

Title: Increasing awareness of gynaecological cancer symptoms and reducing barriers to medical help-seeking: Does health literacy play a role?

Running Head: Literacy, awareness and barriers to help-seeking

Abstract

Health literacy may influence the efficacy of print-based public health interventions. A key part of the UK cancer control strategy is to provide information to the public on earlier diagnosis with a view to improving the UK's relatively poor 1-year cancer survival statistics. This study examined the impact of health literacy on the efficacy of a gynaecological cancer information leaflet. Participants (n=451) were recruited from 17 Cancer Research UK events. Health Literacy was assessed with the Newest Vital Sign (NVS) test. Gynaecological cancer symptom awareness and barriers to medical help-seeking were assessed before and after participants read the leaflet. Symptom awareness improved and barriers to medical help-seeking reduced (p 's<0.001). Symptom awareness was lower in individuals in lower health literacy groups both at baseline and follow-up (p < 0.05, p <0.001 respectively), but there were no significant differences in barriers to medical help-seeking at either time point (p >0.05). As predicted, individuals with lower health literacy benefited less after exposure to the leaflet (p 's<0.01 for interactions). Despite careful consideration of information design principles in the development of the leaflet, more intensive efforts may be required to ensure that inequalities are not exacerbated by reliance on print-based public health interventions.

Introduction

In 2011, the UK Department of Health announced their strategy for improving cancer outcomes. The provision of information to the public was considered central to promoting healthier lifestyles, ensuring earlier diagnosis of cancer, and improving the experience of cancer survivors (Department Of Health, 2011). While a number of different modalities are used to achieve these aims, written information is an important channel through which information is delivered.

For print materials, the health literacy of the target population may be an important factor in determining impact. The Institute of Medicine has defined health literacy as ‘the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions’ (Ratzan & Parker, 2000). A national assessment of health literacy in the US found that more than a third of the general public have basic or below basic health literacy (Kutner, Greenberg, Jin, Paulsen, & White, 2007). In the UK, a nationally representative study using the Test of Functional Health Literacy in Adults (TOFHLA; Parker, Baker, Williams, & Nurss, 1995) reported that 11.4% of adults have marginal or inadequate health literacy (von Wagner, Knight, Steptoe, & Wardle, 2007). Furthermore, a recent survey suggests 15% of the UK population have low general literacy scores (Department of Business, Innovations and Skills, 2011). While the different methodologies used in these surveys prohibit direct comparison, it is fair to say that all indicate a potential challenge to information-transmission using print-based materials.

Health literacy is associated with a wide range of health-related behaviours and outcomes, including self-management behaviour, accident and emergency admissions, morbidity and mortality (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011). Relationships between low health literacy and poor knowledge of health conditions have also been found in several different patient populations (Fransen, von Wagner, & Essink-Bot, 2011; Sobel et al., 2009; Ussher, Ibrahim, Reid, Shaw, & Rowlands, 2010). One of the few studies in the cancer field found that women with low health literacy were less likely to know about the link between lifestyle factors and cancer (e.g. number of sexual
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partners and cervical cancer) and less likely to understand the purpose of screening (Lindau et al., 2002). However, there has been little research on the relationship between health literacy and cancer awareness more generally.

In addition to background knowledge deficits, individuals with lower health literacy may be less likely to improve upon their understanding when exposed to print-based materials. In a study in which participants were presented with excerpts from the NHS Bowel Cancer Screening patient information leaflet ("*Bowel Cancer Screening: The Facts,*") lower health literacy (as measured by the UK TOFHLA (von Wagner et al., 2007) was associated with less information seeking and greater reading effort (von Wagner, Semmler, Good, & Wardle, 2009). Given that a key area of cancer control policy in the UK is promoting awareness of cancer symptoms (Richards, 2009), and print-based information is a common modality through which to deliver this, consideration should be given to evaluating print-based interventions within a health literacy framework.

The present study describes analyses of women's responses to a gynaecological cancer information leaflet which aims to promote prompt medical help-seeking for symptoms. The proposed mechanisms for behaviour change are through increasing symptom awareness and reducing barriers to medical help-seeking, and a 'visit preparation' or 'patient activation' (e.g. McCann & Weinman, 1996) technique in the form of a self-completion symptom checklist. The present study examines the effect of health literacy on these mechanisms of change.

A recent systematic review of interventions to promote awareness of cancer symptoms identified four interventions using print-based information (Austoker et al., 2009; Boundouki, Humphris, & Field, 2004; de Nooijer, Lechner, Candel, & de Vries, 2004; Rimer et al., 2002; Wilt et al., 2001). Although effects were modest and the studies were heterogeneous in terms of intervention type, populations assessed, and outcomes measures, all of them increased at least one element of cancer awareness; however none assessed the impact of health literacy on knowledge acquisition.

Gynaecological cancers were chosen for this study because together they are responsible for over 18,000 cancer cases each year (Cancer Research UK, 2008) and compared with similar European countries, the UK has relatively poor 1-year survival, especially for cervical and uterine cancers (Thomson & Forman, 2009). Awareness of cancer symptoms has been shown to be associated with anticipated time to help-seeking (Robb et al., 2009; Low et al., 2012, submitted) and previous research has shown that symptom misattribution and non-recognition of symptom seriousness is associated with delayed help-seeking for gynaecological cancers (Fitch, Deane, Howell & Gray, 2002; Kidanto, Kilewo & Moshiro, 2002; Cochran, Hacker, & Berek, 1986). Furthermore, cervical cancer is the only gynaecological cancer for which women are regularly screened in the UK. Consequently, the identification of early-onset symptoms by patients and their health-care providers remains the best potential route to improving the early diagnosis for the majority of gynaecological cancers.

Considering the unequal distribution of health literacy across the population and its potential to exacerbate inequalities in health (Berkman et al., 2011), it is important that researchers are mindful of it during the design, testing and evaluation of public health interventions. The research described here examines the association between health literacy and gynaecological cancer symptom awareness and barriers to medical help-seeking, and assesses the effect of health literacy on the preliminary testing of an information leaflet designed to increase these factors in a sample of women from the UK general population.

