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England

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# **National Cancer Registration and Analysis Service**

## **Be Clear on Cancer: Regional Ovarian Cancer Awareness Campaign 2014**

Final evaluation results

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**Public Health England (PHE)**  
**National Cancer Registration and Analysis Service (NCRAS)**  
**Be Clear on Cancer: Regional ovarian cancer awareness campaign 2014**

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Data for this study is based on patient-level information collected by the NHS, as part of the care and support of cancer patients. The data is collated, maintained and quality assured by the National Cancer Registration and Analysis Service, which is part of Public Health England (PHE).

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# 1. Foreword

It gives me great pleasure to introduce this report on the impact of the Be Clear on Cancer regional ovarian cancer awareness campaign which ran from February 2014 to March 2014. It represents the culmination of a huge amount of work by staff in PHE, the Department of Health and Social Care (DHSC) and NHS England (NHSE), together with significant contributions from partner organisations, particularly Cancer Research UK. I would like to thank all involved in this innovative programme. A complex range of analyses and interpretations of data from many sources provide us with insight into the potential impact of the ovarian regional campaign across the patient pathway.

This document examines the evaluation metrics published on the NCRAS website and takes a close look at the findings in the wider context of what we know about ovarian cancer and early diagnosis. The results are not straightforward to interpret. What is clear is that this campaign was successful in raising awareness of bloating as being a symptom of ovarian cancer and prompted more women of all ages to see their GPs with this symptom. This in turn triggered increases in urgent GP referrals for suspected cancer, most notably in those under 50 years of age. However, this is balanced against the fact that we have not been able to demonstrate an improvement in the number of cancers diagnosed or stage at diagnosis as a result of the campaigns. These outcomes are discussed in more detail later in the report under 'Discussion and conclusions'.

Since its creation in 2011, Be Clear on Cancer has become a well-established, award-winning brand, working to improve cancer outcomes and reduce health inequalities. The Independent Cancer Taskforce supported our work in the [2015 Strategy for England](#), recognising how Be Clear on Cancer is making a real difference to people's lives by increasing awareness that many cancers are treatable if caught early. Early diagnosis is crucial to improving outcomes from cancer and other serious diseases. Be Clear on Cancer is part of the national drive to tackle cancer, contributing towards making earlier diagnosis a reality for the thousands of people diagnosed with cancer each year.

The Be Clear on Cancer programme is run by PHE in partnership with DHSC and NHSE, working closely with Cancer Research UK, clinical colleagues and the wider academic and charity sectors.

PHE has been responsible for the development, marketing and evaluation of all campaigns run since April 2013. They have carried out careful evaluation, often using bespoke analyses of complex datasets in order to establish the impact of the campaigns.

**Professor Chris Harrison**

**National Clinical Director for Cancer, NHS England**

**Chair of the Be Clear on Cancer Steering Group (April 2016 to September 2018)**

## Note: Structure of report

This report has been written with a wide range of audiences in mind and includes many sets of individual results and analyses. If read in full, it is very long. It has therefore been divided into clear sections, not all of which will be of interest to every reader. The 'Executive summary' outlines all the major findings and is followed by the main body of the report which gives details of individual results and discusses the extent of campaign impact within the context of the overall patient pathway.

NCRAS also provides a separate paper, 'Be Clear on Cancer evaluation metrics: methodology', which may be of interest as a reference source to some readers. The paper is available on [the NCRAS Be Clear on Cancer webpage](#).

## 2. Executive summary

Ovarian cancer affects 6,300 women in England each year with an associated 3,500 deaths. This makes ovarian cancer the most lethal of the gynaecological malignancies, in part because most women will present when the disease has already disseminated. However, ovarian cancer is a relatively rare condition with a 1:70 lifetime risk.

The objectives of the Be Clear on Cancer (BCoC) campaign were to raise awareness in women and family doctors of the symptoms associated with ovarian cancer, and through this detect the disease at an early and less lethal stage. The following summarises the main findings from the campaign which ran in the North West of England (Merseyside & Cheshire, Greater Manchester, Lancashire and South Cumbria) from February 2014 to March 2014.

### 2.1 Campaign recognition and public awareness

In both the campaign and control regions 77% of respondents were aware of cancer advertising or publicity before the campaign. Awareness at the post-campaign stage increased significantly (to 87%), the same effect was not seen in the control region suggesting that the BCoC campaign contributed to this rise.

In the campaign region, 76% of respondents recognised at least one of the ovarian cancer campaign materials. Recognition levels of the ovarian cancer television and radio advertisements were the highest of any BCoC regional campaigns, while the press/poster advertisements had below average recognition and the leaflets performed in line with average. This indicates that the television and radio advertisements benefitted from the combined effect of both having a similar storyline.

### 2.2 GP attendances

There was a statistically significant increase in GP attendances for symptoms highlighted by the campaign and/or unexplained bloating by women over the age of 50 years in the campaign area, from 22.9 per week in the control period to 50.0 per week with the introduction of the campaign,  $p=0.001$ .

### 2.3 Urgent GP referrals for suspected gynaecological cancers

Urgent GP referrals increased during the campaign by 14.2% to 34.5% depending on the age group. All age groups had a statistically significant increase in urgent GP

referrals, though the highest increase at 34.5% was noted in the population aged under 50 years of age.

#### 2.4 Ovarian cancer diagnoses resulting from an urgent GP referral for suspected gynaecological cancers

The campaign had no impact on the numbers of gynaecological or ovarian cases diagnosed via urgent GP referrals, also known as Two Week Wait referrals (TWW).

#### 2.5 Conversion rate (percentage of urgent GP referrals for suspected gynaecological cancer resulting in a cancer diagnosis)

The campaign had no effect on the conversion rates from urgent GP referrals of suspected ovarian and other types of gynaecological cancers.

#### 2.6 Ovarian cancer diagnoses recorded in the Cancer Waiting Times database

No statistically significant changes occurred within the campaign region. Although there were no increases in ovarian cancer diagnoses, in those under 50 years of age there was an increase in the diagnosis of gynaecological cancers.

#### 2.7 Detection rate (percentage of ovarian cancer diagnoses recorded in the Cancer Waiting Times database resulting from an urgent GP referral for suspected gynaecological cancer)

The detection rate of an ovarian or gynaecological cancer, by age-group, remained unaffected by the campaign.

#### 2.8 Emergency presentations

The campaign did not appear to have an impact on the proportion of women diagnosed with ovarian cancer accessing care via the emergency route. The proportions of women with ovarian cancer diagnosed via emergency presentation during the regional ovarian campaign period were 22% in February 2014 and 35% in March 2014 compared to 24% and 36% for the same months in 2013.

## 2.9 Diagnostic tests

Between April to July 2013 and February to May 2014, there were no statistically significant changes in the number of diagnostic imaging tests (ultrasounds, CT scans, and MRI scans) performed for those aged 50 years and over, and all ages combined.

Compared with a similar period in 2013, the regional campaign in 2014 resulted in a statistically significant increase in serum CA125 testing with the average number of CA125 tests for women of all ages increasing by 80%. Women aged 50 years and over had a 54% increase and women aged under 50 years of age had a 123% increase in testing. There was also an increase in the pre-campaign period when compared to the previous year, although this was not as large as the increase observed during the campaign.

## 2.10 Cancers diagnosed

The regional ovarian campaign does not appear to have had an impact on the numbers of ovarian cancers diagnosed.

## 2.11 Early stage at diagnosis

There was no sustained period where the proportion of cases diagnosed with early stage ovarian cancer during or following the campaign period were the same as, or higher than, the expected proportion for the year.

## 2.12 One-year survival rates

There were no significant differences in one-year survival for women aged 50 years and over diagnosed with ovarian cancer between the analysis period and control period. One-year survival for women diagnosed during the analysis period was 68.5% compared with 69.1% for those diagnosed in the control period.

## 2.13 Overall conclusions

The campaign was successful in delivering the message regarding the symptoms of ovarian cancer as reflected in:

1. The statistically significantly increased number of women attending their GPs
2. Increases in referrals to secondary care
3. Increases in the utilisation of CA125 serum tests for detecting ovarian cancer

However, the overall impact of the campaign was greatest in the under-50 years age group, where ovarian cancer is rare, compared to those over 50 years of age. The campaign did not appear to have an impact on the number of cancers diagnosed or result in a stage shift; this is not unexpected for a regional campaign where there are small numbers of ovarian cancers diagnosed resulting in low statistical power to detect an impact.

The main factors which can explain what happened during this campaign are the non-specific nature of ovarian symptoms, the fact that the campaign's message influenced the under- rather than over-50 years age group, small numbers of ovarian cancers diagnosed resulting in low statistical power to detect an impact, and importantly, the recognition now, verified subsequent to the completion of the campaign, that the majority of ovarian cancers originate in the fallopian tubes. Thus, tests which focus on detecting ovarian pathology and associated symptoms are actually targeting disease which has spread from the fallopian tubes, rather than 'early' stage ovarian disease. The development of methods to detect early stage disease in the fallopian tube is now the next challenge for the clinical community.



## 3. Background to the campaign

### 3.1 History of campaign

The objective of the Be Clear on Cancer (BCoC) ovarian campaign was to increase public awareness of the symptoms of ovarian cancer, with the purpose of encouraging women to seek help earlier from their family doctor, and consequentially enabling diagnosis and intervention at an earlier disease stage to help improve clinical outcomes. The Independent Cancer Taskforce target was to achieve a further 30,000 patients each year surviving their cancer for 10 years or more, by 2020; earlier diagnosis in cancers has been estimated to contribute significantly (11,000) to this target.

The BCoC brand has been used to promote awareness and early diagnosis of specific cancer types since January 2011. The ovarian cancer local campaign pilot was developed using the BCoC branding and ran from 14 January to 17 March 2013. The programme is led by Public Health England (PHE), working in partnership with the Department of Health and Social Care (DHSC) and NHS England (NHSE). BCoC campaigns are usually tested locally and then regionally, with a view to rolling them out nationally if they prove to be effective.

For each BCoC campaign there is a comprehensive evaluation process. Data is collected on a number of metrics to reflect possible campaign impact. These include whether campaigns are raising awareness of signs and symptoms of cancer, more people are going to their GPs with the symptoms highlighted by the campaign, more people are being referred urgently for suspected cancer, there is an increase in diagnostic activity, those referred urgently for suspected cancer are diagnosed with cancer, there are increases in the number of cancers diagnosed, and if there is evidence of a shift towards earlier stage disease and one-year survival.

### 3.2 Ovarian cancer awareness regional campaign

A local BCoC pilot campaign featuring the symptoms of ovarian cancer was developed and ran in 4 areas from 14 January to 17 March 2013. After evaluation of the local pilot campaign it was decided to develop a regional campaign.

The ovarian cancer awareness regional campaign ran in the North West of England (Granada TV region) from 10 February to 16 March 2014. The campaign's core message was 'Feeling bloated, most days, for three weeks or more could be a sign of ovarian cancer. Tell your doctor'.

The regional ovarian cancer campaign used a range of channels to target the age group most at risk of ovarian cancer – women 50 years old and over. These included television, radio, press, online and out of home advertising. The campaign also included face-to-face events in shopping centres, public relations activity and the distribution of leaflets via GP surgeries and other outlets such as pharmacies.

Advertising such as the poster shown below was used to inform women of symptoms potentially indicating ovarian cancer.



**Figure 1: Example of poster used during regional campaign.**

### 3.3 Choice of symptoms and messages

Symptoms of ovarian cancer include abdominal distension, feeling bloated, bowel disturbance, abnormal vaginal bleeding, loss of appetite, urinary frequency, weight loss and dyspnoea. From both prospective and retrospective studies (1), (2) there was consistency noted in the development of 'persistent bloating' as a symptom distinguishing ovarian cancer from other conditions. Therefore, the primary message for the general campaign was selected as:

"Feeling bloated, most days, for three weeks or more could be a sign of ovarian cancer. Tell your doctor".

