be cancer, encouraging help-seeking could not only increase earlier cancer diagnoses but also aid in detection of other potentially treatable conditions.

There has been some qualitative research in the United States examining gynaecological cancer symptom awareness and women's responses to symptoms across all five of the cancer types (Cooper *et al.*, 2012) and some research in the UK exploring symptom awareness for individual gynaecological cancers (Low *et al.*, 2012, 2013). However, to our knowledge, there have been no assessments of the population prevalence of symptoms

encompassing all gynaecological cancers in UK women, nor have the frequency or severity of symptoms or help-seeking responses been investigated. It is important not only to identify symptoms experienced and responses to these symptoms but also to consider the frequency and severity of symptoms, as symptoms that are frequent or severe are more likely to indicate a gynaecological cancer (Olson *et al.*, 2001; Goff *et al.*, 2004). This is the first study to assess the prevalence of symptoms potentially indicative of a gynaecological cancer, as well the frequency and severity of symptoms and current help-seeking behaviour in response to symptoms.

## MATERIALS AND METHODS

**Recruitment.** As part of their omnibus survey (which included modules from different contributors, on a range of non-health topics) we commissioned the market research agency, TNS Global ([www.tns-ri.co.uk](http://www.tns-ri.co.uk), London), to approach 2173 women (age  $\geq 16$  years) using stratified random location sampling. Women were invited to complete our survey module using Computer Assisted Personal Interviewing (CAPI) in the presence of trained interviewers in their own homes, in July 2011. Before deciding whether to participate, potential respondents were given written information about the study due to the sensitive nature of the questions. The information explained that the survey contained questions about bodily changes experienced in the last 3 months, including changes in the reproductive system. It made clear that the module was anonymous and confidential, and that respondents who decided to take part were free to withdraw at any time. The interview was conducted in English, and therefore any women who were not fluent in English were excluded. The study was approved by the UCL Research Ethics Committee (ref. 1122/005).

### Measures

**Demographics.** Respondents were classified as having a higher or lower socioeconomic status (SES) (A, B, C1 vs C2, D, E categories) using the National Readership Survey social grading system (National Readership Survey, 2007). Only 7% of respondents reported minority ethnicities, so they were grouped together and the sample was categorised as 'White' or 'non-White'. We dichotomised age at 45 years because 85% of all new cases of gynaecological cancers in the UK are in women aged  $\geq 45$  years (Cancer Research UK, 2012a, 2012b, 2013a, 2013c, 2013d).

**Symptom reporting.** Women were presented with a list of 13 symptoms (see Table 2), potentially indicative of a gynaecological cancer (sourced from NHS Choices (NHS Choices, 2013)), and asked, 'In the past 3 months, have you experienced any of the following [symptoms]? (please answer each item with 'yes' or 'no'. If you are not sure, or if the item does not apply to you, answer 'no')'. A 3-month reporting time frame was selected as some symptoms could only be detected following at least two menstrual cycles (e.g., inter-menstrual bleeding). In the analyses, it was not possible to stratify symptoms by gynaecological cancer type as many of the symptoms overlap.

**Symptom frequency and severity.** Respondents reporting a symptom were asked, 'Please tell us (as far as you remember) how often you experienced [symptom] in the past 3 months'. Response options included: 'Once', 'twice' (both recoded as 'infrequent'), 'several times' and 'all the time' (both recoded as 'frequent'). They were then asked: 'Using the 5-point scale below, please tell us how bad the [selected symptom] was on the worst day you had it. If it was as bad as you could imagine it could be, score 5. If it was not bad at all, score 1. Please remember you can score any

number from 1 to 5'. Responses were recorded into 'not severe' (scores 1-3) or 'severe' (score 4 or 5). The frequency and severity questions were repeated for each symptom the respondent reported. For some analyses, we divided respondents into two groups: (i) with a symptom that was severe (score 4 or 5), frequent ('several times' or 'all the time') or both and (ii) with a symptom that was neither frequent nor severe. These questions were similar to those used in other studies exploring frequency and severity of symptoms potentially indicative of a cancer (e.g., Goff *et al.* 2004).

**Help-seeking.** To measure help-seeking, we asked, 'Please tell us from the following what, if anything, you did about your [symptom]'. Response options included seeking advice from a pharmacist (chemist); a practice nurse; a GP; going to A&E (the hospital emergency department); asking for advice from a friend/relative; looking for advice on the internet; asking/looking for advice somewhere else; using an own remedy/treating it themselves; and waiting to see if it went away/got worse. For each response option, respondents answered 'Yes' or 'No'. Women were only asked about help-seeking for one randomly system-selected symptom, referred to here as the 'index symptom'. The study was designed in this way to avoid the survey becoming so time-consuming that it would be off-putting to participants.

**Analyses.** Data were weighted by region, age and SES to achieve a nationally representative female sample and were analysed using SPSS version 18.0 (SPSS Inc., Chicago, IL, USA) (SPSS, 2009). We assessed demographic differences between survey responders and non-responders using *t*-tests and  $\chi^2$  tests. We used  $\chi^2$  tests to identify significant demographic differences in symptom reporting and group differences in help-seeking behaviour.

## RESULTS

**Sample characteristics.** Of the 2173 women who took part in the overall TNS omnibus survey, 911 (42%) completed our survey module. Respondents were aged 16-98, with a mean (*M*) age of 45 years. When age was dichotomised, 442 women were aged  $\geq 45$  years and 469 were aged <45 years. Most women were White (93%), married/living as a couple (61%) and had a high SES (60%). Responders to our survey module were significantly younger, had a higher SES, were more likely to have a White ethnicity and were more likely to be married or living as a couple than those who refused to complete the module (see Table 1).

**Symptom reporting.** Just under half of the respondents (44%, 398/911) reported at least one of the 13 symptoms in our survey (*M* = 1.2, range = 0-9), with 'pain in the abdomen, lower back or pelvis' (39%, *n* = 173), 'increased abdominal size' (17%, *n* = 154) and 'increased need to go to the toilet' (15%, *n* = 138) being the most common (Table 2). The median number of symptoms endorsed was 0 (*n* = 513, 56%), with 11% reporting one symptom (*n* = 303), 12% reporting two symptoms (*n* = 108) and 21% reporting three symptoms or more (*n* = 187). The highest number of symptoms experienced was nine, reported by five women (0.5%). Women were more likely to report a symptom indicative of a gynaecological cancer if they were younger (50% of those under 45 vs 37% of those aged 45 and over,  $\chi^2(1, 910) = 14.87, P < 0.001$ ), had a lower SES (49% vs 40% in the higher SES group,  $\chi^2(1, 911) = 7.58, P < 0.01$ ) and were non-White (58% vs 43% in White participants,  $\chi^2(1, 910) = 5.64, P < 0.05$ ).

