

# **Increasing awareness of gynaecological cancer symptoms: a GP perspective**

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## **Abstract**

**Background:** In the UK there has been an effort, through the National Awareness and Early Diagnosis Initiative (NAEDI), to increase early stage diagnoses and ultimately cancer survival. Encouraging early symptom presentation through awareness-raising activities in primary care is one method to achieve this goal. However, understanding general practitioners' (GPs') views about this type of activity is crucial prior to implementation.

**Aim:** To describe GPs' attitudes to raising public awareness of gynaecological cancers, and their views about the potential impact on primary care services.

**Design and setting:** An online survey using a convenience sample recruited from 1860 UK general practices.

**Methods:** An invitation was emailed to GPs via practice managers and included a web-link to a draft education leaflet and an online survey about the impact of sending a leaflet giving information about symptoms associated with gynaecological cancers to all women on GPs' lists. Participants could offer additional free text comments which were coded using content analysis.

**Results:** 621 GPs participated. Most (77%, 477) felt that raising awareness of cancers was important. However only half (50%, 308) indicated they would distribute such a leaflet from their practice. Barriers to implementation included concerns about: financial costs; emotional impact on patients; increased demand for appointments and diagnostic services (e.g. ultrasound).

**Conclusions:** GPs were generally positive about an intervention to improve patients' awareness of gynaecological cancers, but had concerns about increasing rates of presentation. There is a need for research quantifying the benefits of earlier diagnosis against resource costs such as increased consultations, investigations and referrals.

**KEYWORDS:** PRIMARY HEALTH CARE, GENERAL PRACTICE, PATIENT EDUCATION, EARLY DETECTION OF CANCER

**HOW THIS FITS IN:** Raising cancer awareness amongst the public is a recent UK government strategy to encourage symptomatic patients to present promptly in primary care. This study recognises the role of GPs as key stakeholders in individualised interventions located within primary care, and reports the findings of a GP consultation at the development stage of a leaflet intervention aiming to increase awareness of gynaecological cancers. The focus of this study was to identify and quantify levels of support and barriers to the implementation of such an intervention amongst GPs.

## Introduction

There is increasing evidence that cancer survival can sometimes be improved by earlier diagnosis, which is potentially achievable through symptomatic individuals presenting earlier to health professionals (1). This is true for a number of cancers including most of the gynaecological cancers, which have a combined annual incidence second only to breast cancer in the UK (N=19,631, in 2010)(2-5). Thomson and Forman (6) concluded that earlier diagnosis of cervical and uterine cancers could reduce the survival gap between England and European averages, and differences in ovarian cancer survival could also be reduced by earlier diagnosis, although care factors after diagnosis also play a role.

Encouraging earlier presentation of cancer symptoms could be achieved in a variety of ways, including education and information provision (e.g. multi-media campaigns) as well as changes in health care provision (e.g. access to appointments). In the UK there has been a co-ordinated effort between the Department of Health and cancer charities to develop programmes of cancer awareness-raising activities through the National Awareness and Early Diagnosis Initiative (NAEDI). Increasing public cancer awareness via information provision is a key strategy for increasing the rates of earlier presentation (7). The assumption is that education leads to symptom awareness which is a necessary prerequisite to help-seeking behaviour. There is some evidence from evaluation data assessing the impact of UK multi-media cancer awareness campaigns that supports this assumption (8;9). Changes in behaviour, such as increased presentations to the GP (8;9) and attendance at cancer screening (10), have been recorded and associated with an increase in urgent referrals for investigations (8). Evidence that more cancers are being detected, and at an earlier stage, is preliminary. In one encouraging example, a regional evaluation of a lung cancer awareness campaign found a significant increase in the number of small cell cancers staged as 'limited' (i.e. confined to one lung and relatively early in presentation) (8).

Some clinicians have been critical of efforts to educate the public about cancer symptoms as a means of promoting early detection. The impact of education has been labelled by some as 'the curse of awareness' (11), with concerns voiced that campaigns may lead patients to have an exaggerated perception of personal risk and increased anxiety about their health. This may lead to the 'worried well' flooding general practice, resulting in unnecessary

investigations to reassure patients that they do not have cancer (12). There have been no systematic attempts to quantify the extent of GPs' concerns, although GPs are recognised as influential in raising the profile of cancer symptoms among their patients (7). As gatekeepers to secondary care and diagnostic services, GPs are key stakeholders in the development of educational initiatives designed to increase help-seeking behaviour. Therefore GPs' concerns regarding these initiatives must be identified and addressed.