## 4. Ovarian cancer

### 4.1 Background to the problem

Of all the gynaecological malignancies, ovarian cancer has the highest associated death rates. About 6,300 women are diagnosed and 3,500 die from this cancer each year in England (data obtained from National Cancer Registration dataset (3)). The disease in its early stage is mainly curable with surgery, and in selected situations, the addition of adjuvant chemotherapy improves cure rates. However, at presentation to a doctor, 75% of women will have advanced disease, where 5-year survival rates are poor at 40%.

Even though there is some evidence that physical symptoms aligned with ovarian cancer can be present some months or even years preceding a diagnosis, the reality remains that women only present with symptoms associated with disseminated disease (1), (4), (2). On average there is a 3-month time frame from a woman noting the symptoms before seeing her doctor, hence why the term 'the silent killer' is sometimes applied to ovarian cancer. Besides the woman's often limited awareness of potentially serious symptoms, the family doctor is equally challenged, as the symptoms of ovarian cancer are non-specific and easily misinterpreted as being associated with non-malignant and other medical conditions, most commonly bowel disorders. An additional confounding element is the fact that a family doctor in an average practice may only encounter 4 or 5 women with ovarian cancer in their working lifetime, which makes recognition of this disease even more difficult.

Over recent years, publications on survival outcomes in ovarian cancer have shown a consistently lower rate in the UK when compared with countries which have equitable registry data (5), (6). The largest difference is noted in the one-year survival rates – hypothesised to be due to late presentation. This is likely to be influenced by a variety of causes.

### 4.2 Risk factors

There are numerous risk factors associated with developing ovarian cancer, but the main ones are nulliparity (a woman who has never given birth), genetic or family history including BRCA (Breast Cancer gene) mutations, post-menopausal age and associations with other cancer such as breast cancer.

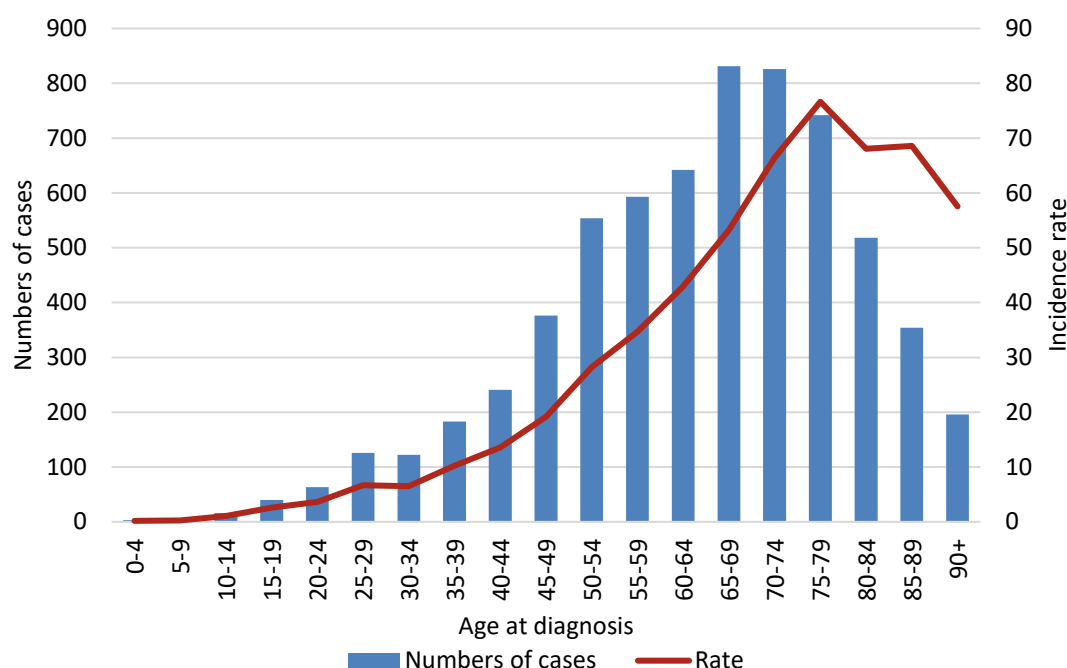
The original theory of ovarian cancer risk was that it was related to the number of ovulatory cycles a woman had in her lifetime. The greater the number, the higher the

probability of developing ovarian cancer. Supporting this theory was the evidence that cessation of ovulation, for example through use of the combined oral contraceptive pill, reduced the risk significantly. Indeed, the protective effect of the oral contraceptive pill can remain for decades from cessation of its use, and presently remains the main non-surgical preventative method available (7). Equally, women who have given birth have reduced incidence of ovarian cancer. The association was hypothesised to be related to the tissue damage which occurs with ovulation and invagination of cells into the ovarian stroma, all of which lead to a milieu conducive to malignant transformation.

In the 1990s, evidence of mutations in the BRCA1 and BRCA2 genes were eventually proven to be attributable to the higher ovarian incidence in certain families, and causative of about 15% of all ovarian cancers. For BRCA1, the lifetime risk of ovarian cancer is about 40% (compared to a general lifetime risk of 1/70) and for BRCA2, it is approximately 20% (8). In these women, the most effective preventative measure remains prophylactic surgery, in the form of bilateral salpingo-oophorectomy (9). Though not 100% efficacious the risk reduction is impressive at about 85-90%. BRCA mutational type tumours (those with 'BRCAness') have also been recognised. In proven disease with BRCA mutations and those with BRCAness, therapies are now available to target and utilise the deficiency to induce cellular apoptosis in these types of tumours (8).

### 4.3 Age

It is important that the disease incidence pertaining to age is emphasised. Ovarian cancer is mainly a disease of post-menopausal women, as shown in Figure 2, and hence studies on population screening programmes have focussed on this age group. The peak in incidence rate is in the 75 to 79 age group.



Source: National Cancer Registration and Analysis Service

**Figure 2: Numbers and age-standardised incidence rate of ovarian cancers (ICD-10 C56-C57) diagnosed in 2016, England by age at diagnosis.**

#### 4.4 Disease types

In general, when discussing ‘ovarian cancer’ such as within this report, the focus is on the commonest and most lethal of the disease type, called ‘high grade serous’ ovarian cancer. This type constitutes over 90% of advanced ovarian disease that presents clinically. This is also the main disease type occurring in women over 50 years of age, and in those with an inherent genetic predisposition.

#### 4.5 CA125

An elevated serum CA125 was first recognised in the 1980s and to be associated with most but not all ovarian cancers (10). Though valuable in clinical practice, the main limitation to the interpretation of CA125 in this evaluation is the fact that many non-malignant conditions can cause elevated levels, for example endometriosis, pregnancy, menstruation, surgery, and a spectrum of infections. Notably, many of these conditions are associated with pre-menopausal women, rendering the CA125 even less reliable in this age group. Other approaches which enhance the diagnostic accuracy of CA125 and ultrasound in the pre-menopausal woman have been proposed by the International Ovarian Tumour Analysis group (11).

## 5. Evaluation metrics

### 5.1 List of evaluation metrics

The evaluation of the regional ovarian campaign is based on the metric analyses defined in Table 1. The **ICD10 codes** listed in this table are the **international standard diagnostic classification system for all general epidemiological and many health management purposes (12)**.

A full definition and explanation of all metrics, along with details of methodology used, can be found in the **National Cancer Registration and Analysis Service Be Clear on Cancer evaluation metrics: methodology document**. 95% confidence intervals are included in some charts where appropriate.

**Table 1: List of campaign evaluation metrics and their descriptions**

Metric		Description	Codes used
Campaign recognition and public awareness		Public awareness and recognition of the campaigns and public knowledge regarding ovarian cancer	N/A
GP attendances		Number of visits to their GP by women for unexplained bloating	Unexplained bloating READ codes <sup>a</sup> (see Table 11)
Cancer Waiting Times (CWT) data:			
	Urgent referrals	Number of urgent GP referrals for suspected gynaecological cancers, also known as Two Week Wait (TWW) referrals	
	Cancer diagnoses resulting from urgent referrals	Number of gynaecological or ovarian cancer diagnoses resulting from an urgent referral for suspected gynaecological cancers, also known as: Two Week Wait (TWW) cancers, 62 day waits and 62-day cancers	ICD10 C51-C58

<sup>a</sup> Data obtained and provided as attendances for 'unexplained bloating'

Conversion rates	Percentage of urgent GP referrals for suspected gynaecological cancers resulting in a gynaecological or ovarian cancer diagnosis	
Diagnoses in CWT-database	Number of gynaecological or ovarian cancer diagnoses recorded in the CWT-database, also known as: CWT cancers, 31 day waits and 31-day cancers	
Detection rates	Percentage of gynaecological or ovarian cancer diagnoses recorded in the CWT-database which resulted from an urgent GP referral for suspected gynaecological cancers	
Emergency presentations	Proportion of women diagnosed with ovarian cancer who first presented as an emergency	ICD-10 C56-57
Diagnostics in secondary care (DID)	Number of imaging tests, including ultrasound, CT and MRI tests, for suspected ovarian cancer and other medical conditions	Ultrasound codes NICIP and SNOMED (see <a href="#">appendix 8.1</a> )
Cancers diagnosed	Number of ovarian cancers diagnosed during and following the campaign period	ICD-10 C48 excluding sarcoma, C56–57
Stage at diagnosis	Proportion of ovarian cancers diagnosed at an early stage (at stage 1 or 2)	ICD-10 C48 excluding sarcoma, C56–57
CA125	The number of CA125 tests conducted for women living in the campaign area	Read codes (see <a href="#">Table 11: List of ovarian campaign related symptom Read codes for CA125 metric</a> )
Survival rates	One-year survival for women aged 50 years and over with their first ovarian cancer diagnosed during and following the campaign period	ICD10 C56-57

When patients are referred, cancer is only a suspicion, with the cancer or other diagnoses to be confirmed. As a result, specific cancer type diagnoses are unknown and so urgent GP referrals for suspected cancer are recorded against a limited number of broad cancer types. One of these broad cancer types is gynaecological cancers, incorporating ovarian cancers, along with several other types of cancer (for example, uterine and cervical). Therefore, these analyses are undertaken for diagnoses of all gynaecological cancers (ICD10 C51-C58) and ovarian cancer (ICD10 C56-C57), although both are related to all urgent GP referrals for suspected gynaecological cancers.

## 5.2 Campaign recognition and public awareness

### 5.2.1 Research methodology

The research was conducted through pre- and post-campaign surveys in campaign and control areas. The test area was the North West of England for the ovarian cancer campaign. The rest of England (excluding the North East, as a similar oesophago-gastric regional campaign ran at the same time in this area) provided the control area. Samples of approximately 300 women aged 50 years and over were interviewed face-to-face in both the campaign and control areas and at both pre- and post-campaign points.

The research was conducted by TNS-BMRB, an independent market research agency specialising in social research. The survey was carried out face-to-face among a representative sample of women aged 50 years and over in England. This was supplemented with additional face-to-face interviews in the North West campaign region. The pre-campaign interviews took place between 13 January 2014 and 2 February 2014 and the post-campaign interviews took place between 17 March 2014 and 6 April 2014.

### 5.2.2 Campaign awareness and recognition

In both the campaign and control regions three quarters (77%) of respondents were aware of cancer advertising or publicity before the campaign. While awareness at the post stage increased significantly in the campaign region (87%), the same effect was not seen in the control region suggesting that the BCoC campaign contributed to this rise.

In the campaign region at the post-campaign stage, two thirds (66%) of those who recalled seeing or hearing something about cancer symptoms spontaneously recalled this as being about bloating, which was up from 12% at the pre-stage and compared with 7% in the control region at the post-campaign stage.

In the campaign region, three quarters (76%) recognised at least one of the ovarian cancer campaign materials. Recognition levels of the ovarian cancer television and radio advertisements were the highest of any BCoC regional campaign (71% and 33% respectively), while the press/poster advertisements had below average recognition (25%) and the leaflets performed in line with average (19%). This indicates that the television and radio advertisements benefitted from the combined effect of both having a similar storyline. While press and posters still gave the same key message, the



shared narrative set up within the television and radio advertisements is likely to have strengthened their mutual recognition.

### 5.3 GP attendances

This metric considers whether the campaign had an impact on the number of women aged 50 years and over living in the campaign area attending a GP with unexplained bloating.