**Frequency and severity of symptoms.** Overall, 35% (*n* = 317/911) of respondents reported a symptom that was frequent and/or severe, and 9% (78/911) had a symptom that was neither frequent nor severe. Less than a third (132/442, 30%) of women aged  $\geq 45$  reported a frequent and/or severe symptom, 14% of the total

**Table 1.** Sociodemographic characteristics of responders and non-responders to the symptom survey module (weighted data, overall *n* = 2173)

	Responders ( <i>n</i> = 911) n%	Non-responders* ( <i>n</i> = 1262) n%	$\chi^2$ (df)
Age (in yrs, (SD), <i>t</i> -test)	45 (7)	49 (22)	5.61 <sup>b</sup>
<b>Socioeconomic status</b>			
ABC1 (higher)	543 (60)	674 (53)	
C2DE (lower)	368 (40)	588 (47)	8.25 (1) <sup>a</sup>
<b>Ethnicity</b>			
White	848 (93)	1097 (88)	
Non-white	62 (7)	154 (12)	17.69 (1) <sup>b</sup>
<b>Marital status</b>			
Single	204 (22)	294 (23)	
Widowed/divorced/ separated	149 (16)	283 (22)	
Married/living as a couple	558 (61)	676 (54)	15.10 (2) <sup>a</sup>
<b>Reported symptoms</b>			
At least one	398 (94)	—	—
None	513 (56)	—	—

\*These women took part in the omnibus survey but opted out of our symptom survey module.

<sup>a</sup>Significant at the 0.001 level.

<sup>b</sup>Significant at the 0.01 level.

sample (*n* = 132/911) (Table 3). There were no significant demographic differences between the two frequency/severity groups. Individual symptom endorsements by age and frequency and/or severity of symptom are reported in Table 2.

**Help-seeking behaviour.** Respondents were asked about help-seeking for a single index symptom. The selection rate for each symptom (expressed as the number of times the symptom was selected as a proportion of the number of times that symptom was endorsed) was fairly similar across symptoms (see Table 2). Just over a third (36%, 142/398) of respondents who reported a symptom had seen a health-care professional (HCP) (pharmacist, GP, practice nurse, A&E) about their index symptom, with most (30%, 120/398) having seen a GP. In symptomatic women, the most common response to the index symptom was to monitor it (54%, 216/398) and the least common response was to go to A&E (6%, 24/398). In the sample as a whole, 16% (*n* = 142/911) of women had seen an HCP about their index symptom and 13% had seen a GP (*n* = 120/911).

Of the older ( $\geq 45$  years) symptomatic women, 37% (*n* = 60/164) had seen an HCP and 33% (54/164) had seen a GP. The most common response to a symptom was to monitor it (49%, 81/164) and the least common response was to visit the A&E department (2%, 4/164). Older women were significantly less likely to have asked a friend or relative for advice (14% vs 28%,  $\chi^2(1, 399) = 11.36, P = 0.003$ ) or to have gone to A&E (2% vs 9%,  $\chi^2(1, 398) = 6.47, P < 0.05$ ) than younger women. The behaviour patterns remained the same for women with a frequent and severe symptom, although more women had sought medical help, with 42% having seen an HCP (135/317).



Table 2. Gynaecological symptoms reported by all respondents (n=911) and by age and frequency and severity

	<45 years (n=469)		>45 years (n=442)		(n=398)	
	Whole sample (n=911)	Frequent and/or severe	Not frequent or severe	Frequent and/or severe	Not frequent or severe	Chance of selection over number of endometria
Symptoms endorsed	n (%) <sup>a</sup>	n (%) <sup>a</sup>	n (%) <sup>a</sup>	n (%) <sup>a</sup>	n (%) <sup>a</sup>	n (%)
Pain in abdomen/over back/pelvis	173 (19)	81 (17)	27 (6)	55 (12)	10 (2)	64/173 (37)
Increased abdominal size	154 (17)	62 (13)	24 (6)	45 (10)	21 (5)	63/154 (41)
Increased need to go to the toilet	138 (15)	60 (13)	13 (3)	51 (12)	13 (3)	46/138 (33)
Increased wind or constipation	121 (13)	43 (9)	15 (3)	46 (10)	17 (4)	44/121 (36)
Difficulty eating/drinking full quickly	116 (13)	53 (11)	14 (3)	40 (9)	7 (2)	49/116 (42)
Heavier/longer periods	107 (12)	52 (11)	24 (5)	23 (5)	7 (2)	34/107 (32)
Pain/discomfort during sex	83 (9)	39 (8)	24 (5)	11 (2)	5 (1)	23/83 (28)
Itching, pain or soreness of vulva	64 (7)	24 (5)	17 (4)	18 (4)	4 (<1)	23/64 (36)
Bleeding between periods	49 (5)	17 (4)	20 (4)	7 (2)	4 (<1)	13/49 (27)
Discharge that smells unpleasant or is blood stained	44 (5)	22 (5)	15 (3)	7 (2)	1 (<1)	9/44 (20)
Bleeding during/after sex	31 (3)	10 (2)	13 (3)	1 (<1)	4 (1)	13/31 (42)
Growth/lump/swollen or sore on skin of vulva	26 (3)	5 (1)	11 (2)	1 (<1)	4 (1)	11/26 (42)
Bleeding after menopause	10 (1)	1 (<1)	3 (<1)	0 (0)	4 (<1)	2/10 (20)

<sup>a</sup>Respondents were able to select more than one symptom, and hence the total percentage will exceed 100%.

Table 3. Symptoms reported by age group (n=911)

	Total sample (n=911)	Women aged <45 (n=469)	Women aged ≥45 (n=442)
	n (%)	n (%)	n (%)
Did not report symptoms	513 (56)	235 (50)	278 (63)
Reported at least one symptom	398 (44)	234 (50)	164 (37)
At least one frequent and/or severe symptom	317 (35)	186 (40)	132 (30)
No frequent or severe symptoms	78 (9)	46 (10)	32 (7)

Among the older women (≥45 years) with an index symptom that was frequent and/or severe (i.e., the most high-risk group), 43% (n=56/132) had seen an HCP and 38% (n=30/132) had seen a GP. These women were most likely to have monitored their symptom (53%, 69/132) and least likely to have visited A&E (3%, 4/132). Older women with frequent and/or severe symptoms were significantly more likely to have seen a GP (38% vs 27%,  $\chi^2$  (1, 397) = 5.11,  $P < 0.05$ ) but significantly less likely to have asked a friend or relative for advice (16% vs 25%,  $\chi^2$  (1, 396) = 4.34,  $P < 0.05$ ) than women who did not fall into this group (see Table 4).

## DISCUSSION

Just under half (44%) of the women in our sample reported a symptom that may indicate a gynaecological cancer, and for a third (35%), the symptom was frequent and/or severe. The rates of GP consultation for potential gynaecological cancer symptoms found here (13% of the women in our total sample, n=120/911) are somewhat lower than those reported by Stapley and Hamilton

Table 4. Help-seeking for one index symptom among respondents who reported a symptom by risk group (n=397)

	Higher-risk women (n=132)	Lower-risk women (n=265)	$\chi^2$ (df)
Response to symptom	n (%)	n (%)	
Monitored symptom	69 (53)	147 (55)	0.28 (1)
Used own remedy/first-aid	59 (45)	104 (39)	1.08 (1)
Sought help from GP	50 (38)	71 (27)	5.11 (1) <sup>*</sup>
Sought help from internet	32 (25)	79 (30)	1.26 (1)
Sought help from friend or relative	21 (16)	67 (25)	4.34 (1) <sup>*</sup>
Sought help from pharmacist	21 (16)	33 (12)	0.90 (1)
Sought help from practice nurse	18 (14)	35 (13)	0.02 (1)
Sought help from somewhere else	14 (11)	30 (11)	0.05 (1)
Sought help from A&E	4 (3)	20 (8)	3.17 (1)

Higher risk = women aged ≥45 years with a frequent and/or severe symptom. Lower risk = women aged <45 years and women with no frequent or severe symptoms.  
<sup>\*</sup>Significant at the 0.05 level.

