



Annual Report 2012 - 2013

developmentplus™

**WE ARE
MACMILLAN.**
CANCER SUPPORT

NHS
Lincolnshire

Public Health
Lincolnshire 

Lincolnshire 
COUNTY COUNCIL

EPOC Annual Report 2012/13

Contents

Introduction	3
CCG's & GP's	5
Volunteering	6
Promotional & Development	8
Screening	11
Campaigns	13

Tables

Number of people spoken to – screening	12
Data Collection	15
Number of people spoken to – general	16
Key Performance Indicators	17

EPOC Annual Report 2012/13

Introduction

Early Presentation of Cancer (EPOC) is a programme built upon community development principles to push forward cancer prevention messages in a fun but informative manner and in a way that is appropriate to individual communities. This will encourage people to present signs and symptoms to their GP earlier therefore improving the outcome and lowering the rate of premature mortality.

The programme began in 2009 funded by NHS Lincolnshire Public Health with 1.5 fte workers. We are now funded by Lincolnshire County Council Public Health (formally NHS Lincolnshire Public Health) and Macmillan Cancer Support until April 14 and Sept 14 respectively, who fund a team of 4 f/t Development Workers.

The aim of the programme is:

To change behaviour and beliefs of the general public and GPs towards cancer; to facilitate earlier presentation of symptoms and early referral of patients with suspect cancer with a view to:

- Reduce premature mortality from cancer across Lincolnshire.
- Reduce the stage of presentation of cancer across Lincolnshire.
- Increase screening attendance across Lincolnshire.
- Improve overall 5 year cancer survival rates for Lincolnshire.
- The long term aim of the programme will be to develop local sustainable groups that will promote the message at the heart of every community, be that a housing estate, a school, a prison or any community of interest, particularly groups where English is not their first language.

The lessons learned from the existing programme will be promoted and marketed at a higher level and work with GP's and NHS Lincolnshire will continue to establish 'hard' evidence of successes

The objectives are to:

- Use community development approaches and training to ensure early presentation and healthy lifestyle messages get right to the heart of the community.
- Encourage volunteering to ensure the long term sustainability of the programme.
- Work with screening teams to improve access to screening and take up of screening appointments.
- Work with CCGs and individual GPs to increase the use of the Rapid Referral Guidelines to support the early diagnosis of cancer
- Work with individual GPs to identify hard to reach communities at higher risk of developing cancer.

Initially the programme was very much focused around raising awareness within the community, however more recently it has developed a much more strategic role, engaging with individual GP's and surgeries to target a specific demographic within communities to improve up take of screening or to address particularly areas with a high prevalence of specific cancers. Developing work with the screening teams has taken a more central focus, enabling a joined up working approach to developing new, targeted campaigns.

EPOC Annual Report 2012/13

Another big change to the programme is to have a much more co-ordinated approach to the work. Initially it was very geographically based, but the impact of something happening across the County within all CCG's is far greater for people affected by cancer and our volunteer groups who we work alongside.

In negotiation with commissioners we have agreed a set of Key Performance Indicators and we have devised a work plan that has 5 key themes which cut across the KPIs and provide a focus for our work across the County. They are:

1. GPs and CCGs

Rapid Referral Guidelines, GP Checklist, other work as requested by CCGs

2. Volunteering

Development of volunteering opportunities to ensure long-term sustainability

3. Promotional and development work

Local work and events – pharmacy campaigns, library drop-ins, work with schools and colleges

4. Screening

Promotion of screening services an improved uptake of services

5. Campaigns

Developing local campaigns according to need and promotion of national campaigns

EPOC Annual Report 2012/13

CCGs & GPs

In 2010 we decided to trial the Macmillan Rapid Referral Guidelines Toolkit with GP's and Dr Irene Carter from the Marisco practice in Mablethorpe agreed to trial them. She and her colleagues were very impressed, with an evaluation showing a much more effective referral rate. Based on this we started to roll out the distribution across all GPs and CCGs.

The Toolkit is a desk top card index which GPs have indicated is easier than an electronic version. Over 400 GPs across all the CCGs have been issued with the toolkits.

We are working with Macmillan to formally evaluate the usefulness of the toolkit by way of a Macmillan survey monkey which will be carried out with all GPs who have been issued with the toolkits. Results of this will be expected in the autumn of 2013. However verbal feedback from West Lincolnshire CCG GP's at their PLT (Protected Learning Time) meeting has been very positive with GP's stating they have found the toolkit very useful.