Methods

Design and Procedure

Between April and August 2011 researchers attended ten of Cancer Research UK's 'Cancer Awareness Roadshows' (London: n = 9; Birmingham: n = 1) and seven 'Race for Life' fundraising events. 'Race for Life' is an event for women, often attended by those who have personally been affected by cancer, or

who know someone who has. As these were fundraising events that might attract women of higher socioeconomic status (SES), the Roadshows, which involve mobile units travelling to the UK's most deprived areas to provide information to the general public, were also used for recruitment.

Women over the age of 18 were invited to participate opportunistically. After informed consent was taken, they completed a health literacy measure. They were then randomly assigned to receive one of four vignettes about gynaecological cancer symptoms: half receiving a vignette on a "well-known" symptom, and half a "less well-known" symptom (Low et al., 2012, submitted; Target Ovarian Cancer, 2009). The vignettes were used in another part of the study to assess the impact of symptom familiarity on anticipated help-seeking. The vignettes are not germane to the analyses reported in this paper and consequently are not described further.¹ After reading the vignette, participants completed measures including gynaecological cancer symptom awareness and barriers to medical help-seeking (Time 1 questionnaire). They then read the gynaecological cancer information leaflet, and completed an identical questionnaire (Time 2 questionnaire) with some additional socio-demographic items. Questionnaires could be completed on paper or laptop. Participation in the study took approximately 20 minutes. Ethical approval was obtained from the University College London Research Ethics Committee.

Gynaecological Cancer leaflet design

The development of the intervention leaflet used in this study was iterative, with successive revisions, and drew on a patient-centred evaluation framework for patient information leaflets (Garner, Ning, & Francis, 2011). In order to ensure that the leaflet would be suitable for the general population a number of steps were followed. Readability statistics were used as the first stage of the

¹ All analyses were repeated with vignette type as a covariate. Significance levels and effect sizes were the same, and therefore no alterations were made to the model. Vignettes are available on request from the corresponding author.

evaluation. The Flesch Kincaid Grade Level was 5.5 (Flesch, 1948) and the SMOG index grade level was 7 (McLaughlin, 1969) demonstrating that the material in the leaflet is suitable for people with a reading age equivalent to that expected of 11 to 13 year olds. The leaflet was tested in three focus groups (two with non-symptomatic women, one with gynaecological cancer survivors), and in one-to-one interviews with three gynaecological cancer survivors. Expert opinions were also sought from six gynaecological cancer specialists.

The leaflet used information design principles such as chunking information together in order to reduce the cognitive load (Wilson & Wolf, 2009); indeed the concept of 'gynaecological cancers' (which includes ovarian, endometrial, cervical, vulval and vaginal cancers) was an effort towards meaningfully combining information on a number of different cancers that were related by the area of the body and some shared symptoms (e.g. abnormal vaginal bleeding can apply to endometrial, vaginal and cervical cancer).

Measures

Participant characteristics

The Index of Multiple Deprivation (IMD) 2007, a measure of neighbourhood deprivation, was used as a proxy for socio-economic status. IMD scores were derived from participants' postcodes and are based on small area geography within England. The IMD 2007 brings together 37 different indicators of deprivation including: income, employment, health and disability, education, barriers to housing and services, living environment and crime. IMD scores range from 0 (least deprived) to 80 (most deprived). In our sample, IMD scores ranged from 1.1 to 61.3. This highest score was divided into three, to create a categorical variable with three groups for low (score between 1.1-21.1), medium (21.2-41.2) and high deprivation (41.3-61.3). Age (18-30; 31-40; 41-50; 51+), ethnicity (white; other), education (up to higher education [below degree]; higher education [degree level or above]), and

familiarity with gynaecological cancer (familiar [participant knew someone or had been diagnosed themselves]; unfamiliar) were also recorded.

Health Literacy

The Newest Vital Sign (NVS: Weiss, Mays, Martz, Castro, DeWalt, Pignone et al., 2005) has been adapted to assess health literacy in the UK population and validated in a separate study (G. Rowlands, personal communication, 25TH March, 2011). The NVS involves the participant reading a nutritional label, followed by six comprehension questions. It was chosen to measure health literacy because it is quick to complete in a time limited setting (participants at “Race for Life” events had to start the event at a specific time,) and assesses a range of health literacy skills including literacy, numeracy and information navigation. Health literacy scores were categorised according to previous research on the NVS (Weiss et al., 2005). The possible range of scores was 0 to 6. Scores of 0-1 were considered ‘low’ health literacy, 2-3 were considered ‘marginal’ health literacy, and scores of 4 and over were considered ‘adequate’ health literacy.

Questionnaire

Survey items were based on questions from the Ovarian and Cervical Cancer Awareness Measures (Ovarian CAM and Cervical CAM) (Simon et al., 2011), which are site-specific versions of the generic Cancer Awareness Measure (CAM) (Stubbings et al., 2009). The items used in this study were adapted to include other additional gynaecological symptoms mentioned in the leaflet.

Gynaecological cancer symptom awareness

Symptom awareness was assessed using a prompted list with the stem: “The following may or may not be warning signs for gynaecological cancer. We are interested in your opinion”. There were 12

symptoms listed. Response options were: “Yes” (score ‘1’), “No” and “Don’t know” (both score ‘0’) giving a possible range of 0 to 12. Higher scores indicate higher symptom awareness.²

Barriers to medical help-seeking

Barriers were assessed using the 10-item scale from the CAM (Stubbings et al. 2009). This includes four emotional barriers (e.g. “I would be too embarrassed”), three service barriers (e.g. “My doctor would be difficult to talk to”) and three practical barriers to medical help-seeking (e.g. “I would be too busy to make time to go to the doctor”). Participants could respond “Yes often”, “yes sometimes”, “no” or “don’t know” to each barrier depending on whether they thought it might “put them off” going to the doctor with a symptom they thought might be serious. The two “yes” responses were scored as ‘1’, while the “no” and “don’t know” responses were coded as ‘0’. A total barriers score was calculated with a possible range of 0 to 10. Higher scores indicate more barriers to medical help-seeking.