(2011) (20%). However, analyses on a subsample of our participants aged 16–29 (to allow a comparison with Stapley and Hamilton's (2011) sample) did show similar rates of consultation (21%; analyses not shown here).

Interestingly, previous research exploring intention to seek help for some of these symptoms in a UK population found that 65–89% of women said that they would go to their GP within 2 weeks if they had one of these symptoms (Target Ovarian Cancer, 2013). Our survey suggests that, although just under half of UK women may currently have a symptom potentially indicative of a gynaecological cancer (n=398/911), only around a third



( $n = 120/398, 30\%$ ) have sought advice from a GP. This percentage is considerably lower than the percentage of women who said that they would seek help promptly for similar symptoms. This suggests that actual help-seeking may be much lower than anticipated help-seeking and adds weight to the evidence that intention may not be translated into behaviour (Sheeran, 2002). This disparity between intention and behaviour in help-seeking may be due to the influences on help-seeking behaviour in response to an actual symptom (Andersen *et al.*, 2009) that participants may not consider in a hypothetical situation.

Our findings suggest that many more women in the UK have symptoms potentially indicative of a gynaecological cancer than seek help for them. Any successful intervention that encourages women with these symptoms to seek help at primary care level could lead to a considerably increased pressure on the primary care system. However, it may not be appropriate to encourage all women with these symptoms to seek help immediately; for some women, it may be advisable to monitor the symptom in the first instance.

It is likely that the majority of symptomatic women in the current sample did not have a gynaecological cancer, based on the incidence rates for these cancers in the UK population. In the highest-risk age groups for cervical cancer (30–34 and 35–39), we would only expect one case in every 5650 and 6173 women, respectively. In the highest-risk age groups for uterine, ovarian, vulval and vaginal cancers (70–74, 80–84, 85+ and 85+ respectively), we would only expect to see one case in every 1101, 1437, 4082 and 23810 women in the UK, respectively (Office for National Statistics, 2012b). These incidence rates mean that, statistically, we would expect to find less than one case of a gynaecological cancer in our sample of 911 women. Encouraging all of the women in our sample to seek help then may not be appropriate and an alternative course of action may be to target higher-risk groups in any intervention aimed at encouraging women with symptoms to seek help. However, encouraging all women with a symptom they report as frequent and/or severe to seek medical help (whether this symptom indicates cancer or a more benign condition) is likely to be of benefit to the patient in terms of receiving treatment and ameliorating discomfort.

Just over a third of the women in our study (35%) reported a symptom potentially indicative of a gynaecological cancer that was frequent and/or severe. As some of the symptoms explored in our study are more likely to indicate a gynaecological cancer if they have such characteristics (Olson *et al.*, 2001; Goff *et al.*, 2004), women with these types of symptoms may be at a higher risk of developing a gynaecological cancer. Furthermore, younger women were more likely to report a symptom, whereas most symptoms are more likely to be indicative of cancer in older women (Cancer Research UK, 2012a; Office for National Statistics, 2012b). For example, abdominal distension, loss of appetite, abdominal pain and urinary frequency all have higher positive predictive values (PPVs) for ovarian cancer in women aged  $\geq 55$ , compared with younger women (Roosing *et al.*, 2010).

If interventions are not only targeted at women with a frequent and/or severe symptom but also at those who are older, the increase in consultations could be minimised. For example, our data showed that only 14% of the women surveyed ( $n = 911$ ) were both older ( $\geq 45$  years) and had a frequent and/or severe symptom, but 5% ( $n = 50/911$ ) had already seen a GP, so around 9% (82/911) of our total sample could be characterised as needing to see their GP urgently. Targeting interventions in this way should ensure that consultations occurring as a result of encouraging earlier help-seeking would be more likely to lead to a cancer diagnosis. In terms of trying to increase early-stage diagnoses of gynaecological cancers, this relatively modest increase in consultations as a result of any successful intervention could potentially be worthwhile.

**Limitations.** Over half (58%) of the women who completed the overall omnibus survey did not agree to complete our questions, which raises the issue of whether our results reflect the true prevalence of possible gynaecological cancer symptoms in the population. However, the final sample was broadly representative of the UK female population in terms of ethnicity and SES (Ipsos MediaCT, 2009; Population, Ethnicity, Religion and Migration (PERM), 2009), despite demographic differences between respondents and non-respondents. Feedback from the interviewers indicated that the reason women gave for refusing or withdrawing was often being embarrassed by the survey content, despite the assured anonymity and the ability to self-complete the survey, suggesting that the data may not be missing at random. It would be difficult to overcome this limitation in any self-report survey with similar content.

Because it is not clear whether embarrassment would be more or less common in women with symptoms, we are unable to speculate about the direction of any possible bias. However, to estimate the impact of the missing data on our findings, we extrapolated the number of women with at least one symptom from our sample ( $n = 911$ ) to a sample including our sample and the non-responders ( $n = 2173$ ), using the demographic information we had for the non-responders (age, SES, ethnicity and marital status). This showed that the number of women that we would expect to report at least one symptom (based on the demographic structure of the sample including the non-responders) ranged from 43% to 45%, very similar to the findings in our final sample ( $n = 911$ ). Of course, these estimations do not take into account alternative reasons for non-response, such as having a symptom and feeling too embarrassed to talk about it.

Because of the small numbers of women endorsing each symptom, we analysed all the symptoms together, rather than individually or by cancer type. This meant we did not report findings on help-seeking for individual symptoms or by gynaecological cancer. However, any frequent or severe symptom would be of concern, and it was therefore important to explore help-seeking responses to all symptoms combined.

The exploration of help-seeking for only one randomly selected index symptom was necessary to reduce the overall length of the survey but may have meant that help-seeking was explored for a symptom that was neither frequent nor severe, when that participant may also have had a symptom that was either frequent, severe or both. We ran an additional analysis (not reported here) to explore how many women this applied to. Our analysis showed that 62 women (7% of the total sample) had a mild, infrequent index symptom and also a frequent and/or severe symptom for which help-seeking was not explored.

We felt that it was important to explore the help-seeking behaviour for all symptom types, including the seemingly less-serious symptoms, as this helps to provide a picture of whether people seek help appropriately. However, we acknowledge that it would have been interesting to have had help-seeking data for all of the symptoms endorsed. This could be a consideration for future research.

Finally, the survey did not go through any rigorous reliability and validity testing. Wherever possible, the items drew on previous published work. For example, the frequency and severity questions are similar to those used in a previously published study exploring ovarian cancer symptoms (Goff *et al.*, 2004). However, future studies using similar measurements may benefit from carrying out psychometric testing before use.