Data on GP attendances for bloating and control symptoms<sup>b</sup> (symptoms selected which are not anticipated to be influenced in any manner by the campaign) was collected from 265 practices<sup>c</sup> (39 in the campaign area, with the remaining 226 outside this area acting as a control group) for 9 defined periods between December 2011 and May 2014. These were the 8-week pre-campaign period (16 December 2013 to 9 February 2014), the 5-week campaign period (10 February 2014 to 16 March 2014) and the 8-week post-campaign period (17 March 2014 to 11 May 2014), and the same weeks in the previous 2 years. Data was adjusted to account for bank holidays and the number of weeks in each period.

Amongst women aged 50 years and over in the campaign area, the number of GP attendances for bloating per week per practice was higher during the campaign period than for all the previous periods. It also remained higher in the post-campaign period than in any of the periods before the campaign. The number of attendances during the campaign period (50 attendances) was significantly higher than the average during all the other periods combined (22.9 attendances after adjustment for bank holidays and the number of weeks in each period,  $p=0.001$ ).

There was a statistically significant increase of 127% in the number of attendances for bloating for women aged 50 years and over in the campaign area, when comparing the campaign period with the same period in 2013 ( $p<0.001$ ). By comparison, over the same period, there was a 3% decrease in attendances for bloating in the control area ( $p=0.759$ ), and 1% increase in attendances for control symptoms in the campaign area ( $p=0.873$ ), neither were statistically significant.

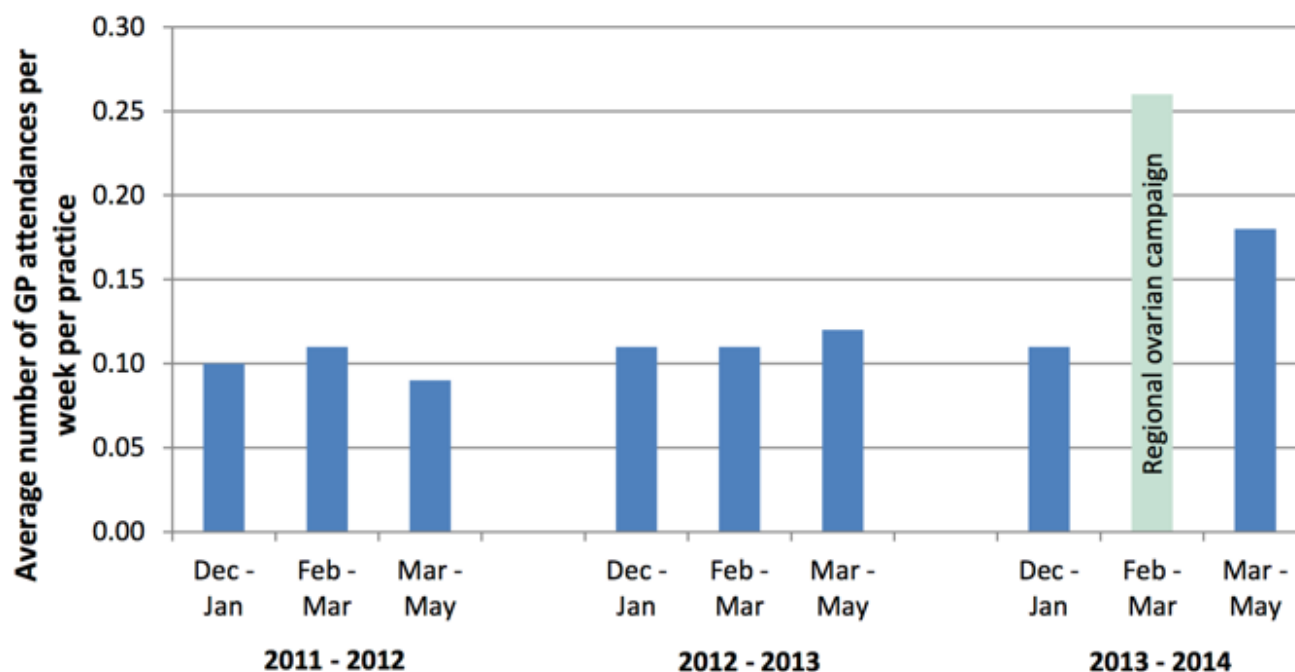
The increase in attendances for bloating during the campaign period, compared to the corresponding period in 2013, was larger for those aged under 50 years (222%,

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<sup>b</sup> These were: headache or migraine; knee, shoulder or neck pain and; urinary tract infection

<sup>c</sup> Organised by local commissioning groups, these practices volunteered to provide data for this project in return for a fixed payment. Compared to all practices nationally, practices submitting data had a similar age- sex population structure but a slightly less deprived population

statistically significant,  $p < 0.001$ ), although this was based on a small number of attendances.



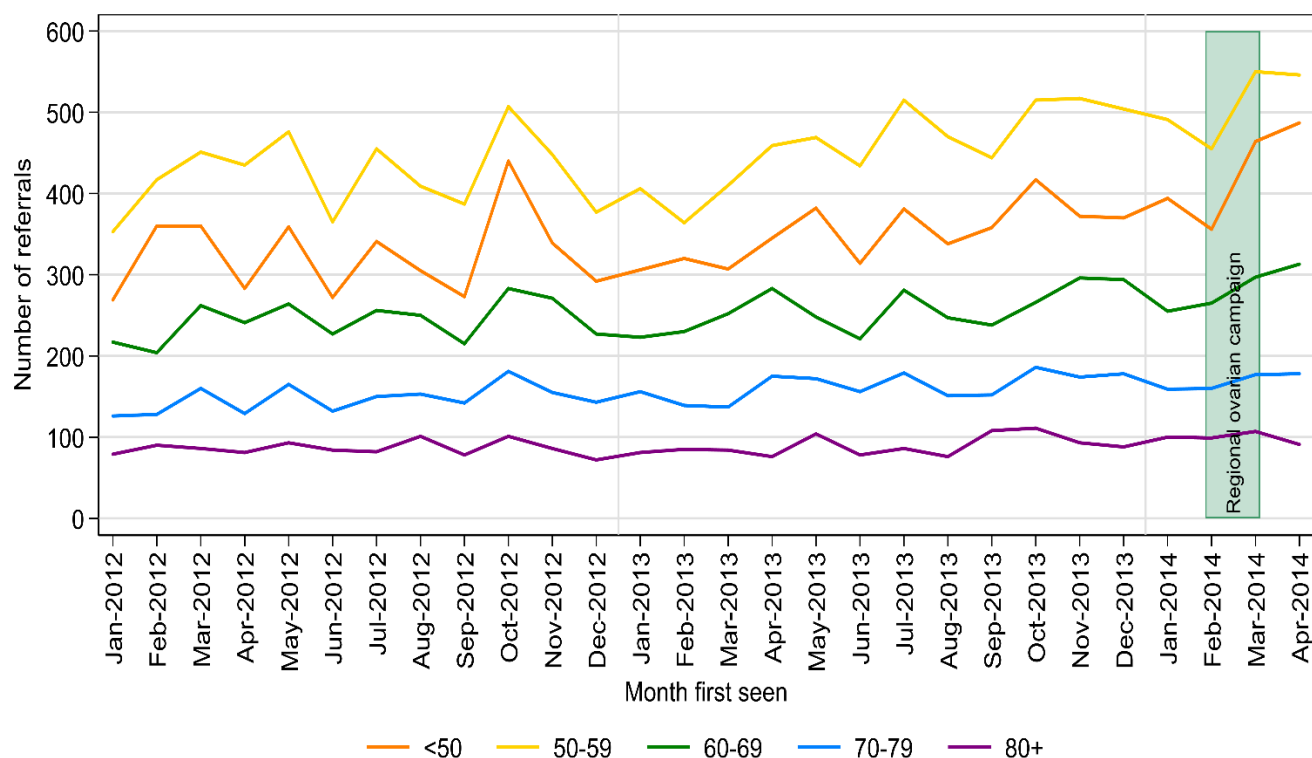
**Figure 3: Average number of GP attendances for bloating per week per practice for women aged 50 years and over in the campaign area during the pre, live and post campaign periods compared with the corresponding periods in the previous two years**

#### 5.4 Urgent GP referral for suspected gynaecological cancers

There were significant increases between the comparison period and analysis period in urgent GP referrals in all age groups (Table 2, Figure 4). This ranged from 14.2% to 34.5% depending on the age group. The largest percentage increase at 34.5% was noted in women under the age of 50 years; this population has a lower incidence of ovarian cancer than women over the age of 50 years.

**Table 2: Number of urgent GP referrals for suspected gynaecological cancers, with referral rate and percentage change in number of referrals, from February to April 2013 and February to April 2014, regional campaign area, by age**

Age Group		February to April				
		Referrals	% change in number	P-value	Referral Rate	
					Estimate	95% CI
<50	2013	972	34.5	<0.001	188.9	(177.2, 201.2)
	2014	1,307			254.0	(240.4, 268.2)
50-59	2013	1,233	25.8	<0.001	1,238.0	(1,169.8, 1,309.1)
	2014	1,551			1,557.3	(1,480.7, 1,636.8)
60-69	2013	765	14.4	0.007	855.0	(795.5, 917.8)
	2014	875			977.9	(914.2, 1,044.9)
70-79	2013	451	14.2	0.039	708.6	(644.7, 777.1)
	2014	515			809.2	(740.8, 882.2)
80+	2013	245	21.2	0.025	529.0	(464.8, 599.5)
	2014	297			641.2	(570.4, 718.5)



**Figure 4: Monthly number of urgent GP referrals for suspected gynaecological cancers from January 2012 to April 2014, regional campaign area, by age**

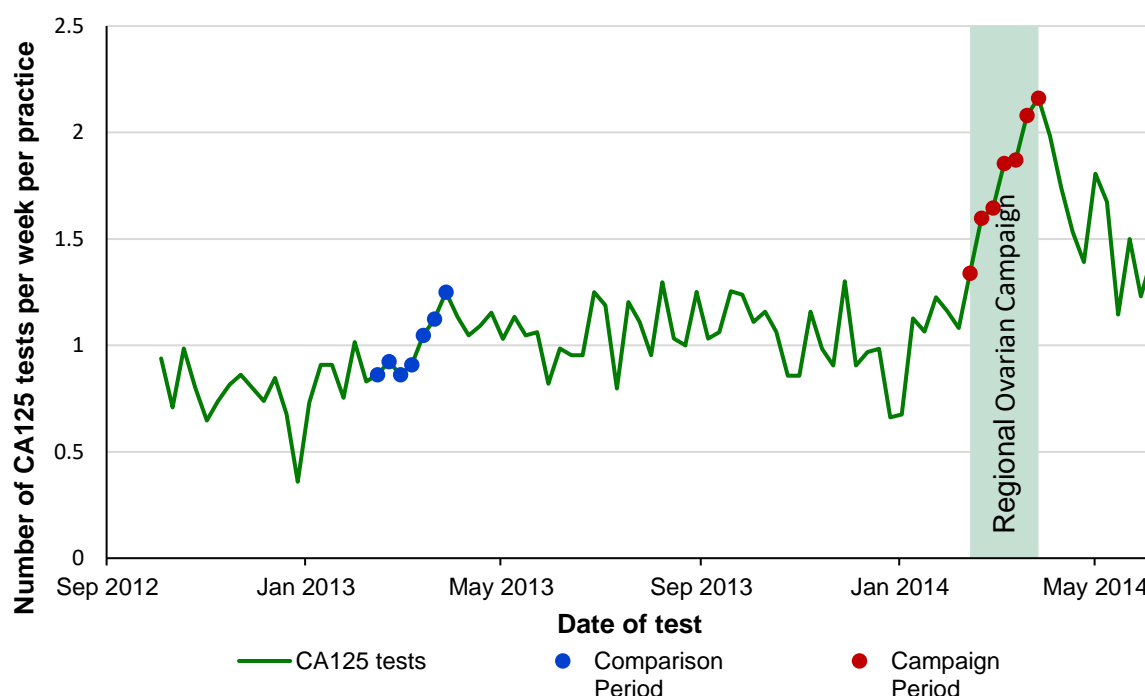
## 5.5 Diagnostic tests

The two tests used during the diagnosis of ovarian cancer are serum CA125 and imaging.