Data Analysis

All analyses were conducted using SPSS Version 18.0. Chi-square tests examined differences in health literacy scores by age, ethnicity, IMD score, education, and familiarity with gynaecological cancer. Analyses of Covariance (ANCOVAs) were used to explore the association between health literacy group and symptom awareness and barriers to medical help-seeking, both pre-intervention (T1) and post-intervention (T2). To test whether the leaflet resulted in increased symptom awareness and reduced barriers to medical help-seeking, repeated measures ANCOVAs looked at changes over time (from T1 to T2) for these variables, and to test the hypothesis that health literacy moderated the effect, we tested the interaction between time and health literacy score on symptom awareness and barriers to medical help-seeking. The analysis was repeated to investigate associations with each of

² A copy of the symptom awareness questions are provided in the appendix.

the different types of barriers to medical help-seeking (service related, emotional and practical). Age, ethnicity, IMD and education were all associated with health literacy scores and therefore entered as covariates in all analyses.

Missing data

482 participants were recruited. Age, education and IMD scores had data that was frequently missing (>5%) and therefore separate response categories were created (Tabachnick & Fidell, 1996). Data were infrequently missing (<5%) for ethnicity, health literacy, awareness at T1 and T2 and barriers to medical help-seeking at T1 and T2, and therefore cases with missing data were excluded from analysis (n= 31). This left a remaining 451 participants data for the analyses.³

Results

Among the 451 women included in the analyses, the mean age was 40.6 (SD= 14.1), with a range of 18 to 83 years. The majority were white (74.3%) and had studied in higher education (56.8%). According to the IMD, 45% were in the least deprived group. Fewer than half knew someone affected by gynaecological cancer (37.9%) (see Table 1).

The majority of participants were classified as having adequate health literacy (61%), with 25.5% in the marginal and 13.5% in the low health literacy category. Higher levels of health literacy were associated with being younger [$\chi^2(8)= 41.9, p<0.001$], white ethnicity [$\chi^2(2)= 8.4, p<0.05$], lower

³ However, six participants had data present for the symptom awareness analyses, but were missing data on barriers to medical help-seeking. Therefore n=445 for the barriers to medical help-seeking analyses.

deprivation [$\chi^2(6)= 14.9, p<0.05$] and higher education [$\chi^2(4)= 70.9, p<0.001$]. There were no differences related to familiarity with gynaecological cancer [$p=0.09$].

Insert Table 1

Gynaecological Cancer Symptom Awareness

Health literacy was associated with symptom awareness at T1 ($F [2,438]=3.3, p<0.05, \eta_p^2=0.02$) and at T2 ($F[2,438]=25.0, p<0.001, \eta_p^2=0.1$). Table 2 shows estimated marginal mean scores for each of the health literacy groups, and their respective confidence intervals at T1 and T2. There were no clear differences between the health literacy groups at T1 as the confidence intervals all overlapped with each other. Pairwise comparisons indicated no statistically significant differences between the individual health literacy groups, although differences between the low and adequate health literacy groups approached significance ($p=0.06$). At T2 there was a graded association between health literacy and symptom awareness, with significant differences between all three groups ($p<0.05$) and no overlapping confidence intervals (see Table 2). Women in the low health literacy group had the lowest awareness and those in the adequate health literacy group had the highest awareness. The partial eta squared values indicate a larger effect size for health literacy at T2 than at T1.

In order to explore whether health literacy facilitated knowledge acquisition, we used a repeated measures ANCOVA with symptom awareness over time as the dependent variable, and health literacy as the independent variable. There was a significant increase in symptom awareness from T1 ($M=5.8, SD=6.0$) to T2 ($M=8.8, SD=4.9$), ($F[1,438]=113.7, p<0.001, \eta_p^2=0.2$) and the partial eta squared value indicated a large effect size (Cohen, 1988). There was a significant interaction between health literacy and symptom awareness ($F[2,438]=5.3, p<0.01, \eta_p^2=0.02$), although this was a small effect. Figure 1 illustrates the health literacy and awareness interaction. The steeper slope for the

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adequate health literacy group than the marginal and low health literacy groups indicates a larger increase in symptom awareness for this group from T1 to T2. Mean change scores for the adequate health literacy group (3.76) and marginal health literacy group (3.16) were larger than the low health literacy group (2.10).

Insert Table 2 and Figure 1

Barriers to medical help-seeking

Health literacy was not associated with the total number of barriers to medical help-seeking reported at T1 ($F[2,434]=2.4$, $p=0.10$, $\eta_p^2=0.01$). However, at T1 there were significant differences across health literacy groups in the number of practical barriers reported ($F[2,434]=4.5$, $p<0.01$, $\eta_p^2=0.02$) and service barriers approached significance ($F[2,434]=3.0$, $p=0.052$, $\eta_p^2=0.01$). There was no association between health literacy and emotional barriers ($F[2,434]=0.2$, $p=0.84$, $\eta_p^2=0.00$).

At T2, there was no association between the total number of barriers to medical help-seeking and health literacy ($F[2,434]=0.1$, $p=0.95$, $\eta_p^2=0.00$) and no association seen for any of the sub-scales (service: ($F[2,434]=0.3$, $p=0.77$, $\eta_p^2=0.00$), practical: ($F[2,434]=0.6$, $p=0.58$, $\eta_p^2=0.00$), emotional: ($F[2,434]=0.7$, $p=0.52$, $\eta_p^2=0.00$). Table 2 shows the mean barriers to medical help-seeking scores for each health literacy group at both time points.

A repeated measures ANCOVA demonstrated a significant decrease in total barriers to medical help-seeking from T1 ($M=3.3$, $SD=4.5$) to T2 ($M=2.6$, $SD=4.5$), ($F[1,434]=17.6$, $p<0.001$, $\eta_p^2=0.04$), although the effect size was small (Cohen, 1988). All types of barriers decreased significantly (practical: ($F[1,434]=3.9$, $p<0.05$, $\eta_p^2=0.01$), service: ($F[1,434]=23.4$, $p<0.001$, $\eta_p^2=0.05$), emotional: ($F[1,434]=6.2$, $p<0.01$, $\eta_p^2=0.01$). There was also a significant interaction between total

barriers and health literacy ($F[2,434]=5.1$, $p<0.01$, $\eta_p^2=0.02$). Figure 2 shows a reduction in barriers from T1 to T2 for the adequate and marginal health literacy groups (respective mean change scores: -1.1, -0.6), but little change for the low health literacy group (mean change = -0.3).