## CONCLUSIONS

There is a clear indication that the occurrence of gynaecological symptoms potentially indicative of cancer in women in the UK is substantially higher than recorded in primary care. Our findings

suggest that the most likely alternative to help-seeking may be to monitor the symptom. However, it may not be appropriate to encourage all women with symptoms to seek help at the primary care level immediately.

Older women were less likely to report a symptom than younger women. Evidence that symptoms are more likely to be indicative of a gynaecological cancer if frequent and/or severe, and that gynaecological cancers are more common at older ages, suggests that targeting interventions towards older women who have a symptom that is frequent or severe could promote appropriate help-seeking without increasing consultations with the 'worried well'.

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### WOMEN'S HEALTH CHECKLIST INFORMATION SHEET AND CONSENT FORM

Before you decide whether to complete this section, you should read this page. Please ask the interviewer if there is anything you are not sure about.

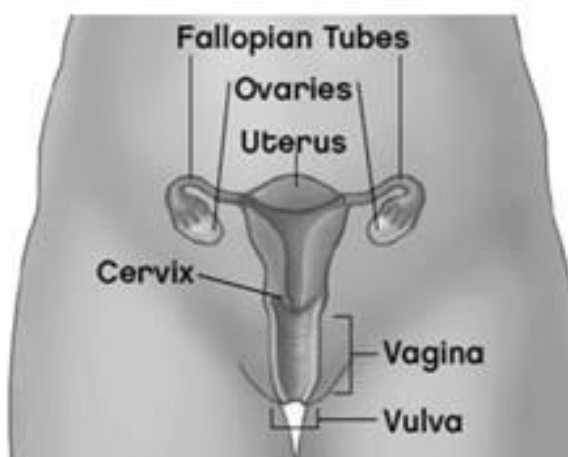
We want to find out more about bodily changes that women in the United Kingdom may be experiencing. In this section we will ask you about changes you may have experienced in the past three months. If you have not experienced any changes, you will be able to say so in the survey.

Some of the questions relate to your reproductive system (female body parts). Not everyone knows where the different parts of the female reproductive system are, so we have included a picture below for you to look at. Please contact the researchers if you have any questions or concerns, or if you would like to see a copy of the results from this section. Their details will be given to you once you complete this section. If you have any questions before you agree to complete this section, please ask the interviewer.

You are free to withdraw from this section at any time without giving a reason. You are free to ask questions at any point during this section. All data collected in this section will be completely anonymous.

This study has been approved by the UCL Research Ethics Committee (project number: 1122/005)

If you are happy with the information given to you and are happy to complete this section, please click on the 'YES' button on the laptop screen. If you are not happy to complete this section, please click 'NO'.





[INTRO/INFORMATION SHEET PAGE]

**Women's Health Checklist Information and consent form**

Q.A. Before you decide whether to complete this section, you should read the following. Please ask the interviewer if there is anything you are unsure of.

We are interested in finding out about bodily changes that women in the United Kingdom may be experiencing. We will ask you about changes you may have noticed in the past three months. If you have not noticed any changes, you will be able to say so in the survey.

Some of the questions are about your reproductive system (female body parts). Not everyone is familiar with the different parts of the female reproductive system, so the interviewer will give you a picture to look at during this section. The interviewer will also give you details of the researchers who are running this section of the survey after you have completed it. Please contact them if you have any questions or concerns, or if you would like to see a copy of the results.

You are free to withdraw from this section at any time without giving a reason. You are free to ask questions at any point during the survey. All data collected in this section of the survey will be completely anonymous.

This section of the survey has been approved by the University College London Research Ethics Committee (project number: 1122/005)

If you have any questions before you agree to take part or during this section, please ask the interviewer.

If you are happy with the information given to you about this section and are happy to complete this section, please click on the 'YES' button at the bottom of this screen. If you are not happy to complete this section, please click 'NO'.

- 1: Yes – I am happy to continue
- 2: No – I do not want to complete this section

**(Routing: If chose code 2 then Close, otherwise go to Q1)**

Q.1 In the past three months, have you experienced any of the following? (please answer each item with 'yes', or 'no'. If you are not sure, or if the item does not apply to you, answer 'no')

Heavier/longer periods (than what is normal for you)

Vaginal bleeding between periods

Vaginal bleeding during/after sex

Vaginal bleeding after the menopause

Vaginal discharge that smells unpleasant or is blood stained

Headache

Increased wind or constipation (more than is normal for you)

Increased abdominal (tummy) size that does not go away (including bloating)

Sore throat

Pain in the abdomen (tummy), lower back or pelvis that does not go away

Pain or discomfort during sex

Itching, pain or soreness of your vulva

Growth, lump, sore or ulcer on the skin of your vulva

Increased need to go to the toilet (more often or more urgently than is normal for you)

Difficulty eating or feeling full quickly

1: Yes

2: No

(Routing - If does not respond "Yes" to any items or only responds "Yes" to 'A headache' and/or 'A sore throat' and no other items, show debrief message and discontinue survey)

Q.2. You have told us that you have experienced [list symptom selected "Yes" in Q1 here] in the past three months. Please tell us (as far as you remember) how often you experienced this in the past three months:

(Do not include Q.1 symptoms 'A headache' or 'A sore throat' in any of the statements below. Repeat question with response options for each statement selected "Yes" in Q.1 individually)

Item 1 selected 'Yes' in Q1

Item 2 selected 'Yes' in Q1

Item 3 selected 'Yes' in Q1

Item 4 selected 'Yes' in Q1, etc.

1: Once

2: Twice

3: Several times

4: All the time

Q.3 Using the 5-point scale below, please tell us how bad the [list symptom selected Yes in Q1 here] was on the worst day you had it. If it was as bad as you could imagine it could be, score 5. If it was not bad at all, score 1. Please remember you can score any number from 1 to 5. We are interested in how bad you feel your [symptom name] was/is:

(Do not include Q.1 symptoms 'A headache' or 'A sore throat' in any of the statements below. Repeat question with response options for each statement selected Yes in Q.1 individually.)

Item 1 selected 'Yes' in Q1  
Item 2 selected 'Yes' in Q1  
Item 3 selected 'Yes' in Q1  
Item 4 selected 'Yes' in Q1, etc.

1: Not bad at all  
2:  
3:  
4:  
5: As bad as it could be

**Q4. REPEAT QUESTION FOR EACH SYMPTOM ENDORSED IN Q1 INDIVIDUALLY.**

Q.4 Were you concerned at all about your [Scripter - list symptom selected Yes in Q1 here]?

(Do not include Q.1 symptoms 'A headache' or 'A sore throat' in any of the statements below. Repeat question with response options for each statement selected Yes in Q.1 individually)

Item 1 selected 'Yes' in Q1  
Item 2 selected 'Yes' in Q1  
Item 3 selected 'Yes' in Q1  
Item 4 selected 'Yes' in Q1, etc.

1: Not at all  
2: Yes, a little  
3: Yes, a lot

Q.4a For this question, we want you to just think about your [randomly select one symptom selected 'Yes' in Q1 here, but not 'A headache' or 'A sore throat']. Please could you tell us what you think was the cause of your [show same randomly selected symptom selected 'Yes' in Q1 here.] that you experienced in the last three months (even if it is different from what you might have been told by a health professional)?