In this study, a leaflet to encourage the earlier presentation of women with gynaecological cancer symptoms was developed. The leaflet, to be directly mailed to women aged 40 and above on GPs' lists contained: i) information about gynaecological cancers including symptoms and signs, ii) a symptom checklist for patients to complete and take to a GP appointment, and iii) acknowledgement of common help-seeking barriers and suggestions of how to overcome these. In addition, one panel of the leaflet included a 'letter' from the GP inviting women to make an appointment if they had any of the symptoms highlighted in the leaflet. Leaflets are a commonly used and relatively inexpensive, but pragmatic approach to imparting health information. They can be used as a stand-alone intervention or embedded within a more extensive multi-media social marketing campaign (see e.g. (18)).

In order to assess GPs' attitudes to raising public awareness of gynaecological cancers and their views about the impact on primary care services, we invited a sample of GPs to comment on a draft version of the leaflet and to give their views about the likely effect of distributing it.

## **Method**

This web-based survey was delivered to a convenience sample of GPs. The design was categorised as service evaluation and was exempt from the requirement to obtain ethical approval (A Nicholson, Lead RM & G Manager at Central and East London CLRN, personal communication, 23<sup>rd</sup> August, 2011).

In October 2011 an email was sent to 1860 practice managers in the UK via the following organisations: the Primary Care Research Network (PCRN), the General Practice Research

Framework (GPRF) and the Society for Academic Primary Care (SAPC). The 1860 practices represented approximately 20% of registered general practices within the UK (excluding Northern Ireland) (19).

Practice managers were asked to forward the email to all doctors (including locums and trainees) working in their surgery. The email gave details of the study, a web-link to the leaflet and to a short (approximately 15-minute) questionnaire. A small incentive was offered, with a prize draw giving the opportunity to win £75 in vouchers or 6 bottles of sparkling wine being held three months after the initial email.

Participation was anonymous, and informed consent assumed if respondents proceeded to the questionnaire. Two reminders to participate were sent to practice managers at three to four week intervals. The website was live between November 2011 and January 2012.

### Measures

The survey was developed in collaboration with the GP researchers in this study (FW and MB) before being piloted with two further independent GPs. There was a mixture of closed and open-response (free text) questions. The questionnaire is shown in Appendix 1 and items included in the analysis are highlighted. The questions included were broadly categorised into the following themes:

#### *Exploring perceived need for, and commitment to, raising awareness of gynaecological cancer symptoms*

Participants were asked what they thought might prevent women from presenting early with symptoms of gynaecological cancers and what suggestions they had for overcoming these barriers. Commitment to raising awareness was assessed using responses to two statements using a five point agreement scale: 'Personally I think that raising awareness of the symptoms of gynaecological cancers is a high priority', and 'I expect that sending out this leaflet to women in my practice would be considered a priority by the practice team'. The five point scale was later categorised into three: 'strongly disagree/disagree', 'unsure' and 'agree/strongly agree'. Respondents were also asked whether they had systems in place

to encourage women with possible gynaecological cancer symptoms to present at their practice with response options of: 'yes', 'no' or 'don't know'.

#### *Support for the leaflet and barriers to implementation*

Respondents were asked to indicate whether in principle they would agree to send the leaflet from their practice ('yes', 'no' and 'maybe') and about the possible impact of doing this by rating their agreement with nine statements (on the same agreement scale as above, later collapsed into three) e.g. 'I expect that sending out this leaflet to women in my practice would be time consuming'.

Respondents were asked about the local availability of diagnostic services for gynaecological cancers and to indicate whether diagnostic testing was available in-house ('yes' or 'no'). Finally, respondents rated ease of access for each of these investigations: CA125 serum test, abdominal ultrasound, trans-vaginal ultrasound, and colposcopy.

#### *Practice and GP characteristics*

Participants provided demographic details about themselves and their practice including: respondent age, gender and ethnicity, practice list size, location (region within the UK as well as practice setting: whether it was 'urban', 'suburban', 'rural' or 'none of these'), ethnic diversity of the patient list, and whether there was a gynaecological specialist at the practice. For the analyses, ethnic diversity of the patient list was collapsed from four categories ('very mixed across ethnicities', 'a mix of two main ethnicities', 'a majority of one ethnicity' and 'almost exclusively one ethnicity') into two categories: 'mixed ethnicities' and 'majority of one'; and GP ethnicity was collapsed into two categories: 'White' and 'not White'.

#### Analysis

Content analysis (20) was used to convert free text comments into numerical data that could be summarised alongside the quantitative responses. Data were analysed using IBM

SPSS version 20 (21). Proportions and frequencies were calculated and group differences were tested using Chi-square analyses and ANOVA. Quotes from the free text comments illustrate findings described in the results.