### 5.5.1 CA125

Analysis considered three periods: a 10-week pre-campaign period (2 December 2013 to 9 February 2014), a 7-week campaign analysis period (10 February 2014 to 30 March 2014), and a 7-week post-campaign period (31 March 2014 to 8 June 2014). All three periods were compared with the corresponding period in 2012/13. In addition, results were compared for practices in the campaign area (North West) and for practices in a control area (rest of England). Adjustments were made to account for bank holidays, the number of weeks in each period and the number of practices submitting data to The Health Improvement Network (THIN) database each week. Analysis considered the average number of CA125 tests per week per practice.

The average number of CA125 tests per week per practice peaked during the campaign analysis period (Figure 5). Although the number fell in the post-campaign period, it remained higher in June 2014 than before the campaign.



Source: The Health Improvement Network

**Figure 5: Average number of CA125 tests per week per practice, North West, women, all ages**

Comparing the campaign analysis period in 2014 with the comparison period in 2013, there was a statistically significant increase of 80% ( $p<0.001$ ) in the average number of CA125 tests per week per practice for women of all ages in the campaign area. There was a 54% ( $p<0.001$ ) increase in the average number of CA125 tests per week per practice for women aged 50 years and over, compared to a larger, 123% ( $p<0.001$ ), increase for women aged under 50 years.

There was also an increase in the average number of CA125 tests per week per practice for 2013/14, when compared with the same months in 2012/13, for both the pre-campaign period (a statistically significant 27% increase) and the post-campaign period (a statistically significant 47% increase), Table 3.

**Table 3: Average number of CA125 tests per week per practice during the pre- campaign, campaign analysis and post-campaign periods in 2013/14, compared with the corresponding periods in 2012/13, North West, all ages**

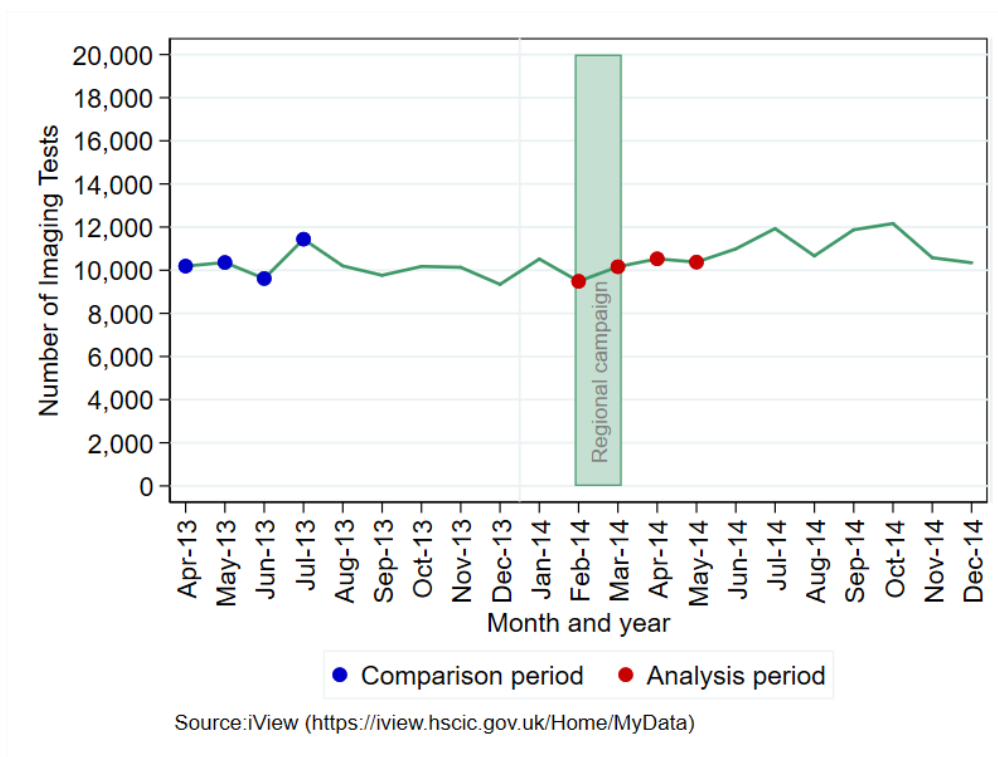
Period	2012/13	2013/14	Percentage change	p-value
Pre-campaign	0.78	0.98	26.7	<0.001
Campaign analysis	1.00	1.79	80.0	<0.001
Post-campaign	1.05	1.54	46.7	<0.001

### 5.5.2 Diagnostic imaging tests

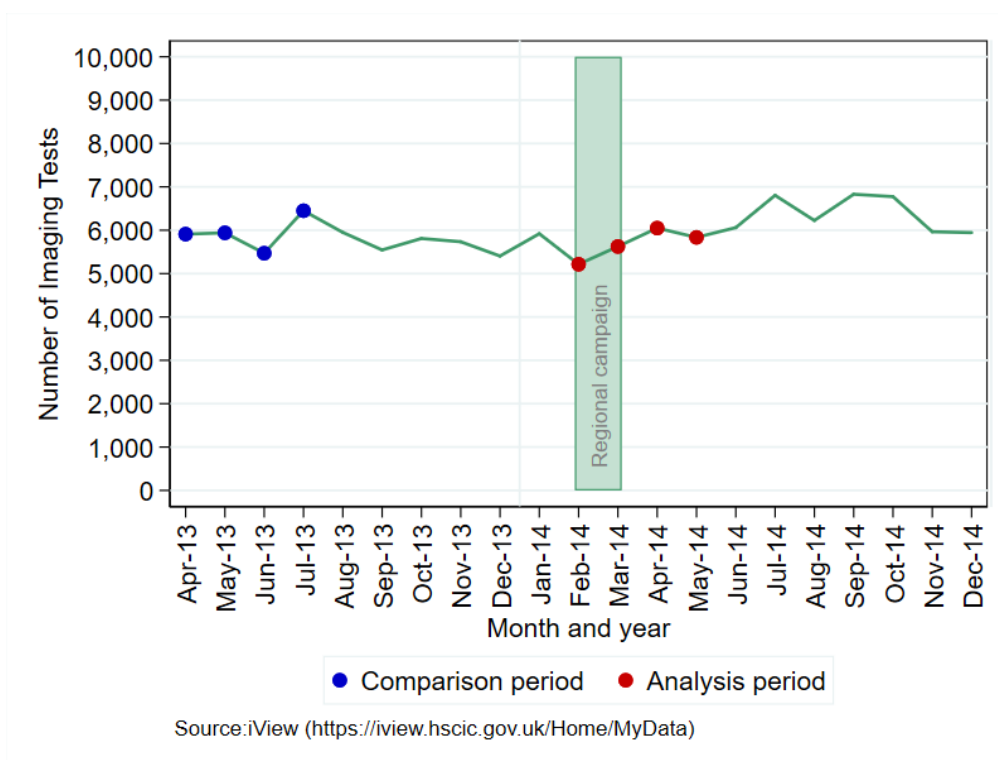
Ultrasound scans, CT and MRI scans are all imaging modalities which can be employed in the diagnostic journey for ovarian cancer. The numbers of imaging tests for suspected ovarian cancer and other medical conditions for the periods April to July 2013 and February to May 2014 are shown in Table 4 and Figures 6 and 7. The results are for women of all ages, and those over the age of 50 years. There was a 4.4% decrease in the number of imaging tests used during and subsequent to the campaign for women aged over 50 years and a 2.5% decrease for women of all ages. However, the changes in the number of imaging tests were not statistically significant.

**Table 4: Number of ultrasounds, CT-scans and MRIs in April to July 2013 and February to May 2014, North West of England (Greater Manchester, Lancashire & South Cumbria, Cheshire & Merseyside)**

Age Group	April to July 2013	February to May 2014	Percentage change	p-value
50 years and over	23,770	22,725	-4.4	0.367
All ages	41,605	40,550	-2.5	0.575



**Figure 6: Monthly number of ultrasounds, CT-scans and MRIs in April 2013 to December 2014, North West of England (Greater Manchester, Lancashire & South Cumbria, Cheshire & Merseyside) all age groups**



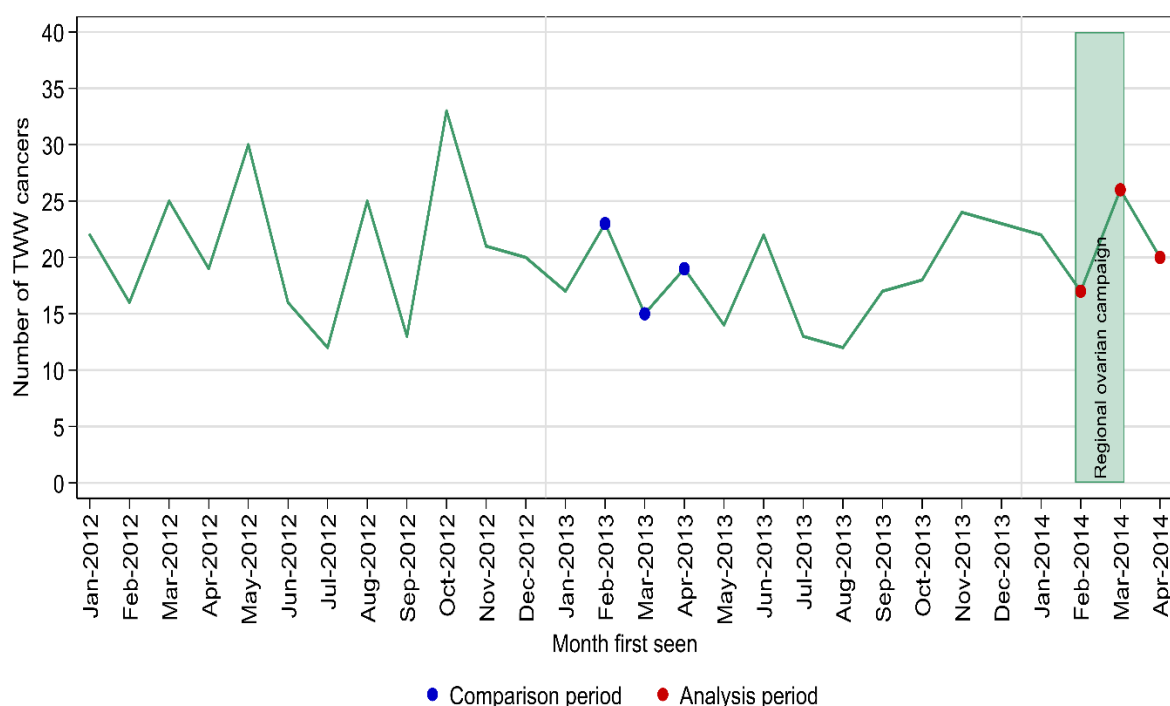
**Figure 7: Monthly number of ultrasounds, CT-scans and MRIs in April 2013 to December 2014, North West of England (Greater Manchester, Lancashire & South Cumbria, Cheshire & Merseyside) 50 years and older**