Open-ended

- 1: Don't Know
- 2: Refused

Q.5. Still thinking about your [same randomly selected symptom selected 'Yes' in Q1 here], please tell us from the following what, if anything, you did about your [same randomly selected symptom selected 'Yes' in Q1]. Please answer 'Yes' or 'No' to each option:

If you are not sure or don't know for any option, please select 'No'

**(Show "Used to..." 1<sup>st</sup>, "Waited to see..." 2<sup>nd</sup>, "I asked/looked for advice..." last, and rotate the other 6 statements between those)**

- Asked for advice from a pharmacist (chemist)
- Asked for advice from a practice nurse
- Asked for advice from a GP
- Went to A&E (the hospital emergency department)
- Asked for advice from a friend/relative
- Looked for advice on the internet
- Asked/looked for advice somewhere else
- Used my own remedy/treated it myself
- Waited to see if it went away/got worse

- 1: Yes
- 2: No

**(If 'Yes' selected for any of the first 4 statements, go to Q.5A, otherwise close section)**

Q.5a. You said you [randomly select one response option saying 'Yes' from the first 4 statements of Q.5. If only one response option from the first 4 statements is 'Yes', select that one] about your [show symptom randomly selected in Q.5 question text]. If you asked for advice on or talked about any other bodily change at the same time, please tell us by selecting what you talked about from the list below. Please select all that apply.

(Do not include Q.1 symptoms 'A headache' or 'A sore throat' or the statement randomly selected in Q.5 text in any of the statements below. Show all statements on one screen. Multicode)

Item 1 selected 'Yes' in Q1

Item 2 selected 'Yes' in Q1

Item 3 selected 'Yes' in Q1

Item 4 selected 'Yes' in Q1, etc.

Did not ask for advice or talk about any other bodily change

(Routing – If 'Yes' selected for statements 2-4 at Q.5, go to Q.5B, otherwise close section)

Q.5b You said that you [select the same response option selected in Q5a, taken from Q5] for your [show statement randomly selected in Q.5 question text]. From the following please could you tell us what the outcome was? Please answer 'yes' or 'no' to each option:

Further investigation or tests

Treatment for your bodily change

Told to come back if it doesn't go away/gets worse

Diagnosis of your bodily change (an explanation of the cause of your problem)

1: Yes

2: No

(If 'Yes' selected for 'Diagnosis', go to Q.5C, otherwise close section)



Q.5c. Finally, you said that you were given a diagnosis for your **[show symptom randomly selected in Q.5 question text]**. Please could you briefly tell us what the diagnosis (the cause of your problem) was, to the best of your knowledge? Please write clearly and in block capitals.

Open-ended

1: Don't Know

2: Refused

**(show Debrief Message below on separate page)**

Women's Health Checklist Survey

Thank you for your time.

Please remember that this survey is anonymous and we will not be able to pass on any information to your GP, nurse or any other health professional.

If you are worried about any symptoms we have talked about in this section of the survey, or if you have any symptoms that are persistent (symptoms that don't go away), please see your GP, visit [www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk) or call NHS Direct on 0845 46 47. They will be happy to talk to you and will expect you to call if you are worried.

If you want to see a copy of the report or if you have any questions about this section of the survey, please contact Miss Emma Low (contact details below) for more information:

Miss Emma L. Low BSc MSc  
Health Behaviour Research Centre  
University College London  
1-19 Torrington Place  
London, WC1E 6BT

Email: [e.low@ucl.ac.uk](mailto:e.low@ucl.ac.uk)  
Tel: 020 7679 1726

You will also be given a copy of this sheet to keep for your records and in case you do need to contact us.

**CLOSE SURVEY**

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UCL RESEARCH ETHICS COMMITTEE  
GRADUATE SCHOOL OFFICE



18 March 2011

**Notification of Ethical Approval**

**Ethics Application: 1122/005: Prevalence of gynaecological symptoms and help-seeking beliefs and behaviours in a UK female population**

I am pleased to confirm that in my capacity as Chair of the UCL Research Ethics Committee, I have approved your study for the duration of the project (i.e. until March 2012).

Approval is subject to the following conditions:

1. You must seek Chair's approval for proposed amendments to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing the 'Amendment Approval Request Form'.

The form identified above can be accessed by logging on to the ethics website homepage: <http://www.grad.ucl.ac.uk/ethics/> and clicking on the button marked 'Key Responsibilities of the Researcher Following Approval'.

2. It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. Both non-serious and serious adverse events must be reported.

**Reporting Non-Serious Adverse Events**

For non-serious adverse events you will need to inform Helen Dougal, Ethics Committee Administrator ([ethics.ucl.ac.uk](mailto:ethics.ucl.ac.uk)) within ten days of an adverse incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Chair or Vice-Chair of the Ethics Committee will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

**Reporting Serious Adverse Events**

The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator immediately the incident occurs. Where the adverse incident is unexpected and serious, the Chair or Vice-Chair will decide whether the study should be terminated pending the opinion of an independent expert. The adverse event will be considered at the next Committee meeting and a decision will be made on the need to change the information leaflet and/or study protocol.

---

On completion of the research you must submit a brief report (a maximum of two sides of A4) of your findings/concluding comments to the Committee, which includes in particular issues relating to the ethical implications of the research.

With best wishes for the research.

Yours sincerely

**Chair of the UCL Research Ethics Committee**

Cc: E1

## Appendix 8. Ethical approval letter for study four

UCL RESEARCH ETHICS COMMITTEE  
GRADUATE SCHOOL OFFICE



14 May 2012

### **Notification of Ethical Approval**

**Project ID: 2734/001: Women's beliefs, attributions and responses to bodily changes: an interview study**

I am pleased to confirm that in my capacity as Chair of the UCL Research Ethics Committee I have approved your study for the duration of the project i.e. until October 2013.

Approval is subject to the following conditions:

1. You must seek Chair's approval for proposed amendments to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing the 'Amendment Approval Request Form'.

The form identified above can be accessed by logging on to the ethics website homepage: <http://www.grad.ucl.ac.uk/ethics/> and clicking on the button marked 'Key Responsibilities of the Researcher Following Approval'.

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The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator immediately the incident occurs. Where the adverse incident is unexpected and serious, the Chair or Vice-Chair will decide whether the study should be terminated pending the opinion of an independent expert. The adverse event will be considered at the next Committee meeting and a decision will be made on the need to change the information leaflet and/or study protocol.

On completion of the research you must submit a brief report (a maximum of two sides of A4) of your findings/concluding comments to the Committee, which includes in particular issues relating to the ethical implications of the research.

With best wishes for the research.

Yours sincerely

**Chair of the UCL Research Ethics Committee**

Cc: E

UCL Research Ethics Committee, c/o The Graduate School, North Cloisters, Wilkins Building  
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Tel: +44 (0)20 7679 7844 Fax: +44 (0)20 7679 7043  
ethics@ucl.ac.uk  
www.ucl.ac.uk/gradschool

## WOMEN'S HEALTH QUESTIONNAIRE

This questionnaire is about bodily changes women **over the age of 30** may be experiencing and what they think about them.