We have also created a 'checklist' for patients to support them to talk about cancer when they visit their GP. This lists some of the signs and symptoms of the 5 main cancers, breast, bowel, cervical, prostate and lung. It is aimed at helping people, who might not know how to start the conversation, and who will be worried and stressed, talk to the doctor and ensure that they don't forget anything during their visit.

Currently, in the Boston area EPOC and Public Health are working with Practice Managers and nursing staff to look at ways in which the programme is best placed to support GP practices to deliver quality premiums around cervical screening uptake across Lincolnshire East CCG. There is a particular drive to encourage women between the ages of 25-49 to attend and working with Mosaic data will mean that the programme will be able to identify particular social dynamics and geographical areas of high DNA rates and EPOC will target these groups directly, within the communities in which they live and the places they work and socialise in. Following the Boston lead this work will be rolled out along other identified areas within Lincolnshire East CCG and the Campaign materials created by EPOC to support the campaign will also be used across all other geographical areas currently covered by the programme.

The patient checklists have proved a really useful tool to help people communicate their worries to the nurse or GP. A College nurse states that they have proved "really effective in helping adults with learning difficulties communicate their worries and questions about their signs and symptoms".

EPOC Annual Report 2012/13

Volunteering

Over the year we have recruited 13 new volunteers across the areas. This makes a total of 58 (registered) volunteer across all areas. These volunteers have attended 207 events over the year making a total of 497 across all years. Volunteers are a very important part of the sustainability of the EPOC work; we would not be able to attend as many events if we did not have such committed people to work with us. They also spread the work in their day to day lives, which is invaluable.

In Lincoln we have a well-established volunteer base with a very experienced and committed lead volunteer who co-ordinates activities across the City. In other areas volunteering has developed in different ways:

- HMP North Sea Camp, which is run by inmates who have adopted the name EPOC Ambassadors. Prison services are so pleased at the success of this programme they want to roll it out across other prisons. We are also working with the University of Lincoln who are making a video about health in Prisons.
- In Lincoln the volunteers now have a market stall every month and are getting people re-visit month after month.
- Lincolnshire Schools Football Association EPOC Ambassadors, who play in a league and take the men's cancer messages across every time they play. They were also picked to be ball boys for an England V Wales international game and they wore their EPOC 'Balls' t-shirts.
- A coffee morning group has been developed on a large housing estate in Boston with the aim of improving attendance at screening appointments.

Because of the rural nature of Lincolnshire, it is can prove difficult to form volunteer groups across villages and districts. However the team bring volunteers from across the county together for volunteer support / training days.

Volunteering within workplaces and community groups has been increased through workplace training and community presentations. These types of volunteers provide the basic information on signs and symptoms in the places they go to regularly, e.g. an office reception or community hall. This means they can keep an eye on replacing leaflets, and offer support to those worried about cancer using our 'Use the C WORD' training, in turn directing them to see their GP if worried.

Volunteers have also attended introduction sessions where they get the opportunity to meet volunteers from other areas and get an up-date from the EPOC team about what is happening within the programme and are given the opportunity to feed ideas and suggestions to the team. We currently have volunteers doing work for the 'Pink Pants' Campaign that will promote the importance of attending cervical screening appointments; this work includes canvassing women within their area about their experiences of screening and what information they think we should be providing as part of the promotion and a young student from Mablethorpe Learning Centre has created the logo the campaign will be using. Other training courses are taking place such as Event Planning and Community Engagement and at the last meeting the volunteers identified other courses and training they would like to undertake. It is hoped that this can be done on a by-monthly basis where possible and across all the different areas in order to introduce the volunteers to each other's patch.

EPOC Annual Report 2012/13

The year before last a woman came to the Lincoln market stall, she walked past but after a little bit of time she returned and looked at leaflets. Our Volunteer asked her if she could help. It came to light that she had found a lump in her breast but was too scared to attend the doctors. The EPOC volunteer spent time talking to her and discussing the importance of early presentation and sharing personal experiences. The lady returned to the stall to say thank you as she attended the doctors and the lump which was cancerous had been removed. She said that if she hadn't seen the stall that day or hadn't been able to talk to someone she would have waited even longer before she had gone to her GP.

EPOC Annual Report 2012/13

Promotional and Development

We continue to promote our work in articles and publications both locally and nationally. Every quarter we have a full page article in Engage magazine which is circulated to all over 50's in Lincolnshire by Age UK. We have also had articles published in the County News magazine which goes to every house in the County. We contribute regularly to the Macmillan publication MacVoice, which is a national magazine for Macmillan funded professionals. We have taken part in Radio interviews with BBC Radio Lincolnshire, who welcomed our open conversation about Boobs and Balls self-examination and our most recent campaign 'Use the C WORD –Talk about Cancer'.