Further analysis of the different types of barriers to medical help-seeking demonstrated no significant interactions between health literacy and practical ($F[2,434]=2.4$, $p=0.09$, $\eta_p^2=0.01$) or emotional barriers ($F[2,434]=2.6$, $p=0.08$, $\eta_p^2=0.01$), but there was a significant interaction between health literacy and service related barriers ($F[2,434]=3.4$, $p<0.05$, $\eta_p^2=0.02$). Similarly to the overall total barriers results, the adequate health literacy group showed the greatest reduction in service related barriers to medical help-seeking from T1 to T2 (mean change = -0.47) with smaller reductions for the marginal and low health literacy groups (respective mean change = -0.28 and -0.21).

Insert Figure 2

Discussion

In this community-based study in the UK, a written information leaflet significantly improved awareness of gynaecological cancer symptoms and reduced perceived barriers to medical help-seeking, however, there were differences in the effectiveness of the leaflet between health literacy groups.

Symptom awareness at baseline and follow-up were significantly different across the health literacy groups with a graded association with health literacy, such that women with adequate health literacy had the highest symptom awareness and those with low health literacy had the lowest levels of symptom awareness (although these differences only reached statistical significance at T2). There

were no significant differences between health literacy groups at baseline or follow up in the total reported barriers to medical help-seeking.

The important result was that the effectiveness of the intervention was moderated by health literacy, with a smaller increase in symptom awareness, and a smaller decrease in total barriers to medical help-seeking, in women with lower health literacy. Interestingly, in the barriers sub-analysis, there was a significant interaction between health literacy and service related barriers, with women with adequate health literacy showing a greater reduction than the marginal or low health literacy groups. This pattern was not observed for the practical or emotional barriers, where comparable reductions between the health literacy groups were found.

While previous estimates of health literacy have been made in the UK population (von Wagner et al., 2007), this is among the first to use the UK NVS. In this sample, 13.5% of women had low health literacy, 25.5% had marginal health literacy and 61% had adequate health literacy. The prevalence of low health literacy is in line with the levels of general literacy in England (Department of Business, Innovation and Skills, 2011). Individuals with low health literacy were more likely to be older, less educated, from a lower SES group and of non-white ethnicity. The differences in the measures used, and the female-only sample, suggests care should be taken when comparing prevalence estimates with previous findings (e.g. von Wagner et al., 2007), but the associations with socio-demographic variables are in the expected directions.

Research is ongoing to explore the levels of gynaecological cancer awareness in the UK female population (e.g. Low et al, 2012, submitted), and this study adds to our knowledge. At baseline, women were able to recognise fewer than 6 symptoms of gynaecological cancer, and cited at least three barriers to medical help-seeking. Our findings and those of others, suggest a lack of public awareness of gynaecological cancer symptoms and significant barriers to seeking medical help which are likely to be contributing to delay in diagnosis in the UK.

Our findings add to a large body of research showing that health literacy is associated with knowledge of health conditions (Fransen et al., 2011; Sobel et al., 2009; Ussher et al., 2010). However, health literacy was not directly associated with barriers to medical help-seeking at either time point in this study. This finding contributes to an on-going debate within the field of health literacy regarding construct definition (Baker, 2006). Some researchers have chosen to interpret health literacy as the capacity of the individual to acquire, process and evaluate new health information (Wolf et al., 2009), while others have argued that motivation should form a part of the construct (Nutbeam, 1998). Our analysis of barriers to help-seeking support viewing health literacy (as measured by the NVS) as a skills-based construct, and one that is not necessarily directly associated with volitional and socio-cognitive constructs. For example, we found no differences at T2 for the emotional (e.g. embarrassment) and practical (e.g. busy lifestyle) barriers, but there was a significant interaction between health literacy and service barriers, which may reflect skills such as making appointments and communicating with healthcare professionals. This pattern of results would be expected if health literacy measures a person's ability to function adequately in a healthcare environment, rather than their motivation to do so.

The findings presented here will be of interest to researchers investigating the area of symptom awareness. Previous studies have shown cancer awareness differs by levels of social deprivation (Power, Simon, Judzcyk, Hiom, & Wardle, 2011; Robb et al., 2009), but health literacy has received little attention in this literature thus far. This study is among the first to demonstrate differences in awareness across health literacy groups. Attempts to improve awareness of cancer symptoms should consider how to optimise interventions for all health literacy groups. For example, additional resources using alternative media (e.g. supplementary multimedia material) or more intensive healthcare professional support as seen elsewhere (e.g. Linsell et al., 2009) may be required if low health literacy groups are to achieve the same amount of gains from public health interventions (Clement, Ibrahim, Crichton, Wolf, & Rowlands, 2009; Sheridan, Halpern, & Viera, et al., 2011).

Achieving this in a cost-effective manner may be difficult, although large-scale multimedia symptom awareness interventions are being implemented (Richards, 2011).

A strength of this study is that large changes were demonstrated in awareness and barriers to medical help-seeking which were achieved with a low intensity intervention that could be implemented within existing National Health Service resources. A second strength of the research is the use of a prospective design, which though it does not guarantee causality, does give insight into the potential mechanisms that could underlie changes in symptom presentation behaviour when the leaflet is utilised, for example, in a primary care setting. A further strength is that this is among the first studies to use the UK version of the NVS in a community setting. Although the NVS has undergone testing of criterion validity through comparison with other tests of health literacy validated for use in the UK, such as the UK TOFHLA (von Wagner et al., 2007) and the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al., 1993; Ibrahim et al., 2008), the associations with symptom awareness found in this study provide predictive validity for the measure.