Some of the bodily changes we are interested in refer to the female reproductive system. To make it clear what parts of the female reproductive system we are referring to, we have included a picture on the next page for you to look at.

You should only participate if you want to. Choosing not to take part will not disadvantage you in any way. You may withdraw from participation at any time without having to give a reason.

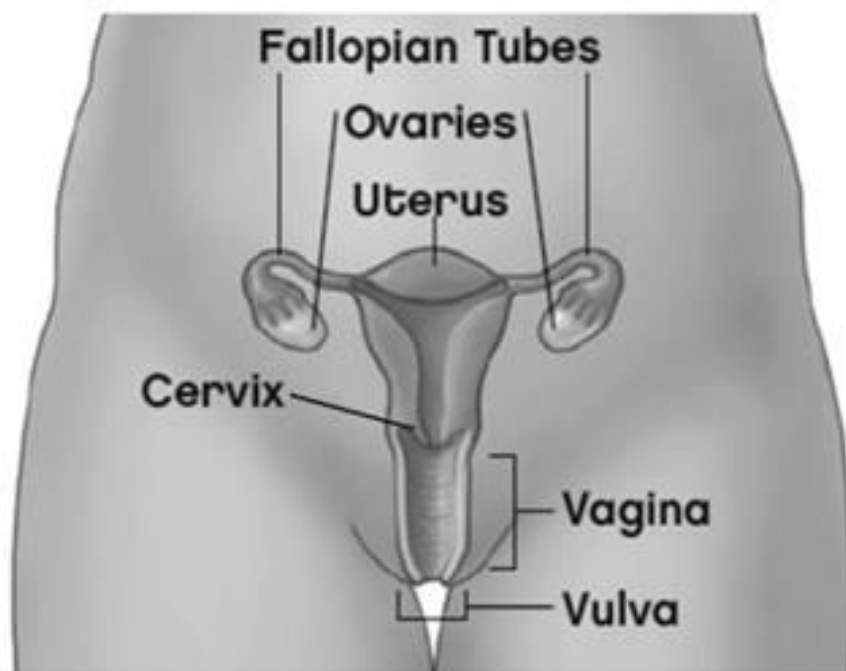
If there is anything you are not sure about or if there is any more information you require before you decide to take part, please ask one of the research team who will be happy to answer your questions. If you have any questions in the future, the researcher's contact details are at the end of this questionnaire. Completion of the questionnaire will be taken as your consent to participate.

All data will be collected and stored in accordance with the Data Protection Act 1998 and this study has been approved by the UCL Research Ethics Committee (project number: **2734/001**).

This questionnaire should take no longer than 5-10 minutes to complete.



## FEMALE REPRODUCTIVE SYSTEM





1. In the past **three months**, have you experienced any of the following? Please answer **all** questions - tick 'YES' for each bodily change you have experienced or 'NO' if you have not experienced the bodily change. If you are not sure or the item doesn't apply to you, please tick 'NO'.

	YES	NO
a) Heavier/longer periods (than what is normal for you)	<input type="checkbox"/>	<input type="checkbox"/>
b) Vaginal bleeding between periods	<input type="checkbox"/>	<input type="checkbox"/>
c) Vaginal bleeding during/after sex	<input type="checkbox"/>	<input type="checkbox"/>
d) Vaginal bleeding after the menopause	<input type="checkbox"/>	<input type="checkbox"/>
e) Vaginal discharge that smells unpleasant or is blood stained	<input type="checkbox"/>	<input type="checkbox"/>
f) Increased wind or constipation (more than is normal for you)	<input type="checkbox"/>	<input type="checkbox"/>
g) Increased abdominal (tummy) size that does not go away (including bloating)	<input type="checkbox"/>	<input type="checkbox"/>
h) Pain in the abdomen (tummy), lower back or pelvis that does not go away	<input type="checkbox"/>	<input type="checkbox"/>
i) Pain or discomfort during sex	<input type="checkbox"/>	<input type="checkbox"/>
j) Itching, pain or soreness of your vulva	<input type="checkbox"/>	<input type="checkbox"/>
k) Growth, lump, sore or ulcer on the skin of your vulva	<input type="checkbox"/>	<input type="checkbox"/>
l) Increased need to empty your bladder (more often or more urgently than is normal for you)	<input type="checkbox"/>	<input type="checkbox"/>
m) <b>Changes</b> in your bowel habit (e.g. constipation or diarrhoea)	<input type="checkbox"/>	<input type="checkbox"/>
n) Difficulty eating or feeling full quickly	<input type="checkbox"/>	<input type="checkbox"/>

If you answered 'YES' to any of the items above, please continue with the questionnaire.

If you answered 'NO' to ALL of the items above, please hand the questionnaire back to the researcher. The researcher will offer you the opportunity to place your details on our panel of participants who are interested in taking part in future studies. Thank you for your time.

2. For each bodily change you experienced, can you tell us (as far as you remember) how often you experienced this in the last three months?

Please only complete the items which you have experienced.

	ONCE OR TWICE	SEVERAL TIMES	ALL THE TIME
a) Heavier/longer periods (than what is normal for you)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Vaginal bleeding between periods	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Vaginal bleeding during/after sex	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Vaginal bleeding after the menopause	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Vaginal discharge that smells unpleasant or is blood stained	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Increased wind or constipation (more than is normal for you)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Increased abdominal (tummy) size that does not go away (including bloating)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Pain in the abdomen (tummy), lower back or pelvis that does not go away	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) Pain or discomfort during sex	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) Itching, pain or soreness of your vulva	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) Growth, lump, sore or ulcer on the skin of your vulva	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l) Increased need to empty your bladder (more often or more urgently than is normal for you)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m) Changes in your bowel habit (e.g. constipation or diarrhoea)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n) Difficulty eating or feeling full quickly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. Please tell us whether you have sought advice from a health care professional (GP, nurse, hospital emergency department, or pharmacist) about your bodily change or not.

If you did something else or sought advice elsewhere, other than the healthcare professionals listed, please tick 'didn't seek advice'. Please leave blank any bodily changes that do not apply to you.

	SOUGHT ADVICE	DIDN'T SEEK ADVICE
a) Heavier/longer periods (than what is normal for you)	<input type="checkbox"/>	<input type="checkbox"/>
b) Vaginal bleeding between periods	<input type="checkbox"/>	<input type="checkbox"/>
c) Vaginal bleeding during/after sex	<input type="checkbox"/>	<input type="checkbox"/>
d) Vaginal bleeding after the menopause	<input type="checkbox"/>	<input type="checkbox"/>
e) Vaginal discharge that smells unpleasant or is blood stained	<input type="checkbox"/>	<input type="checkbox"/>
f) Increased wind or constipation (more than is normal for you)	<input type="checkbox"/>	<input type="checkbox"/>
g) Increased abdominal (tummy) size that does not go away (including bloating)	<input type="checkbox"/>	<input type="checkbox"/>
h) Pain in the abdomen (tummy), lower back or pelvis that does not go away	<input type="checkbox"/>	<input type="checkbox"/>
i) Pain or discomfort during sex	<input type="checkbox"/>	<input type="checkbox"/>
j) Itching, pain or soreness of your vulva	<input type="checkbox"/>	<input type="checkbox"/>
k) Growth, lump, sore or ulcer on the skin of your vulva	<input type="checkbox"/>	<input type="checkbox"/>
l) Increased need to empty your bladder (more often or more urgently than is normal for you)	<input type="checkbox"/>	<input type="checkbox"/>
m) Changes in your bowel habit (e.g. constipation or diarrhoea)	<input type="checkbox"/>	<input type="checkbox"/>
n) Difficulty eating or feeling full quickly	<input type="checkbox"/>	<input type="checkbox"/>

## ABOUT YOU

What is your current age? \_\_\_\_\_ YEARS

Which of these best describes your ethnic group?