Over the last year, we have been limiting the number of groups we attend, using our time for larger gathering where we can get the message to a mass audience. These include:

- Moy Park – this is a large food processing and packing factory with a lot of migrant workers. Our development worker was invited to a Health Day of which 23 people attended from Lithuania, Russia, Portugal and Poland. We were able to distribute information in the various languages that they spoke.
- Barnardo's – the team provided training to staff to enable them to talk to vulnerable families about cancer. This has led to plans to work with the young people involved too.
- Asda – the team provide information and signposting for staff in various stores around the County.
- North Kesteven & West Lindsey District Councils – staff have provided Healthy Lifestyle and Boobs and Balls sessions in various locations for members of staff. In North Kesteven this has progressed to the team delivering regular workshops on community based Fit for Life courses that are organised by Health Trainers.
- RAF – staff have provided display materials and information for civilian and RAF notice boards and accommodation blocks at RAF Cranwell and have attended numerous health events at the Waddington, Cranwell and Conningsby RAF bases. EPOC has supplied the Dental Corp with information to help them develop a mouth cancer awareness programme.
- Lincolnshire County Council (Children's Services) – regular Healthy Life Styles and Boobs and Balls sessions have been delivered to young people attending local youth clubs. Youth Workers have been supplied with awareness information for them to use with young people to create their own awareness displays.
- And of course the Lincolnshire Show with our colleagues from Health & Screening services.

As well as the specific work with employee groups we have contributed to a County wide initiative with libraries and pharmacies. This work involved linking in with national campaigns and providing the venues with local information to create their own awareness displays. EPOC also held regular information and drop-in events within the pharmacies and libraries. This has been a great opportunity to work alongside the libraries and other organisations to introduce the C-WORD and GP checklist leaflets. Most libraries have asked that we return on a monthly basis to introduce each month's cancer awareness campaigns and leave information stands, boards or leaflets with them.

EPOC Annual Report 2012/13

At a Health and Wellbeing Day in April 2012, organised by EPOC and taking place at The Source in Sleaford, a lady in her early 40's approached the EPOC Development Worker to discuss concerns she had about breast lumps. She was given information leaflets in her own language (Chinese) and encouraged to visit her GP to get her symptoms checked out. Eight months later the lady visited the EPOC Drop-In session at Sleaford Library to say that after reading the leaflets she had visited her GP to discuss her symptoms. Further investigations revealed that she had breast cancer and after surgery and 7 weeks of radiotherapy she is currently cancer free. She believes that the information she received from EPOC saved her life, she had previously been unable to find information in her community in her own language and presumed that the lumps were normal for a woman of her age.

Similarly we have been working with the pharmacies on introducing the C-WORD campaign into the community. There has been a mixture of information stands, volunteer hand-outs and poster/leaflet campaigning. We are planning on following this work up with bespoke training for the pharmacy staff.

Work with schools and colleges have formed a large part of the work this year too. Colleges have included:

- Mablethorpe – working with students in an eight week programme, this has resulted in them making a video, which supports young people to present any worrying symptoms to their GP.
- Skegness – Health and Social Care students produced promotional materials of a very high standard. They also worked with the Mablethorpe students to put on a joint event to showcase the materials they have produced over the year.
- Boston – the Health and Wellbeing team at the college contacted the team to request input into their Health promotion Calendar Events. They particularly wanted information re Boobs and Balls. This was the first event a new young (only 18) volunteer attended, the students responded to her very well and it spurred her to carry out a piece of work in her old school – Boston Grammar.
- Grantham – regular information stands around healthy living and promotional events at fresher's and returners fairs. The college has been supplied with awareness and healthy lifestyle information in various formats and languages so that it can be used for in-house awareness campaigns and as part of health and social care lessons.
- Lincoln – the team has been working with Lincoln College now for some years and runs workshops over 2 days, sometimes working with single sex groups which provides a very different setting for discussions.
- Foundry Learning Centre Gainsborough – extended work with young women around the use of sun beds and skin cancer.

EPOC Annual Report 2012/13

As a result of involvement with the Healthy Schools Initiative we have delivered sessions to Early Years Practitioners throughout the County. Under the banner of the 'use the C Word' promotion we have run sessions on 'Talking about Cancer' and resource packs have been requested for all group attendees to take into their own work areas.