This study has limitations. The lack of behavioural data prohibits us from inferring that the higher levels of awareness and reduced barriers to medical help-seeking will translate into more prompt help-seeking. However, such findings are supported by a number of frameworks (e.g. Andersen, Cacioppo, & Roberts, 1995; Scott & Walter, 2010). Because of time limitations for participants, we were unable to measure other aspects of knowledge acquisition, for instance, by assessing participants' comprehension of gynaecological cancer symptoms and barriers to medical help-seeking through assessing anticipated time to help-seeking for gynaecological cancer symptoms. This has been planned for future evaluations of the leaflet. As noted, a prospective study design was used, but the very short time scale of assessment was a limitation. In particular, it is difficult to quantify the importance of the health literacy effect, and a longer term follow-up could have demonstrated whether the effects were transient or persistent as has been done in other studies (e.g. Linsell et al., 2009). Lastly, the population recruited for this study could be considered to have a vested interest in

learning about the disease because of their high likelihood of knowing someone with a gynaecological cancer. This could reduce the generalizability of our findings to the general population. However, the aim of this study was to demonstrate the potential efficacy of such an intervention and thus it constitutes a key part of the development process. The next stage of the research process will be conducted within the general population in a primary care setting.

In conclusion, this study reported on the efficacy of a written information leaflet to promote symptom awareness and reduce barriers to medical help-seeking. **Low health literacy individuals were considered to benefit less from the intervention itself as they displayed smaller increases in symptom awareness and smaller reductions in barriers to medical help-seeking after viewing the leaflet when compared to marginal and adequate health literacy groups.** While the intervention was successful in increasing awareness and reducing barriers to medical help-seeking across all health literacy groups, more intensive interventions involving healthcare professional interaction or alternative media (e.g. supplementary multimedia material) may be needed to ensure inequalities are not exacerbated by future public health interventions, with specific focus on the needs of people with low health literacy.

References

Andersen, B. L., Cacioppo, J. T., & Roberts, D. C. (1995). Delay in seeking a cancer diagnosis: delay stages and psychophysiological comparison processes. *British Journal of Social Psychology*, 34(1), 33–52.

- Austoker, J., Bankhead, C., Forbes, L. J. L., Atkins, L., Martin, F., Robb, K., . . . Ramirez, A.J. (2009). Interventions to promote cancer awareness and early presentation: systematic review. *British Journal of Cancer*, *101*, S31-S39.
- Baker, D. W. (2006). The Meaning and the Measure of Health Literacy. *Journal of General Internal Medicine*, *21*(8), 878-883.
- Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., & Crotty, K. (2011). Low health literacy and health outcomes: an updated systematic review. *Annals of Internal Medicine*, *155*(2), 97–107.
- Boundouki, G., Humphris, G., & Field, A. (2004). Knowledge of oral cancer, distress and screening intentions: longer term effects of a patient information leaflet. *Patient Education and Counseling*, *53*(1), 71-77.
- Cancer Research UK (2008). *Cancer statistics for the UK*. Retrieved on 18th January 2012, from <http://info.cancerresearchuk.org/cancerstats/>
- Clement, S., Ibrahim, S., Crichton, N., Wolf, M., & Rowlands, G. (2009). Complex interventions to improve the health of people with limited literacy: A systematic review. *Patient Education and Counseling*, *75*(3), 340-351.
- Cochran, S.D., Hacker, N.F., & Berek, J. (1986). Correlates of Delay in Seeking Treatment for Endometrial Cancer. *Journal of Psychosomatic Obstetrics and Gynecology*, *5* (4), 245.
- Cohen, J. (1988) *Statistical power for the behavioral sciences*. Erlbaum, Hillsdale, NJ.
- Davis, T. C., Long, S. W., Jackson, R. H., Mayeaux, E. J., George, R. B., Murphy, P. W., & Crouch, M. A. (1993). Rapid estimate of adult literacy in medicine: a shortened screening instrument. *Family Medicine*, *25*(6), 391-395.
- de Nooijer, J., Lechner, L., Candel, M., & de Vries, H. (2004). Short- and long-term effects of tailored information versus general information on determinants and intentions related to early detection of cancer. *Preventive Medicine*, *38*(6), 694-703.

Department for Business Innovations and Skills. (2011). *Skills for Life Survey: Headline Findings*. BIS Research Paper number 57. London, UK.

Department of Health. (2011). *Improving outcomes: a strategy for cancer*. Department of Health.

Retrieved on 10th January 2012 from,

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_123371

Fitch, M., Deane, K., Howell, D. & Gray, R.E. (2002) Women's experiences with ovarian cancer: reflections on being diagnosed. *Canadian Oncology Nursing Journal*. 12 (3). 152- 68.

Flesch, R. (1948). A new readability yardstick. *The Journal of Applied Psychology*, 32(3), 221-233.

Fransen, M. P., von Wagner, C., & Essink-Bot, M. L. (in press). Diabetes self-management in patients with low health literacy: Ordering findings from literature in a health literacy framework. *Patient Education and Counseling*.

Garner, M., Ning, Z., & Francis, J. (in press). A framework for the evaluation of patient information leaflets. *Health Expectations*.

Ibrahim, S. Y., Reid, F., Shaw, A., Rowlands, G., Gomez, G. B., Chesnokov, M., & Ussher, M. (2008). Validation of a health literacy screening tool (REALM) in a UK Population with coronary heart disease. *Journal of Public Health*, 30(4), 449-455.

Kidanto, H.L., Kilewo, C.D. & Moshiro, C. (2002). Cancer of the cervix: knowledge and attitudes of female patients admitted at Muhimbili National Hospital, Der Es Salaam. *East African Medical Journal*. 79 (9). 467- 475.

Kutner, M., Greenberg, E., Jin, Y., Paulsen, C., & White, S. (2007). *Literacy in everyday life: Results from the 2003 National Assessment of Adult Literacy*. Washington, DC: US Department of Education.