- |  |   |
|--|---|
| <input type="checkbox"/> White British                                   | <input type="checkbox"/> White and Black Caribbean  |
| <input type="checkbox"/> White Irish                                     | <input type="checkbox"/> White and Black African    |
| <input type="checkbox"/> Any other white background                      | <input type="checkbox"/> White and Asian            |
|  | <input type="checkbox"/> Any other mixed background |
| <input type="checkbox"/> Indian  | <input type="checkbox"/> Black Caribbean            |
| <input type="checkbox"/> Pakistani                                       | <input type="checkbox"/> Black African              |
| <input type="checkbox"/> Bangladeshi                                     | <input type="checkbox"/> Any other Black background |
| <input type="checkbox"/> Any other Asian background                      |   |
| <input type="checkbox"/> Chinese   |   |
| <input type="checkbox"/> Any other ethnic background not mentioned above |   |

What is your marital status?

- |  |  |
|--|--|
| <input type="checkbox"/> Single/never married          | <input type="checkbox"/> Divorced          |
| <input type="checkbox"/> Married/living with partner   | <input type="checkbox"/> Widowed           |
| <input type="checkbox"/> Married separated from spouse | <input type="checkbox"/> Civil partnership |

What is the highest level of education qualification you have obtained?

- |  |   |
|--|---|
| <input type="checkbox"/> Degree or higher degree                           | <input type="checkbox"/> O Level or GCSE equivalent (Grade A-C) |
| <input type="checkbox"/> Higher education qualification below degree level | <input type="checkbox"/> O Level or GCSE (Grade D-G)            |
| <input type="checkbox"/> A-levels or Highers                               | <input type="checkbox"/> No formal qualifications               |
| <input type="checkbox"/> ONC/BTEC  | <input type="checkbox"/> Other _____                            |

Are you currently:

- |   |  |
|---|--|
| <input type="checkbox"/> Employed full-time | <input type="checkbox"/> Full-time homemaker         |
| <input type="checkbox"/> Employed part-time | <input type="checkbox"/> Retired                     |
| <input type="checkbox"/> Unemployed         | <input type="checkbox"/> Student                     |
| <input type="checkbox"/> Self-employed      | <input type="checkbox"/> Disabled or too ill to work |

Does your household own a car or van?

- No
- Yes, one
- Yes, more than one

Please tick the box which best describes your living arrangement:

- |  |  |
|--|--|
| <input type="checkbox"/> Own outright                                  | <input type="checkbox"/> Rent privately                          |
| <input type="checkbox"/> Own with mortgage                             | <input type="checkbox"/> Squatting                               |
| <input type="checkbox"/> Rent from Local Authority/Housing Association | <input type="checkbox"/> Other (e.g. living with family/friends) |

Are you registered with a GP (doctor)?

- Yes  No

Please tick the income bracket which best describes your household income (include any benefits or other sources of income you may receive)

- |   |   |
|---|---|
| <input type="checkbox"/> Less than £5,000 per year  | <input type="checkbox"/> £30,000 - £39,999 per year |
| <input type="checkbox"/> £5,000 - £9,999 per year   | <input type="checkbox"/> £40,000 - £49,999 per year |
| <input type="checkbox"/> £10,000 - £19,999 per year | <input type="checkbox"/> £50,000 - £59,999 per year |
| <input type="checkbox"/> £20,000 - £29,999 per year | <input type="checkbox"/> £60,000 or more per year   |
| <input type="checkbox"/> Do not wish to answer      |   |

Have you ever been diagnosed with a serious illness?

- Yes (please specify \_\_\_\_\_)  No
- Do not wish to answer



## Thank you for your time!

Please remember that we will not be able to pass on any information to your GP, nurse or any other health professional.

If you are worried about any bodily changes we have talked about in this questionnaire, or if you have any bodily changes that are persistent (don't go away), please see your GP, visit [www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk) or call NHS Direct on 0845 46 47. They will be happy to talk to you and will expect you to call if you are worried.

If you want to see a copy of the report or if you have any questions about this questionnaire, please contact [redacted] (contact details below) for more information:

Email: [redacted]

Tel: [redacted]

**Are you interested in women's health research?**

If so, we are looking for women over the age of 30 to complete a five minute, confidential online survey about their current health.

The survey is for a research study at University College London about women's health and responses to changes in their bodies. We would like to invite some of the women who complete the survey to take part in further, paid research. Details of this will be provided during the survey.

If you would like to participate, please enter the following link into your internet browser. This will take you straight to the survey.

<https://www.surveymonkey.com/s/BSL8HX8>

Questions? Please contact the researcher:

## Appendix 11. Email text used for recruitment for study four

Good morning,

My name is Emma Low and I am a PhD student at University College London (UCL). I am currently looking for women aged 30 years and over to participate in some research and was wondering whether I would be able to contact women through your organisation.

I'm interested in looking at the attributions women make to changes in their bodies and what action, if any, they take in response to these bodily changes. In order to explore this, I would like women over the age of thirty to complete a short questionnaire (which they can do in person or online). It shouldn't take more than 5-10 minutes at most.

The initial questionnaires are anonymous.

From these questionnaires, I would then like to offer women the opportunity to participate in an interview. Only if they are interested in participating in an interview would I ask for contact details. Women who are interested in completing an interview and who do so, will be given £10 to reimburse them for their time.

If you think that you might be interested, I have a more information about the study, which I will happily send to you.

Our study would ensure confidentiality to all participants and it has been approved by an ethics board within our university. Again, I'm happy to provide more information on this if you would be interested.

I do hope that this may be of interest to your organisation and look forward to hearing from you.