For the content analysis, a coding framework was developed to describe free text responses in terms of the range of beliefs expressed, and the numerical frequency with which they occurred. A belief was defined as a specific idea, and could be a single word or several sentences of text coded for manifest meaning. Beliefs for each question were coded separately and recorded only once per participant per question. The framework was developed by two researchers (RE and MS) using a thematic approach (22). A cyclical process of coder training, testing and revision was followed to refine the categories and codes. Inter-rater reliability was calculated (IRR; Cohen's Kappa) based on data from 10% of the sample (n=60). All the kappa values were within the acceptable range (all greater than 0.8,  $p < 0.001$  with the exception of one, 'suggestions for overcoming barriers' which was 0.7,  $p < 0.001$ ) (23). The remaining data were then coded using NVivo 9 (24). After coding it was possible to produce numerical tables where columns represented beliefs and rows represented participants. Each cell contained either a 0 or 1 to represent absence or presence of a belief.

## **Results**

A total of 621 GPs responded. The response rate could not be calculated as the numbers of GPs recruited and working at each practice could not be identified. The overwhelming majority of respondents worked in England (99%, see Table 1). Comparison with statistics for England (25) suggests the sample over-represented the 40-49 age range (37% versus 32% nationally), and that there was a greater proportion of female GPs in our sample than would be expected (58% vs. 46%), although retainers and registrars were not included in the national figures. The mean list size in our sample (10,039) was bigger than the national



average of 6,651. This may reflect the larger representation of practices from the Midlands and Eastern England where there are typically larger practice sizes.

### Exploring the need and support for raising awareness of gynaecological cancer symptoms

#### *Reasons for longer time to presentation*

The majority of GPs (86%, 532/621) offered at least one reason for late presentation among women with gynaecological cancer symptoms (see Table 2). Only a few (2%, 14/621) reported that women attended promptly with such symptoms. The most frequently cited cause of longer time to presentation was low awareness (43%, 267/621) resulting in patients failing to understand the significance of symptoms. The vague nature of many of the symptoms associated with gynaecological cancers, particularly ovarian cancer, was highlighted as a key cause of longer time to presentation (20 %, 124/621) e.g.

*“[symptoms]...are very non-specific and confused with events such as menopause, gaining weight or [confused with] GI symptoms” #433.*

Another frequently cited barrier was patients' embarrassment (32 %, 199/621), including embarrassment about: the involvement of the uro-genital area, symptoms potentially related to sex (e.g. post-coital bleeding), and the possibility of discussing symptoms with a male GP. Other emotional barriers identified by GPs included fear, anxiety and stigma associated with a cancer diagnosis (19%, 116/621). These barriers were thought to lead to denial and ultimately a longer time to presentation, e.g. *“They may fear cancer so bury their head in the sand and avoid the GP” #507.*

#### *Suggestions for improving early presentation*

The majority (70 %, 433/621) of GPs offered ideas about how to improve early presentation. The most common suggestion was patient education (51%, 316/621), through national media and local community campaigns, practice specific initiatives, or opportunistic conversations with patients. Other suggested solutions involved improved health care provision (14%, 90/621), such as increasing access to appointments and to female doctors, as well as encouraging all staff to be more approachable e.g. *“good general practice and approachable primary care (includes GPs, nurses, receptionists etc.)” #213.* Health

professional training (3%, 16/621) was suggested by a few as a way to “ensure all GPs are aware of ALL symptoms and keep up-to-date with protocols and pathways” #280. Overall, 106 GPs (17%) specifically cited the educational leaflet as a useful intervention: “I think leaflets such as this can convince them [women] of the importance of presenting” #199. A quarter of respondents (25%, 152/621) reported that they already had systems in place to encourage women with possible gynaecological cancer symptoms to present promptly at their practice, e.g. “Posters in waiting room. Give health promotion and advice at contraceptive and smear appointments” #722.

#### *Levels of commitment to raising awareness and support for using the gynaecological cancers information leaflet*

The majority of GPs (77%, 477/621) believed that raising awareness of gynaecological cancers was a priority in general terms. However, for their own practice, most were more cautious and only 16% (100/621) agreed that raising awareness would be a priority for them.