## 5.6 Ovarian cancer diagnoses resulting from an urgent GP referral for suspected gynaecological cancers

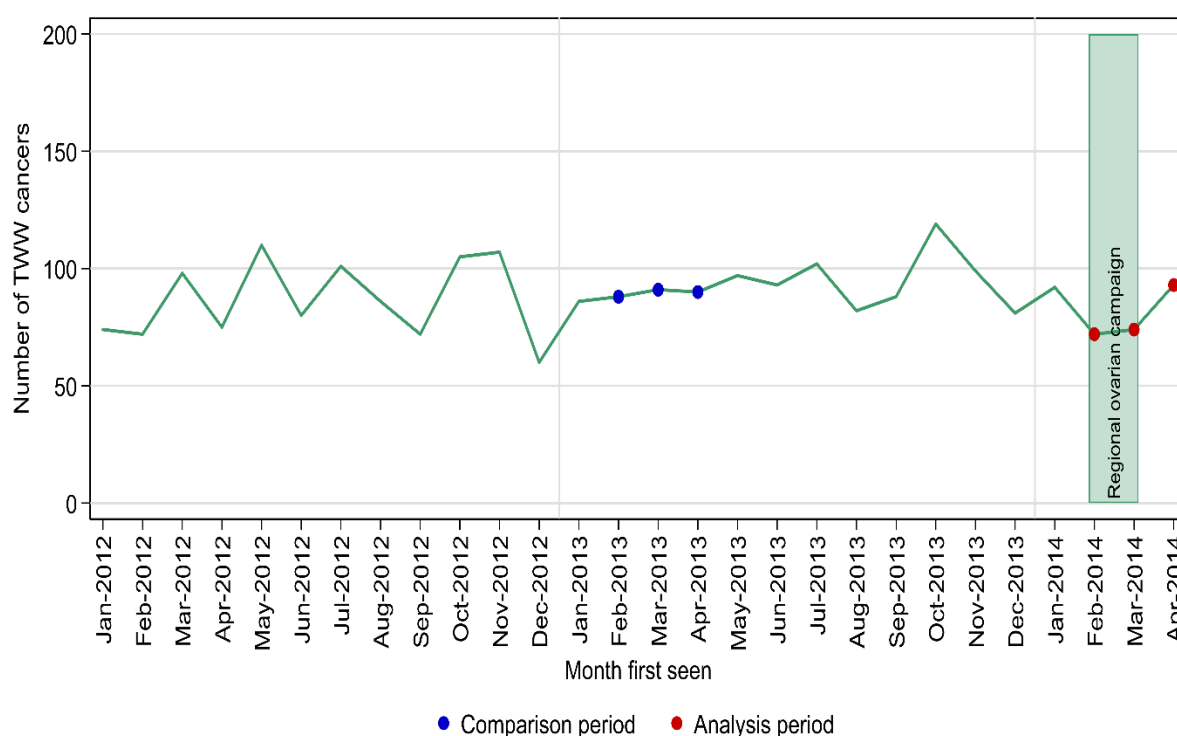
The number of urgent GP referrals increased during the analysis period compared to the control period, however the number of gynaecological cancer diagnoses resulting from an urgent GP referral remained largely unchanged (232 cases in February to March 2013 versus 235 in February to March 2014,  $p=0.890$ ), as did the number of ovarian cancer diagnoses resulting from an urgent referral for suspected cancer (57 cases in February to March 2013 versus 63 in February to March 2014,  $p=0.584$ ). See Table 5, Figures 8 and 9.

**Table 5: Number of ovarian and gynaecological cancer diagnoses resulting from urgent GP referrals for suspected gynaecological cancers, with percentage change in number of cancers, from February-April 2013 and February-April 2014**

Cancer type	Overall	February to April			
		TWW cancers		% change in number	P-value
		2013	2014		
Ovarian cancer	Regional campaign area	57	63	10.5	0.584
	Control area	269	239	-11.2	0.183
Gynaecological cancer	Regional campaign area	232	235	1.3	0.890
	Control area	985	996	1.1	0.805



**Figure 8: Monthly number of ovarian cancer diagnoses resulting from an urgent GP referral for suspected gynaecological cancers from January 2012 to April 2014, regional campaign area**



**Figure 9: Monthly number of ovarian cancer diagnoses resulting from an urgent GP referral for suspected gynaecological cancers from January 2012 to April 2014, control area**

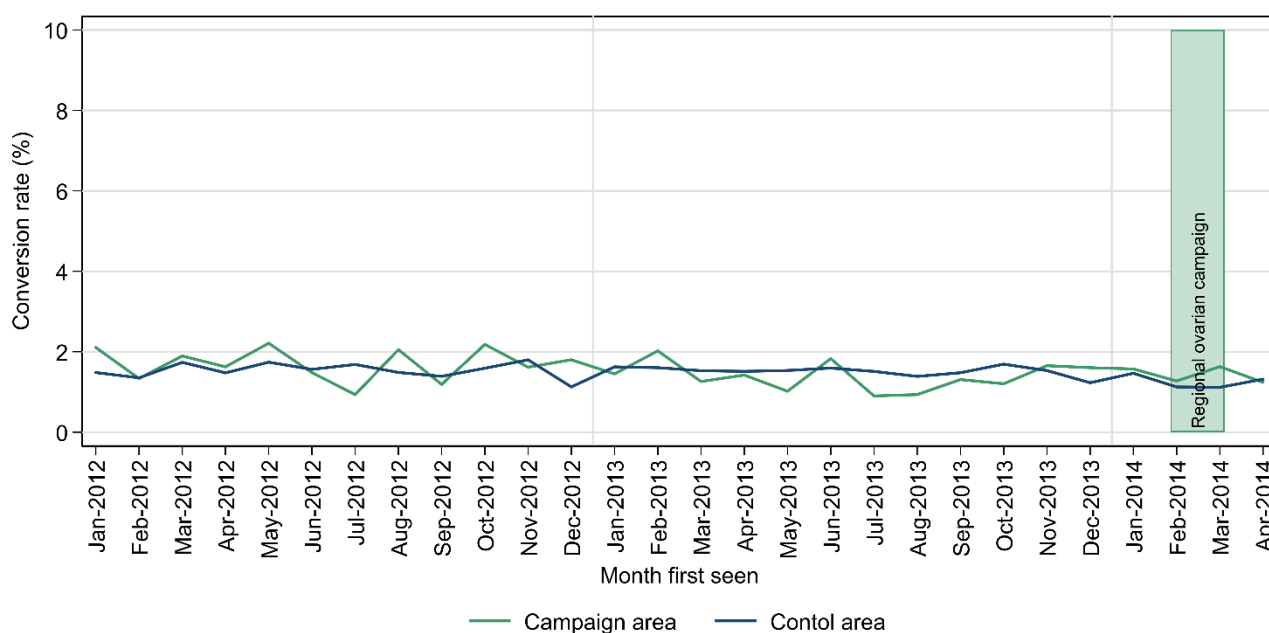
### 5.7 Conversion rate (percentage of urgent GP referrals for suspected gynaecological cancer resulting in a cancer diagnosis)

Though the actual number of gynaecological and ovarian cancers resulting from an urgent GP referral during the campaign and control periods remained static, there were statistically significant decreases in the conversion rate for urgent GP referrals for suspected ovarian cancer in the control area and for suspected gynaecological cancer in both the regional and control areas (Table 6). However, these results appear to be consistent with long term trends (Figures 10 and 11).

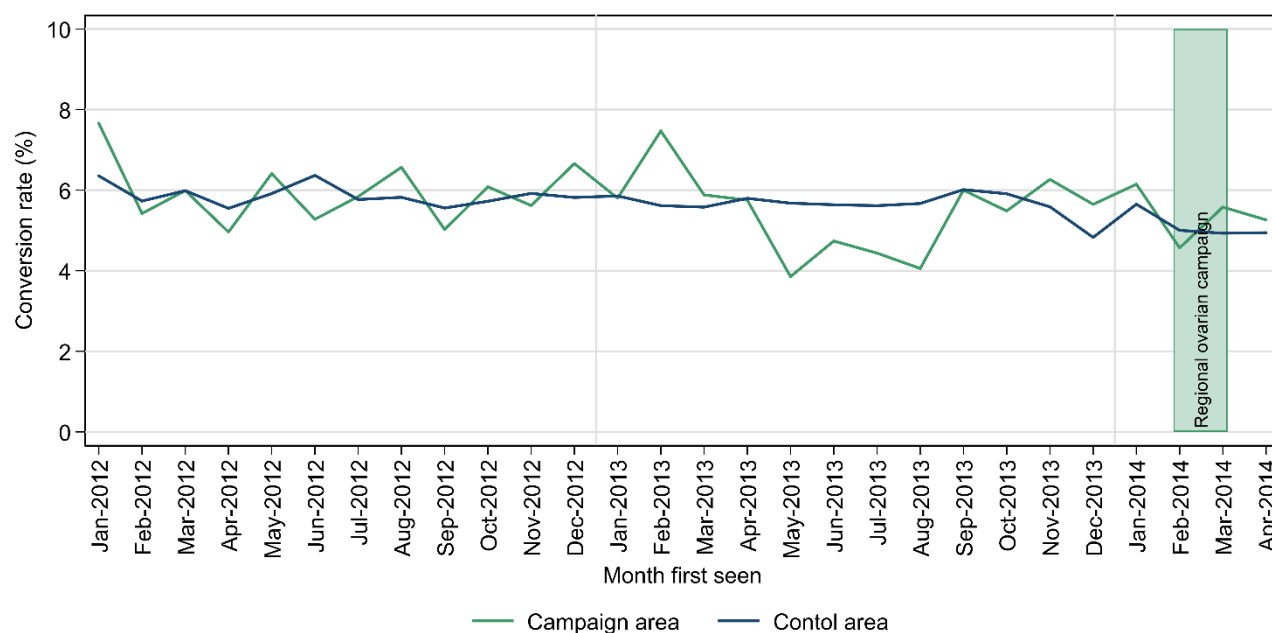


**Table 6 : Ovarian and gynaecological cancer conversion rates for urgent GP referrals for suspected gynaecological cancers, with change, from February to April 2013 and February to April 2014**

Cancer type	Overall	February to April					
		2013		2014		% -point change	P-value
		Conv. Rate (%)	95% CI	Conv. Rate (%)	95% CI		
Ovarian cancer	Regional campaign area	1.6	(1.2, 2.0)	1.4	(1.1, 1.8)	-0.2	0.527
	Control area	1.5	(1.4, 1.7)	1.2	(1.0, 1.3)	-0.4	0.003
Gynaecological cancer	Regional campaign area	6.3	(5.6, 7.2)	5.2	(4.6, 5.9)	-1.2	0.024
	Control area	5.7	(5.3, 6.0)	5.0	(4.7, 5.3)	-0.7	0.002



**Figure 10: Monthly ovarian cancer conversion rates for urgent GP referrals for suspected gynaecological cancers from January 2012 to April 2014**



**Figure 11: Monthly gynaecological cancer conversion rates for urgent GP referrals for suspected gynaecological cancers from January 2012- to April 2014**