Lindau, S. T., Tomori, C., Lyons, T., Langseth, L., Bennett, C. L., & Garcia, P. (2002). The association of health literacy with cervical cancer prevention knowledge and health behaviors in a

- multiethnic cohort of women. *American Journal of Obstetrics and Gynecology*, 186(5), 938-943.
- Linsell, L., Forbes, L. J. L., Kapari, M., Burgess, C., Omar, L., Tucker, L., & Ramirez, A. J. (2009). A randomised controlled trial of an intervention to promote early presentation of breast cancer in older women: effect on breast cancer awareness. *Br J Cancer*, 101(S2), S40-S48.
- Low, E.L., Simon, A.E., Lyons, J., Romney-Alexander, D., & Waller., J. What do British women know about cervical cancer symptoms and risk factors? *European Journal of Cancer*. Submitted 2012.
- McCann, S., & Weinman, J. (1996). Empowering the patient in the consultation: a pilot study. *Patient Education and Counseling*, 27(3), 227-234.
- McLaughlin, G. H. (1969). SMOG grading: A new readability formula. *Journal of Reading*, 12(8), 639-646.
- Nutbeam, D. (1998). Health promotion glossary. *Health Promotion International*, 13(4), 349-364.
- Parker, R. M., Baker, D. W., Williams, M. V., & Nurss, J. R. (1995). The test of functional health literacy in adults. *Journal of general internal medicine*, 10(10), 537-541.
- Power, E., Simon, A.E., Judczyk, D, Hiom, S, & Wardle, J. (2011). Assessing awareness of colorectal cancer symptoms: Measure development and results from a population survey in the UK, *BMC Cancer*, 11(366).
- Ratzan, S. C., & Parker, R. M. (2000). Introduction. *National Library of Medicine current bibliographies in medicine: Health literacy* (pp. 19-30). Bethesda, MD: National Institutes of Health, U.S Department of Health and Human Services.
- Richards, M. A. (2009). The National Awareness and Early Diagnosis Initiative in England: assembling the evidence. *British Journal of Cancer*, 101(S2), S1-S4.
- Richards, M. (2011). Be clear on cancer: national campaign to promote earlier diagnosis of bowel cancer. Retrieved on 12th January 2012 from, <http://www.dh.gov.uk/health/2011/11/bowel-cancer-letter/>

- Rimer, B. K., Halabi, S., Sugg Skinner, C., Lipkus, I. M., Strigo, T. S., Kaplan, E. B., & Samsa, G. P. (2002). Effects of a mammography decision-making intervention at 12 and 24 months. *American Journal of Preventive Medicine, 22*(4), 247-257.
- Robb, K., Stubbings, S., Ramirez, A., Macleod, U., Austoker, J., Waller, J., . . . Wardle, J. (2009). Public awareness of cancer in Britain: a population-based survey of adults. *British Journal of Cancer, 101*(S2), S18-S23.
- Rowlands, G., Khazaezadeh, N., Oteng-Ntim, E., Seed, P., Barr, S., & Weiss, B. D. (Submitted) Validation of a measure of Health Literacy in the UK: the Newest Vital Sign.
- Scott, S., & Walter, F. (2010). Studying Help-Seeking for Symptoms: The Challenges of Methods and Models. *Social and Personality Psychology Compass, 4*(8), 531-547.
- Simon, A.E., Wardle, J., Grimmett, C., Power, E., Corker, E., Menon, U., . . . Waller, J. (in press) Ovarian and cervical cancer awareness: development of two validated measurement tools. *Journal of Family Planning and Reproductive Health Care.*
- Sheridan, S.L., Halpern, D.J., Viera, A.J., Berkman, N.D., Donahue, K.E., & Crotty, K. (2011) Interventions for individuals with low health literacy: A systematic review. *Journal of Health Communication, 16*: S30-54.
- Sobel, R. M., Paasche-Orlow, M. K., Waite, K. R., Rittner, S. S., Wilson, E. A. H., & Wolf, M. S. (2009). Asthma 1-2-3: a low literacy multimedia tool to educate African American adults about asthma. *Journal of Community Health, 34*(4), 321-327.
- Stubbings, S., Robb, K., Waller, J., Ramirez, A., Austoker, J., Macleod, U.,...Wardle, J. (2009). Development of a measurement tool to assess public awareness of cancer. *British journal of cancer, 101*, S13–S17.
- Tabachnick, B.G. & Fidell, L.S. (1996) *Using Multivariate Statistics* (3rd Edition.) New York: Harper Collins.
- Target Ovarian Cancer. (2009). Initial Results - Target Ovarian Cancer. Retrieved April 18, 2012, from <http://www.targetovariancancer.org.uk/page.asp?section=424&search=>

- Thomson, C. S., & Forman, D. (2009). Cancer survival in England and the influence of early diagnosis: what can we learn from recent EUROCARE results? *British Journal of Cancer*, *101*, S102-109.
- Ussher, M., Ibrahim, S., Reid, F., Shaw, A., & Rowlands, G. (2010). Psychosocial Correlates of Health Literacy Among Older Patients With Coronary Heart Disease. *Journal of Health Communication*, *15*(7), 788-804.
- von Wagner, C., Knight, K., Steptoe, A., & Wardle, J. (2007). Functional health literacy and health-promoting behaviour in a national sample of British adults. *Journal of Epidemiology and Community Health*, *61*(12), 1086 -1090.
- von Wagner, C., Semmler, C., Good, A., & Wardle, J. (2009). Health literacy and self-efficacy for participating in colorectal cancer screening: The role of information processing. *Patient Education and Counseling*, *75*(3), 352–357.
- Weiss, B. D., Mays, M. Z., Martz, W., Castro, K. M., DeWalt, D. A., Pignone, M. P., . . . Hale, F.A. (2005). Quick assessment of literacy in primary care: the newest vital sign. *The Annals of Family Medicine*, *3*(6), 514–522.
- Wilson, E. A. H., & Wolf, M. S. (2009). Working memory and the design of health materials: a cognitive factors perspective. *Patient Education and Counseling*, *74*(3), 318-322.
- Wilt, T. J., Paul, J., Murdoch, M., Nelson, D., Nugent, S., & Rubins, H. B. (2001). Educating men about prostate cancer screening. A randomized trial of a mailed pamphlet. *Effective Clinical Practice: ECP*, *4*(3), 112-120.
- Wolf, M. S., Wilson, E. A. H., Rapp, D. N., Waite, K. R., Bocchini, M. V., Davis, T. C., & Rudd, R. E. (2009). Literacy and Learning in Health Care. *Pediatrics*, *124*, S275-S281.