Half the sample (50%, 308/621) agreed in principle that they would send out the research leaflet from their practice. A minority (12 %, 77/621) said they would not use the leaflet; whilst around a third (37%, 229/621) were undecided (‘maybe’). Endorsement was not related to GP characteristics of gender ( $\chi^2(2,610)=2.96, p=0.228$ ), age ( $F(2,603)=2.697, p=0.068$ ) or ethnicity ( $\chi^2(2,604)=0.274, p=0.874$ ), nor to practice characteristics of practice setting ( $\chi^2(4, 575)=2.94, p=0.568$ ), ethnic diversity of patients ( $\chi^2(2,611)=1.092, p=0.579$ ), or practice size ( $\chi^2(2,604)=1.611, p=0.447$ ). However, GPs who reported having a gynaecological specialist in the practice were more likely to agree to send out the leaflet than those from practices with no gynaecological specialist (55% vs. 45%;  $\chi^2(2,611)=6.133, p=0.047$ ).

As shown in Table 3, a greater proportion of GPs who said they would send out the leaflet thought that it would impact positively on women.

#### Barriers to using the gynaecological cancers information leaflet

A third (36%, 224/621) of respondents gave one or more free text comments in response to questions about whether they were prepared to distribute the leaflet, and their perceived barriers to its implementation are grouped by theme below. There were 637 comments in total. A few comments (7%, 42/637) were positive endorsements or support for this intervention, while about half (46%, 295/637) described the perceived potential negative impact of the leaflet on patients or practices. The remainder referred specifically to the content (13%, 84/637) and suggestions for change to either the leaflet or how it was disseminated (22%, 138/637).

A few GPs felt that they needed additional information (4%, 25/621) before making a decision about the leaflet. While for some this was about seeking the opinions of colleagues, for others it was about needing to know the likely impact e.g. *“I would want to see some evidence that there is a benefit, preferably from a good quality RCT showing that the leaflet actually results in a benefit (gynae cancers diagnosed sooner with corresponding clinical benefit) greater than the harms (costs, unnecessary investigations and consequences of that, stress to women)”*#213.

#### *Financial concerns*

As reported in Table 4, over half the GPs agreed that it would be easy to mail out the leaflet (56%, 350/621), but most thought it would be costly (72%, 445/621). Alternatives to a mail out were suggested and these included: having the leaflets available in the practice to pick up, displaying the information as a poster, sending the leaflet with other correspondence, distributing leaflets electronically, or posting it on the practice website.

#### *Impact on patient behaviour*

About two thirds of the GPs (65%, 404/621) believed that the leaflet could increase patients' fear of gynaecological cancers, and three quarters (74%, 450/621) felt that it would lead to a significant increase in the number of appointments made (see Tables 3 and 4), at a time when resources were already tight and there was pressure to reduce budgets. One respondent noted that *“None of us are looking for extra work and this represents one of*

*many invitations from different interest groups asking people to make appointments which are already difficult enough to obtain”#303.*

### *Impact on diagnostic services*

The majority (85%, 527/621) said that they felt that their current access to diagnostic services locally was ‘just about right’ or ‘more than enough’ to meet demand. Similarly, most felt that access to specific investigations was ‘extremely’ or ‘quite’ easy. Just under half of the respondents reported that they could carry out diagnostic testing within their practice (43%, 267/621). Free text comments revealed that some GPs (9%, 53/621) were concerned about waiting times, particularly for non-urgent ultrasounds, where clinical presentation does not warrant referral via the two-week wait rule. *“Ease of access: we just have to write a request and wait. Speed of access: that's a different and rather more pertinent question” #218.*

Only a few GPs (3%, 17/621) felt that secondary services would be unable to cope with any increase in demand, leaving patients alerted to the possibility of a problem but having to wait significant lengths of time before accessing diagnostic services. As a result, some felt that resources should be directed to diagnostic services rather than raising awareness: *“I think it is almost more important to provide the imaging services so that when GPs are concerned they can send the patients for hopefully a reassuring ultrasound within a week or two” #211.*

## **Discussion**

### Summary

Despite general support for raising awareness of cancers and educational leaflets, only a small proportion of the GPs considered this activity a priority for their practice.

Reservations about awareness campaigns, and sending leaflets out in particular, included concerns about raising patient anxiety, the possible pressure on appointments and referrals, and the financial impact. Some reservations stemmed from the need for any intervention to

be evidence-based and there is, as yet, only limited published evidence that links raising patient awareness with earlier stage at diagnosis and no evidence as yet of any impact on mortality rates (8). GPs are best placed to give informed views on how to design and implement interventions that target their practice populations effectively.

### Strengths and limitations

This is the first study that gives a voice to an important stakeholder group in the debate about the benefits and costs of implementing individualised cancer awareness education within primary care.

Approaching GPs directly might be more effective in achieving a more representative sample than we achieved: this sample comprised a majority of female respondents, which is perhaps not surprising in a study about cancers affecting women. This may have led to an over-estimation of the priority attached to raising awareness of gynaecological cancers, and it might explain the discrepancy between the numbers who perceived it to be a personal rather than a practice priority.