## 5.8 Ovarian cancer diagnoses recorded in the Cancer Waiting Times database

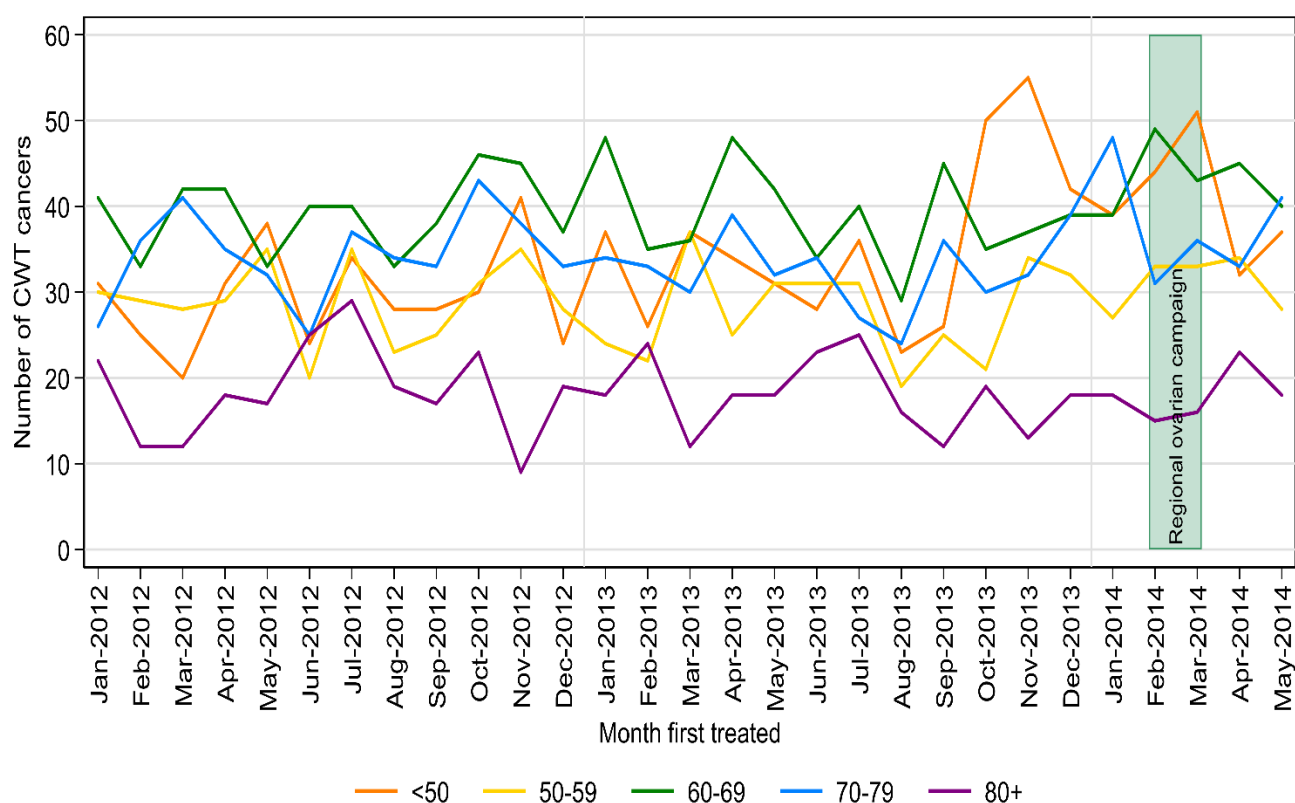
The number of gynaecological and ovarian cancers recorded in the Cancer Waiting Times (CWT) database are shown in Tables 7 and 8, and Figure 12. Comparing March to May 2013 with March to May 2014, there were no statistically significant changes in the numbers of ovarian cancers or gynaecological cancers recorded in the CWT database for the regional campaign area or control area. It is possible that the campaign, through raising awareness of ovarian cancer, raised awareness of or generated a wider interest in other gynaecological cancer symptoms.

**Table 7 : Number of ovarian and gynaecological cancer diagnoses recorded in the Cancer Waiting Times database, with percentage change in number of cancers, from March to May 2013 and March to May 2014**

Cancer type	Overall	March to May			
		CWT cancers		% change in number	P-value
		2013	2014		
Ovarian cancer	Regional campaign area	139	148	6.5	0.595
	Control area	621	582	-6.3	0.261
Gynaecological cancer	Regional campaign area	470	510	8.5	0.201
	Control area	2,009	2,025	0.8	0.801

**Table 8 : Number of ovarian and gynaecological cancer diagnoses recorded in the Cancer Waiting Times database, with percentage change in number of cancers, from March to May 2013 and March to May 2014, regional campaign area, by age**

Cancer type	Age group	March to May			
		CWT cancers		% change in number	P-value
		2013	2014		
Ovarian cancer	<50	26	24	0.0	1,000
	50-59	30	30	0.0	1.000
	60-69	36	41	13.9	0.569
	70-79	31	34	9.7	0.710
	80+	16	17	6.3	0.862
Gynaecological cancer	<50	102	120	17.6	0.227
	50-59	93	95	2.2	0.884
	60-69	126	128	1.6	0.900
	70-79	101	110	8.9	0.535
	80+	48	57	18.8	0.379



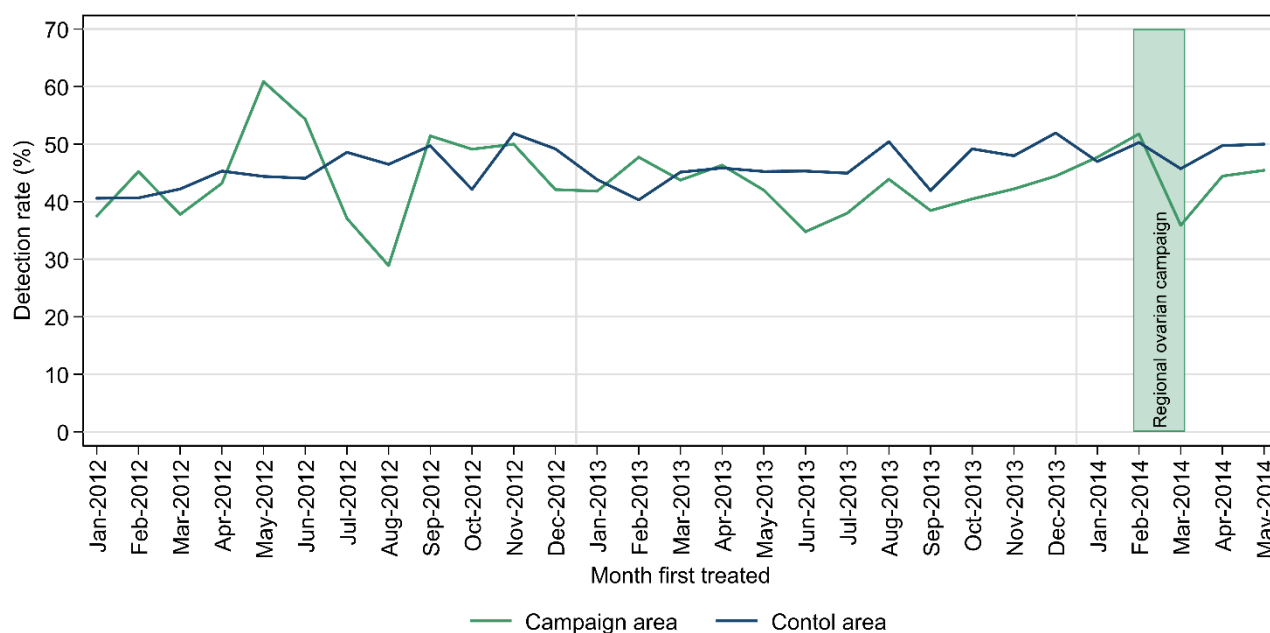
**Figure 12: Monthly number of gynaecological cancer diagnoses recorded in the Cancer Waiting Times database, from January 2012 to May 2014, regional campaign area, by age**

### 5.9 Detection rates (percentage of ovarian cancers diagnosed from Cancer Waiting Times resulting from an urgent GP referral for suspected gynaecological cancer)

Though the campaign seemed to have an impact on the number of urgent GP referrals, particularly in those under 50 years of age, with a 34.5% rise in referrals in the campaign areas, the detection rate for an ovarian or other gynaecological cancer based on age remained unaffected by the campaign (Table 9, Figure 13).

**Table 9: Detection rate for ovarian and gynaecological cancer diagnoses, with change, from March to May 2013 and March to May 2014, regional campaign area, by age**

Cancer type	Age group	March to May					
		2013		2014		% point change	P-value
		Det. Rate (%)	95% CI	Det. Rate (%)	95% CI		
Ovarian cancer	<50	42.3	(25.6, 61.1)	26.9	(13.7, 46.1)	-15.4	0.244
	50-59	50.0	(33.2, 66.8)	46.7	(30.2, 63.9)	-3.3	0.796
	60-69	44.4	(29.5, 60.4)	56.1	(41.0, 70.1)	11.7	0.307
	70-79	32.3	(18.6, 49.9)	29.4	(16.8, 46.2)	-2.8	0.804
	80+	56.3	(33.2, 76.9)	52.9	(31.0, 73.8)	-3.3	0.849
Gynaecological cancer	<50	27.5	(19.7, 36.8)	22.5	(15.9, 30.8)	-5.0	0.394
	50-59	51.6	(41.6, 61.5)	47.4	(37.6, 57.3)	-4.2	0.561
	60-69	63.5	(54.8, 71.4)	60.2	(51.5, 68.2)	-3.3	0.584
	70-79	55.4	(45.7, 64.8)	51.8	(42.6, 60.9)	-3.6	0.598
	80+	64.6	(50.4, 76.6)	59.6	(46.7, 71.4)	-4.9	0.604



**Figure 13: Monthly detection rate for ovarian cancer diagnoses, from January 2012 to May 2014**

## 5.10 Emergency presentation rates

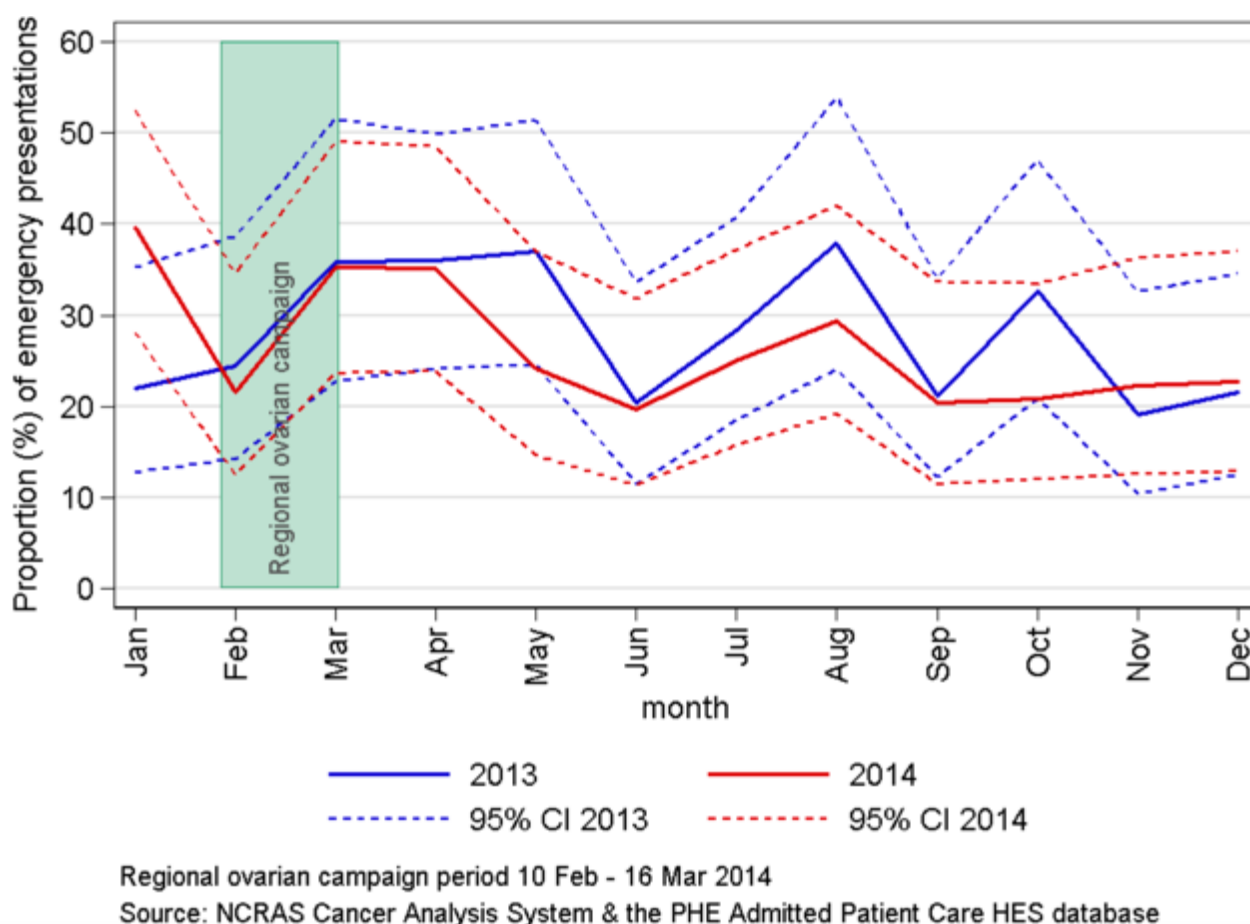
Ovarian cancer diagnosed via emergency presentation is associated with poorer survival outcomes. This important parameter was assessed to see if the campaign had influenced this route of accessing care.

The Hospital Episode Statistics (HES) derived emergency presentation metric is calculated from inpatient data and uses the methodology set out in the cancer outcomes metric specification. It measures the proportion of women diagnosed with ovarian cancer who first presented as an emergency.