Kindest regards



**Women's beliefs, attributions and responses to bodily changes**  
**Topic guide**

**INTRODUCTION**

- Introduce self and make clear not from medical background (therefore unable to advise medically)
- Thank participant for attending
- Explain study:
  - Interested in finding out a bit more about women's thoughts, beliefs and behaviours in response to one of the bodily changes in the questionnaire (remind women about the bodily changes)
  - Wanted to talk to women who have had one of the bodily changes

**[SHOW LAMINATED SHEET WITH BODILY CHANGES LISTED]**

- Brief outline of interview:
  - Thoughts about bodily change. Advice been sought from any one or anywhere.
  - Shouldn't last any longer than an hour

**[CONSENT FORM, CONFIDENTIALITY, INTERVIEW TAPE RECORDED, PARTICIPANT PAYMENT FORM, ANY QUESTIONS]**

*NOTE: If participant uses term 'symptom', interview may continue to use this term.*

**BODILY CHANGE EXPERIENCES AND BELIEFS**

- Show list of bodily changes and ask which participant has had in past three months
- Currently experiencing bodily change?
- When did bodily change start? Or when last without bodily change? **[Explore each change separately]**
- How long bodily change lasted for or longest period they lasted when experienced (persistence)

- How often bodily change experienced (every day? Once?) Did this change? Why? At what point? Feelings about this?
- If persistent – has it been constant? Or does it come and go?
- Did it interfere with your life? How much did it impact on your life? In what way?
- Did the severity/impact change? Why? When? Feelings about this?
- Levels of concern about bodily change & what about the bodily change was concerning. Did this change? Why? At what point? Feelings about this?
- Perception of what bodily change may be due to? (more than one idea about cause?) Did this change? Why? At what point? Influences?

#### **BODILY CHANGE BEHAVIOURS**

- Sought advice about bodily change from anywhere or anyone?
  - What you did?
  - Advice from who/where? Family/friends/internet/GP etc

#### ***[IF SOUGHT ADVICE FROM SOMEWHERE OTHER THAN HCP/ DIDN'T SEEK ADVICE]***

- Where?
- What prompted looking for advice/other course of action considered, used?
- What was advice?
- Did you think about seeking help from a HCP?
- Did you think you needed to seek help?
  - If not, why?
  - If yes, why didn't you seek help? Perception of bodily change cause changed? Advice from another source changed decision? Bodily change itself changed (severity/frequency) Any other influences?

#### ***[IF DIDN'T SEEK ADVICE]***

- Did you think about seeking help from a HCP?
- Did you think you needed to seek help?
  - If not, why?
  - If yes, why didn't you seek help? Perception of bodily change cause changed? Advice from another source changed decision? Bodily change itself changed (severity/frequency) Any other influences?

- What influenced decision not to seek medical help?
  - What do you think would happen if you sought help?
  - Do you feel able to seek help? Why not?
  - Is there something else you felt was more appropriate?
  - What other things might have influenced your decision?
  - What would have had to change about the bodily change to make you want to or seek help?
- Do anything else about bodily change? Self-medication?

*[IF SOUGHT HELP FROM HCP]*

- What was advice?
- What was it about the bodily change that made you seek help? What aspects of the bodily change did you notice the most?
- What was it about the bodily change that bothered you the most? (severity/frequency/persistency?)
- Anything else influence your decision to go to HCP?
  - What triggered the decision to go?
- Do you recall the time periods involved in the decision to seek help?
  - How long in days/weeks it took to decide that what you were experiencing was a bodily change which required medical help?
  - How long in days/weeks it took to decide to seek help?
  - How long in days/weeks it took to make an appointment?
- Outcome of seeking medical advice?
  - Diagnosis? Wait & see? Come back if persists/worsens?
    - If diagnosis, what was it?
    - Thoughts about diagnosis? (explore reasons for thoughts)
  - Treatment?
- Overall experience after visiting GP/HCP?
  - Feelings/thoughts about the decision
  - Feelings/thoughts about the appointment (HCP helpful? Listened? Understanding?)
  - Confident talking to HCP (why? Intelligent? Family member in medicine?)
  - HCP response to bodily change
  - Thoughts on influences on HCP response to bodily change? Gender/ethnicity? SES influences?

- In hindsight, would you handle appointment differently? More insistent? Research before appointment? Why?

#### **MEDICAL BACKGROUND**

*Note: Remind participant that they do not have to answer any questions which may make them feel uncomfortable*

- Any other conditions/illnesses?
- Worried about / feel at risk of developing any other illnesses? Why? (because of family/lifestyle etc)

#### **CLOSING THE INTERVIEW**

- How did you find the interview?
- Were there any important issues for you that haven't been raised here? Or is there anything else you would like to talk about?
- Explain to participant that if they are worried about anything we have talked about, they should contact their GP or NHS Direct (provide copy of debrief sheet with NHS Direct contact information and researcher contact information)
- Explain to participant that if they wish to see the results of the study, they may contact the researcher's, who will provide this once published. They may also contact the researcher if they have any concerns or questions about the study
- Reassure about confidentiality and that the recording will be deleted after being transcribed (and participants cannot be identified from recording)

END



Appendix 13. Initial coding frame for study four

<p><b>CHART 1. PARTICIPANT INFORMATION</b> Study ID number 1. Age 2. Ethnicity 3. Socioeconomic status (high, mid or low) 4. Symptoms experienced 5. Symptom severity 6. Symptom frequency 7. Symptom duration 8. Other medical conditions (either myself or someone close)</p> <p><u><b>APPRAISAL INTERVAL</b></u></p> <p><b>CHART 2. DETECTION OF BODILY CHANGE</b> Identifier 1. Prompts to symptom detection 2. Bodily change fits into 'normal life' 3. Symptom detection is overridden by other distractions</p> <p><b>CHART 3. SYMPTOM ATTRIBUTIONS</b> Identifier 1. Existing condition/illness/disease/surgery/injury 2. Just me, always had it or natural causes 3. Hereditary or genetic 4. Contraception or medication 5. Don't know or nothing 6. Possibly illness 7. Thrush 8. Age or aging related 9. Emotional causes 10. Environment 11. Something I have done or am doing 12. Influences on attributions</p>	<p><b>CHART 4. SELF-MANAGEMENT BEHAVIOURS</b> Identifier 1. Barriers to self-management 2. Non-medical self-management 3. Outcomes of self-management 4. Over-the-counter medications</p> <p><u><b>APPRAISAL AND HELP-SEEKING INTERVALS</b></u></p> <p><b>CHART 5. SYMPTOM EXPERIENCE</b> Identifier 1. Experiencing symptom currently 2. Feelings about symptoms 3. Symptom impact on life 4. Symptoms linked 5. Symptom resolves itself</p> <p><b>CHART 6. SELF-MANAGEMENT BEHAVIOURS</b> Identifier 1. Barriers to self-management 2. Non-medical self-management 3. Outcomes of self-management 4. Over-the-counter medications</p> <p><b>CHART 7. FEEL AT RISK OF</b> Identifier 1. Another illness, condition or disease 2. Cancer 3. None 4. STDs or STIs</p>	<p><b>CHART 8. GENERAL HEALTH BEHAVIOURS &amp; BELIEFS</b> Identifier 1. Healthy person 2. Knowledge 3. Not worried, a complainer or prone to hypochondria 4. Prefer non-medical interventions/distrusting of medicines 5. Worried about health generally 6. Body as a whole</p> <p><b>CHART 9. RESPONSES TO SYMPTOMS</b> Identifier 1. Lay or non-specific sources 2. Self-management, learn to live with it or ignore it 3. Monitor the symptom 4. Saw a HCP 5. Saw a non-medical professional</p> <p><u><b>HELP-SEEKING INTERVAL</b></u></p> <p><b>CHART 10. HELP-SEEKING</b> Identifier 1. Barriers to help-seeking 2. Influences on help-seeking 3. Feelings about seeking help</p>
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