Table 1. Demographic characteristics of sample by health literacy group

	Low Health Literacy (n= 61)	Marginal Health Literacy (n=115)	Adequate Health literacy (n=275)	Total Sample (n=451)
	n (%)	n (%)	n (%)	n (%)
Age Group*				
18-30	6 (4.8)	24(19.2)	95 (76.0)	125 (27.7)
31-40	5 (5.7)	24 (27.6)	58 (66.7)	87 (19.3)
41-50	12 (13.6)	23 (26.1)	53 (60.2)	88 (19.5)
51+	22 (22.4)	28 (28.6)	48 (49.0)	98 (21.7)
Missing ^a	16 (30.2)	16 (30.2)	21 (39.6)	53 (11.8)
Ethnic Group*				
White	39 (11.6)	79 (23.6)	217 (64.8)	335 (74.3)
Other	22 (19.0)	36 (31.0)	58 (50.0)	116 (25.7)
Deprivation*				
Low	15 (7.4)	52 (25.6)	136 (67.0)	203 (45.0)
Medium	26 (17.0)	43 (28.1)	84 (54.9)	153 (33.9)
High	10 (20.0)	12 (24.0)	28 (56.0)	50 (11.1)
Missing ^a	10 (22.2)	8 (17.8)	27 (60.0)	45 (10.0)
Education*				
< degree level	30 (17.6)	60 (35.3)	80 (47.1)	170 (37.7)
> degree level or equivalent	18 (7.0)	47 (18.4)	191 (74.6)	256 (56.8)
Missing ^a	13 (52.0)	8 (32.0)	4 (16.0)	25 (5.5)
Familiar with gynaecological cancer				
No	38 (13.8)	61 (22.2)	176 (64.0)	275 (61.0)
Yes	21(12.3)	52 (30.4)	98 (57.3)	171 (37.9)
Missing	2 (40.0)	2 (40.0)	1 (20.0)	5 (1.1)

*Included as covariates in final analyses

^a Number of participants for which there was missing data on this variable. These participants were kept in the analyses by creating a separate response category in the variable.

Table 2. Adjusted means of symptom recognition scores and barriers to medical help-seeking across health literacy groups before and after the intervention

		Recognition of symptoms ^a	Barriers to medical help-seeking			
			Total ^b	Emotional ^c	Practical ^d	Service ^d
Health Literacy group	Mean	Mean	Mean	Mean	Mean	
	(95% CI)	(95% CI)	(95% CI)	(95% CI)	(95% CI)	
Pre-intervention (T1)	Low	5.25	2.92	1.27	0.59	1.07
		(4.39- 6.12)	(2.27- 3.57)	(0.90-1.64)	(0.37-0.81)	(0.81- 1.32)
	Marginal	5.79	3.17	1.39	0.73	1.05
		(5.03- 6.55)	(2.60- 3.74)	(1.07-1.72)	(0.54- 0.92)	(0.83-1.28)
	Adequate	6.46	3.64	1.40	0.94	1.31
		(5.75- 7.18)	(3.11- 4.18)	(1.09-1.71)	(0.76-1.12)	(1.10-1.52)
Post-intervention (T2)	Low	7.35	2.67	1.24	0.58	0.85
		(6.65- 8.06)	(2.01- 3.33)	(0.88- 1.59)	(0.35- 0.81)	(0.61- 1.10)
	Marginal	8.95	2.53	1.17	0.60	0.77
		(8.33- 9.57)	(1.96- 3.11)	(0.86- 1.48)	(0.40- 0.80)	(0.55-0.98)
	Adequate	10.22	2.55	1.03	0.69	0.83
		(9.64- 10.80)	(2.01- 3.09)	(0.74- 1.32)	(0.50- 0.88)	(0.63- 1.03)

^a Range of scores 0-12. Higher scores indicate higher symptom awareness.

^b Range of scores 0-10. Higher scores indicate higher total barriers to medical help-seeking.

^c Range of scores 0-4. Higher scores indicate higher emotional barriers to medical help-seeking.

^d Range of scores 0-3. Higher scores indicate higher practical/ service related barriers to medical help-seeking.

Controlling for age, ethnicity, education and IMD scores.

Figure 1. Change in symptom awareness for each health literacy group from T1 to T2