Data was extracted on 19 October 2016 for women admitted in 2013 and 2014, resident in the North West of England, with a primary diagnosis of ovarian cancer (ICD-10 C56-57). Results for the campaign year (2014) were compared with 2013.

There were 572 women admitted with ovarian cancer in 2013 and 158 were diagnosed through emergency presentation. In 2014, there were 633 and 168 respectively.

There were no significant differences in the proportions of ovarian cancers diagnosed via emergency presentation in the regional pilot area in 2014 compared with 2013 (Figure 14). The proportions of women with ovarian cancer diagnosed via emergency presentation during the regional ovarian campaign period were 22% in February 2014 and 35% in March 2014 compared to 24% and 36% for the same months in 2013.

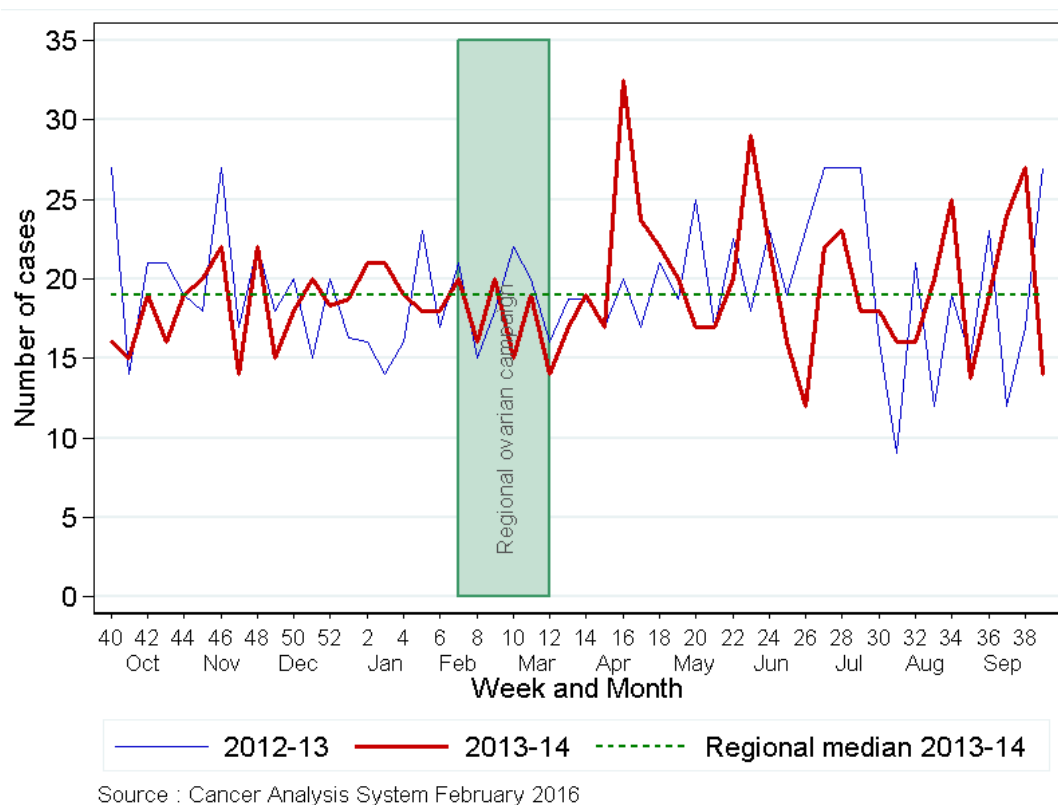


**Figure 14: Proportion of emergency presentations and 95% confidence intervals for ovarian cancer by month, regional campaign – North West England, 2013 and 2014**

### 5.11 Cancers diagnosed

This metric considers whether the regional ovarian cancer campaign had an impact on the number of newly diagnosed cases of ovarian cancer (ICD-10 C48 excluding sarcoma, C56–57), for women of all ages resident in the North West of England. Data was extracted from the national cancer registration dataset (3) for the diagnosis period October 2012 to September 2014. The analysis period was defined as 2 weeks after the start of the campaign (week 9 of 2014) to 2 months after the end of the campaign (week 21 of 2014). The numbers of cases diagnosed per week in the analysis period were compared with the overall median for October 2013 to September 2014. The campaign was considered to have a possible impact if a) the numbers of cases per week were the same or higher than the median for 5 or more consecutive weeks and b) this sustained period started during the analysis period.

There were no sustained periods where the numbers of ovarian cancers were the same as or higher than the 2013 to 2014 median (Figure 15). The regional ovarian campaign does not appear to have had an impact on the numbers of ovarian cancers diagnosed in the North West of England.



**Figure 15: Number of newly diagnosed cases of ovarian cancer by week, North of England Cancer Network, October 2012 to September 2014, all ages**

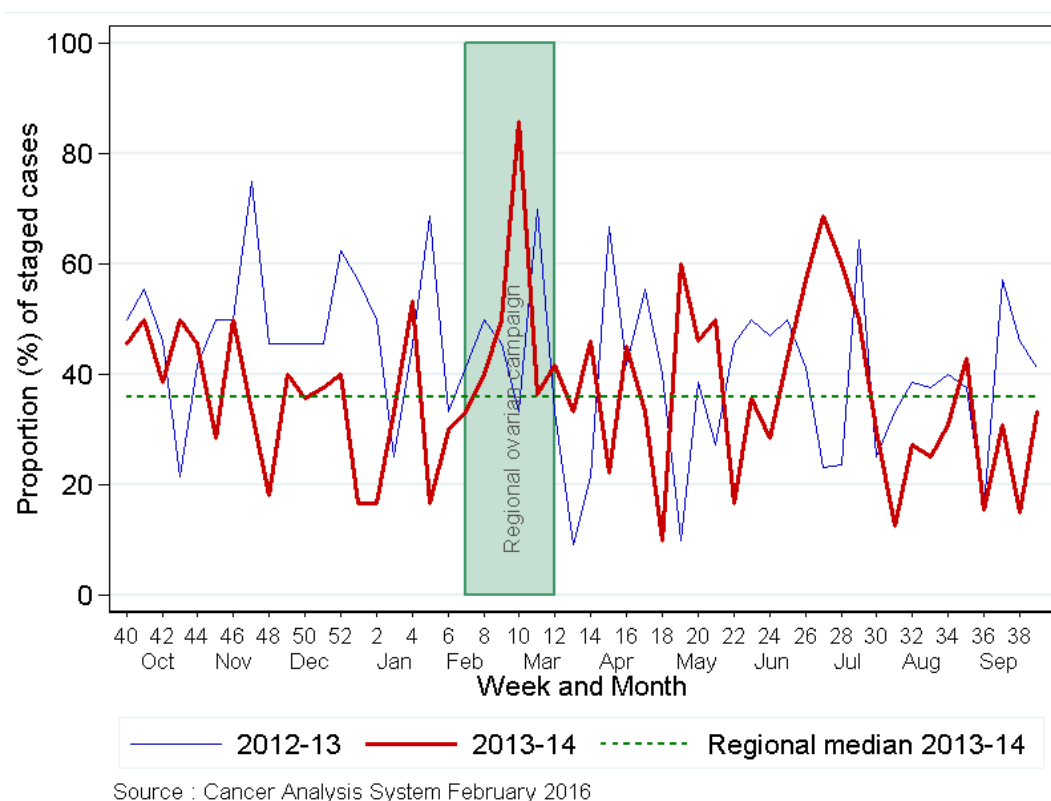
## 5.12 Early stage at diagnosis

For ovarian cancer, stage at diagnosis can be recorded in the cancer registration data using two possible classification systems. The Tumour, Nodes and Metastases classification (TNM) is used for most cancer sites, including gynaecological cancers; in the registration data this can be obtained from multiple sources of information. The Federation of Gynaecologists and Obstetricians (FIGO) staging system is only used for gynaecological cancers. The analysis for stage at diagnoses for ovarian cancer is based mainly on TNM information, sometimes combined with FIGO information (Figures 15 and 16). In addition, results were produced on FIGO alone (Figures 17 and 18).

One premise behind the BCoC ovarian campaign was to facilitate the diagnosis of the disease earlier, and possibly at an earlier stage of the disease, where interventions afford better survival outcomes.

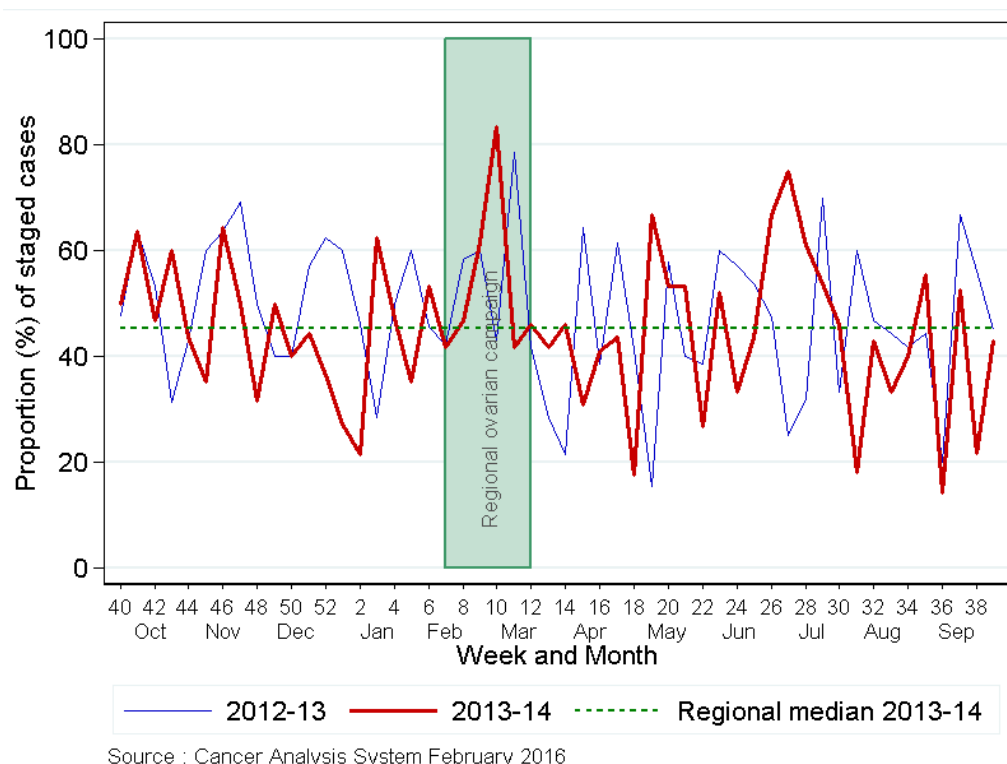
Data was extracted from the national cancer registration dataset for the diagnosis period October 2012 to September 2014. The analysis period was defined as 2 weeks after the start of the campaign (week 9 of 2014) to 2 months after the end of the campaign (week 21 of 2014). The proportion of early-staged cases per week during the analysis period was compared with the overall median proportion for October 2013 to September 2014. The campaign was considered to have a possible impact if a) the proportion per week was the same or higher than the median for five or more consecutive weeks and b) this sustained period started during the analysis period.

During the analysis period, there were no sustained periods where the weekly proportions of early stage ovarian cancers equalled or exceeded the annual median for early stage (Figures 16 to 19).