Health professional surveys typically have a low response rate (26;27), but the number of participants in this survey compared to the potential numbers contacted was possibly lower than similar studies (28). Despite this, and the fact that we could not calculate an accurate the response rate, the decision to contact GPs via professional organisations was beneficial in rapidly gaining access to a large number of GPs across the UK.

### Comparison with existing literature

The reasons offered by GPs for why women with gynaecological cancer symptoms may present late in primary care are broadly similar to those previously discussed in the literature (29-31). Patient education was the most frequent suggestion for improving early presentation. However, GPs were understandably concerned about the potential for a negative impact on patients. Concerns about raising patient anxiety as a result of education are not supported by evidence in the literature, which shows little or no impact on 'current

state' anxiety in samples exposed to cancer-awareness information (32-34). GP education in relation to cancer awareness should include this information. GPs also expressed concern that increasing symptom awareness might lead to unnecessary investigations and associated patient distress. Evidence from existing gynaecological cancer literature comes from trials of population screening for ovarian cancer and suggests that when women receive an abnormal result - which on subsequent testing is normalised (false positive) - they do not report long-term distress (35). However there is the possibility that these false positive results lead to unnecessary surgical intervention which has a risk of complications (36). Promoting symptom awareness as reported here is not the same as population screening; GPs triage patients deciding who has further investigations and so theoretically false positive results and their consequences should be fewer, but this needs to be quantified through research.

In terms of cost, the increase in cost of more frequent investigations must be off set against any potential reduction in cancer morbidity and mortality. The potential economic impact of earlier diagnosis initiatives has been modelled for some cancers (including breast, colorectal, lung and melanoma) leading to the conclusion that such initiatives would at least be cost-effective, although not cost-saving (37).

The intention of awareness-raising activities is to increase the number of symptomatic presentations, but GPs understandably expressed concern that such interventions might generate a large number of unnecessary presentations. Research that quantifies the likely increase in appointments and their outcome in terms of positive diagnoses is still needed. Preliminary work from national campaigns using the Be Clear on Lung Cancer branding, suggests that the increase in patient consultations is manageable ( $\leq 3$  additional presentations per practice per week) (38). However the individual-level approach defined in our study, with a targeted leaflet sent to patients on GPs' lists has not yet been assessed for its impact on patient behaviour. Previous studies using this approach have only looked at intermediate patient outcomes – i.e. those that precede behaviour, such as changes in beliefs or knowledge (15). Potentially, this type of GP-endorsed direct mailing might produce a more powerful behavioural response. This hypothesis is now being tested by

distributing the gynaecological cancer leaflet described in this study to ten pilot practices in and around North London.

Cancer symptoms can be non-specific and diagnostic delays have been linked to both misattributions by clinicians and a failure to investigate symptoms which appear ambiguous (29;39;40). An increase in cancer-specific training and widespread implementation of decision support tools for GPs may increase their confidence in identifying patients with potential cancer symptoms. Significant progress has been made in this area recently (41;42) particularly in relation to the risk assessment tools (RATs) developed by Hamilton et al (43)(lung and bowel cancers), and Hippisley-Cox and Coupland's 'QCancer' risk scores (44;45)(which included gynaecological cancers in women), although how well they work in practices in general is not yet established. An effective approach may be to run public awareness campaigns in conjunction with GP education programmes. This approach was recently used to increase presentations to GPs and referrals for chest X-rays, and led to a 27% increase in lung cancer diagnoses in intervention areas compared to controls, although this difference was not statistically significant (9).

One important issue addressed in the current survey was access to diagnostic tests. Improving direct GP access to diagnostic tests for cancer has been an important part of the NAEDI strategy, with access to ultrasound identified as one of four top priorities (46). It was therefore reassuring to find that participating GPs generally reported good access to diagnostic services. However, concern was still expressed about waiting times and the possibility that a primary care intervention might exacerbate pressure on secondary care services. One recent report (39), showed that a sample of GPs (n=402) perceived significant improvements in access to ultrasound, but one in four tests was still taking more than a month. Greater dissemination of information on diagnostic service capacity limitations will help GPs make an informed decision about participation in awareness-raising activities.

### Implications for research and practice

This survey shows that GPs are mainly supportive of projects to raise awareness of cancer but that they are concerned at the possible negative impact on patients, their own workload and the availability of services in secondary care. We need to know more about the cost

benefit of public cancer awareness interventions. An understanding of the impact on workload is vital if GPs are to commit time and money to such intervention.



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