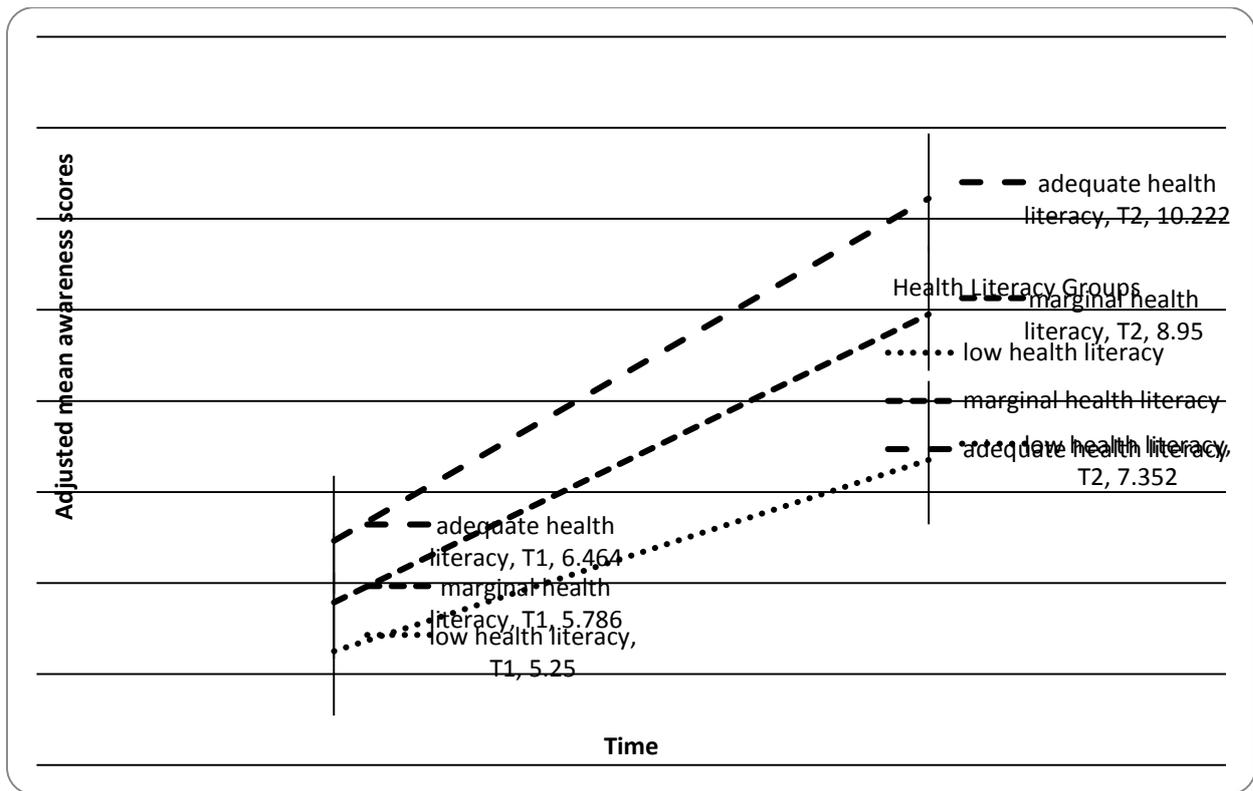
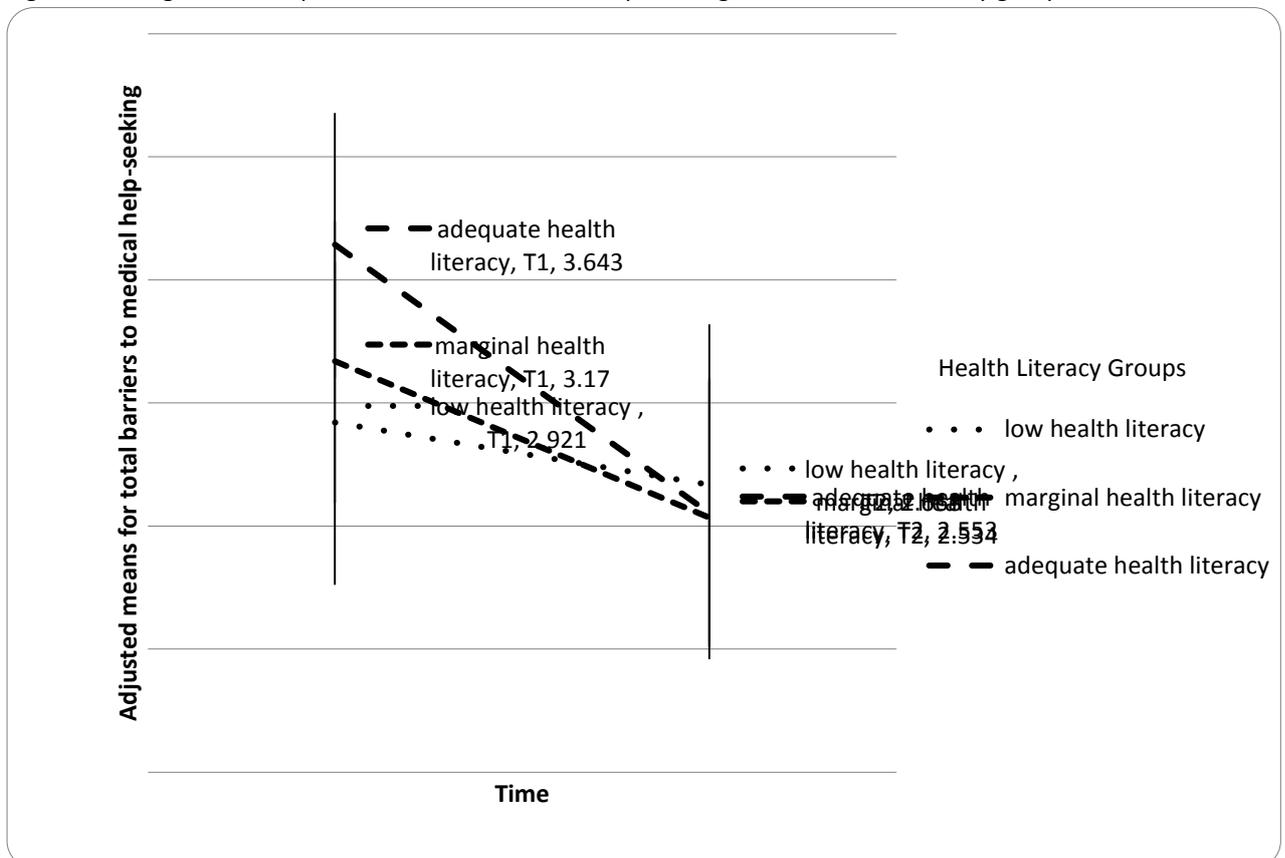


Figure 2. Change in total reported barriers to medical help-seeking for each Health literacy group from T1 to T2



Appendix: Symptom awareness questionnaire items

The following may or may not be warning signs for gynaecological cancers. We are interested in your opinion. For each one, please say whether you think that it is a warning sign for gynaecological cancer by ticking the relevant box:

	Yes	No	Don't know
Pelvic/abdominal pain that doesn't go away	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vaginal bleeding between periods	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Longer or heavier periods than usual	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lower back pain that doesn't go away	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Persistent vaginal discharge with an unpleasant odour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bleeding after the menopause	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Soreness or lump on the vulva (outer part of vagina)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bloating / swollen tummy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Loss of appetite / feeling full quickly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain/ discomfort during sex	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Persistent diarrhoea or other changes in bowel habits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Needing the toilet more often or more urgently	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>