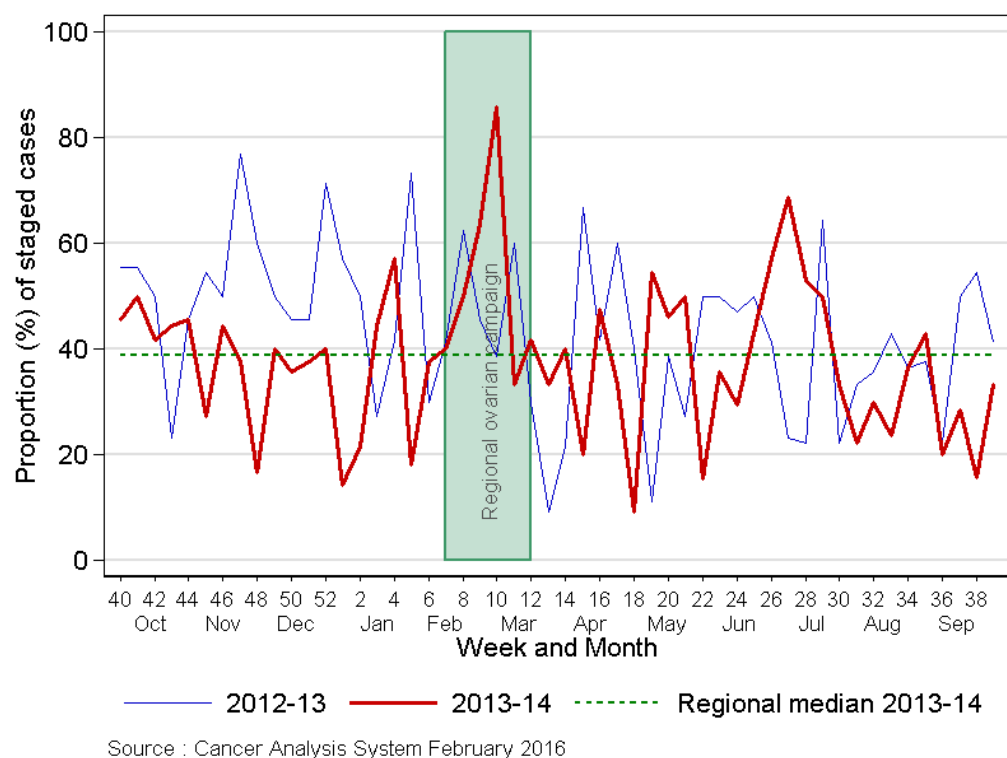


**Figure 16: Proportion of ovarian cancer diagnosed at stage 1 or 2 by week, North West of England, October 2012 to September 2014, 50 years and over**

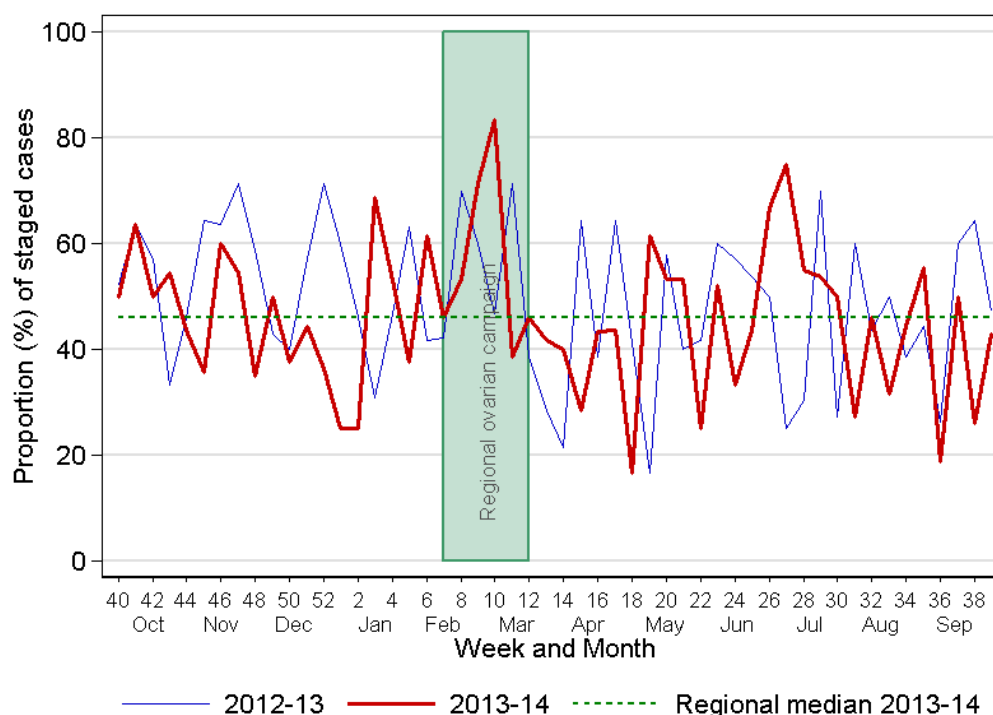




**Figure 17: Proportion of ovarian cancer diagnosed at stage 1 or 2 by week, North West of England, October 2012 to September 2014, all ages**



**Figure 18: Proportion of ovarian cancers diagnosed at FIGO stage 1 or 2 by week, North West of England, October 2012 to September 2014, women aged 50 years and over**



Source : Cancer Analysis System February 2016

**Figure 19: Proportion of ovarian cancer diagnosed at FIGO stage 1 or 2 by week, North West of England, October 2012 to September 2014, all ages**

### 5.13 One-year survival rates

Data for women resident in the regional pilot area (North West of England) was extracted from the national cancer registration dataset. Women were followed up until December 2016 to obtain their last known vital status. The analysis period was defined as 2 weeks from the start of the campaign (1 March 2014) to 2 months after the end of the campaign (31 May 2014). One-year age specific net survival was calculated using the methodology outlined in the Office for National Statistics: Cancer Survival Statistical Bulletins. Net survival refers to the probability of surviving cancer accounting for other causes of death. The one-year survival for women diagnosed in the analysis period was compared with those diagnosed from 1 January to 28 February 2014 and from 1 June to 31 December 2014.

There were no significant differences in one-year survival for women aged 50 years and over diagnosed with ovarian cancer between the analysis period (March 2014 to May 2014) and comparison period (January, February, June to December 2014) (Table 10). One-year survival for women diagnosed during the analysis period was 68.5% compared with 69.1% for those diagnosed in the comparison period.

**Table 10: One-year net survival (%) for women aged 50 and over diagnosed with ovarian cancer during the analysis period, 1 March to 30 May 2014, compared with the rest of 2014**

<b>Comparison Period</b>	<b>February to May 2014</b>
1 January 2014 to 28 February 2014, 1 June 2014 to 31 December 2014	1 March 2014 to 31 May 2014
69.1% (95% CI: 65.5 – 72.7)	68.5% (95% CI: 61.8 – 75.1)

## 6. Discussion and conclusions

Ovarian cancer, proportionally, has the highest death rate of the gynaecological cancers, and survival outcomes in the UK are poorer than those of comparable countries (6). Recognising the public health issue, the Chief Medical Officer report of 2014 recommended that the clinical care of ovarian cancer should be explored in order to identify any areas which could be addressed to improve outcomes (13). The BCoC campaign objectives were also focussed on improving outcomes through the education of women and GPs as to the most common symptoms associated with this relatively rare malignancy. This would hopefully speed the referral process for more women, and possibly lead to a diagnosis at an earlier disease stage, which would improve survival outcomes.

However, research began to emerge challenging the accepted knowledge of ovarian cancer biology. In the late 2000's it was proposed that many, if not all, 'high grade serous' ovarian cancers, arose from the distal portion of the fallopian tube (14). High grade serous carcinomas account for the majority of advanced stage ovarian cancers, and it is mainly this subgroup which contributes to the poor survival pattern in this disease. Consequently, symptoms attributed to potentially 'early stage' ovarian cancer were in fact those related to fallopian tube carcinomas which had spread to the ovaries. Evidence continues to accumulate supporting the fallopian tube as the origin of high grade serous ovarian cancers (15), (16).

The outcomes of screening trials in ovarian cancer act as supportive evidence to the dilemma in detecting early stage 'ovarian' cancer. Two randomised controlled trials on population screening for ovarian cancer - comparing ultrasound and serum CA125 as the screening tools - have been reported. In a US study, no stage shift or improvement in survival was found in the screened population, resulting in the Food and Drug Administration declaration that population screening for ovarian cancer was not justifiable (17). A larger UK screening study (UKCTOCS) has yet to report on the primary endpoint of the study, i.e. mortality rates. However, this study concurred with the US trial in that no stage shift from late to early was found in the screened population (18). Presently, a real challenge exists in developing appropriate and effective investigations in detecting early disease or its precursors within the fallopian tubes.

The BCoC campaign achieved its objective with regards to the dispersion of public messages. This is evidenced by the increase noted in GP attendances, TWW referrals and CA125 serum tests. However, the impact was mainly in women less than 50 years of age, for whom the incidence of ovarian cancer is low compared to those over 50 years of age. Notably, the campaign did omit to emphasise the age spectrum in the

posters used, which may be one contributor to this outcome, though indicating the efficacy of poster advertising. The increased attendance of women in the low risk category and referrals via the TWW system, did not lead to an increase in the detection of ovarian cancers via this route. The campaign did not appear to have an impact on the number of cancers diagnosed or to result in a stage shift; this is not unexpected for a regional campaign where there are small numbers of ovarian cancers diagnosed resulting in low statistical power to detect an impact.

The major impact on the under-50 age groups is also apparent with regards to serum CA125 tests, with more than a doubling of such tests in this age group. The test is easy to undertake in a GP practice, and generally performed before or in conjunction with a scan. The increase in tests, which were presumably based on symptoms, did not yield a higher diagnosis of ovarian cancers. Symptoms of bloating due to normal cyclical menstruation are common in the pre-menopausal woman, and it may be hypothesised that advertising these symptoms could have generated concerns and the increased desire to seek medical advice, even when the CA125 level was reported as normal.

The campaign would therefore have benefitted from greater clarity as to the target population. This would align the target population with that used in the population screening trials. Whether this would have changed the findings is questionable, as even in those over the age of 50 years, there was no increase in ovarian cancer detection rates in the campaign areas.

There are some unmeasured elements which were beyond the remit of the campaign. For example, there may have been an increase in anxiety amongst women who thought they may be suffering from ovarian cancer symptoms. Alternatively, there may have been benefits for women with ovarian cancer who were able to be more rapidly referred to cancer services due to seeking advice from their GP. The cost-efficacy elements of the campaign are also unknown, and not within the remit of this evaluation.

Educating the population about symptoms associated with cancer would seem a logical and reasonable course of action. However, in the case of ovarian cancer, a rare condition, the desired outcomes of diagnosis at an earlier disease stage or improved survival were not achieved.

## 7. Appendix

### 7.1 List of ovarian campaign symptom Read codes for CA125 metric

Ovarian symptoms	
Code*	Description
44a6.00	CA125 level
44a6000	Serum CA 125 (cancer antigen 125) level
44a1.00	Carbohydrate antigen 125 level

\*For selection of NW region the 'Cheshire & Mersey' and 'Greater Manchester, Lancashire and South Cumbria' Clinical Senate geographies were used. These were the closest to the campaign region possible using the clinical senate geography, which is the only regional breakdown available for THIN.

### 7.2 DID Imaging code list used in the analysis of the impact on diagnostic imaging

#### NICIP codes

UABDO	US Abdomen
UABPE	US Abdomen and pelvis
UADRB	US Adrenal Both
UABDA	US Anterior Abdominal Wall
ULABD	US Lower abdomen
UUPPA	US Upper abdomen
CABDO	CT Abdomen
CABPE	CT Abdomen and pelvis
CABPEC	CT Abdomen and pelvis with contrast
CABDOC	CT Abdomen with contrast
MPELV	MRI Pelvis
MPEGY	MRI Pelvis gynaecological
MRECT	MRI Pelvis rectum
MSIJB	MRI Pelvis SIJ Both
MPELVC	MRI Pelvis with contrast

#### SNOMED codes

45036003	US Abdomen
420052009	US Lower abdomen

418398002	US Upper abdomen
432853001	US Anterior abdominal wall
313631000000108	US Anterior abdominal wall
418394000	US Abdomen and pelvis
184391000000107	US Abdomen and pelvis
241480000	US Adrenals
169070004	CT Abdomen
32962002	CT Abdomen with contrast
419394006	CT Abdomen and pelvis
432370003	CT Abdomen and pelvis with contrast
183881000000104	CT Abdomen and pelvis
310111000000101	CT Abdomen and pelvis with contrast
2690005	MRI Pelvis
826591000000107	Gynaecological MRI Pelvis
314571000000106	MRI Pelvis with contrast
433138001	MRI Pelvis with contrast
241629006	MRI Rectum
420078000	MRI Sacroiliac joints

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