Because of this work in schools and colleges we are considering writing an Accredited Course that could be offered that would add to the learners CV in the longer term. developmentplus is an Accredited Centre with National Open College Network and we will look into the development of this over 2013 /14.

The biggest promotional event of the year is of course The Lincolnshire Show, where the team and their volunteers shared space with the screening teams. This was very well attended and generated requests to work with the Girl Guides Association, Sleaford Children's Centre and the Healthy Schools Co-ordinators.

EPOC Annual Report 2012/13

Screening

Screening take up across the County is patchy to say the least, with some CCG areas having some of the lowest take up in England. One of our key targets this year was to improve the take up, by promotion, myth busting and working closely with local people in the areas where take up is low and finding out 'why' people don't keep their appointments then addressing this with the surgeries and screening providers.

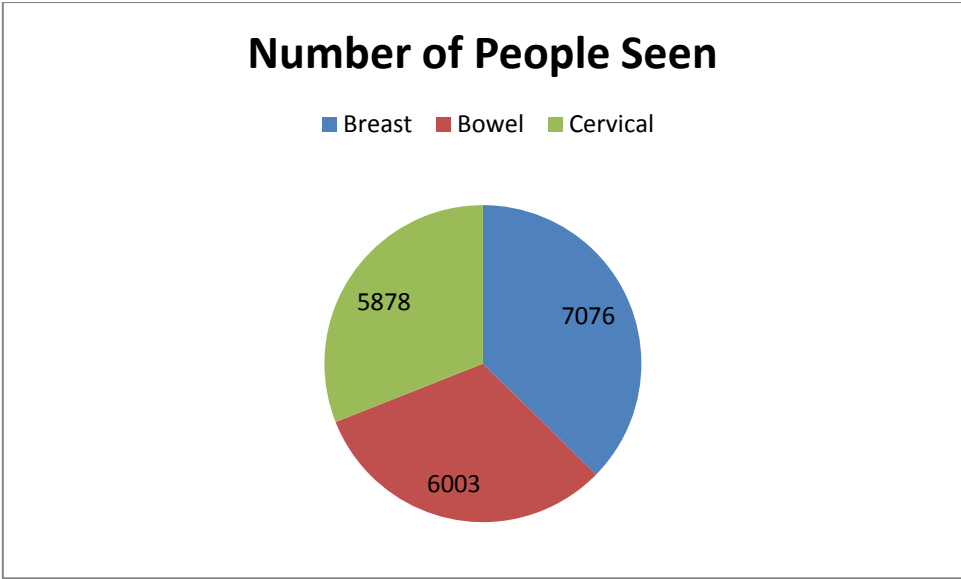
We provide information relating to all national screening campaigns, such as:

- Bowel screening, this provided the focus for one of our articles in Age UK's Engage magazine as it specifically targeted the age group where it is most prevalent. Home testing kits are promoted on our information stands and we actively encourage people to use them.
- Cervical screening, this affects women of all ages, so a campaign is being designed to ensure we get the right message across to the right people. HPV vaccination is offered to all young women in year 8 (12+) – but they have to have all 3 treatments for it to be effective and many will receive the first 2 but then miss the 3rd as it is not made clear the importance of completing the course. We are designing specific information to raise awareness of this. Older women also fear the 'smear test' and just don't attend.
- Breast screening, is so important and readily available, but again women do not take advantage of it when they are called. The reason a lot of women give is that they have not felt a lump; however when we ask them to feel for the lumps in our prosthetic breasts they realise how difficult it is to find them. Again, it is essential that women are screened to identify any abnormalities at an early stage. When we are working with young people we also promote self-examination to young men as the prevalence of breast cancer in men is growing.

Screening teams are now working alongside us at community events and this partnership is ensuring that the 'screening saves lives' message is getting out in to the heart of communities.

M is a volunteer for Skegness; she joined due to having been through breast cancer 4 times and having had a mastectomy. She wanted to talk to people about the importance of attending screening and catching it early. Whilst talking to a lady she works with the lady told M she was worried about puckering of her nipples but because she hadn't got a lump she thought it wasn't breast cancer, and that it was just something that happened as you got older. M convinced her just to get it checked out, and gave her one of our checklist leaflets as a way of broaching the subject with her GP. A few weeks later the lady approached M and told her that she had been to her doctor who had sent her to the hospital for an ultrasound and mammogram – it turned out she had breast cancer and was starting treatment. The GP had told her she was quite advanced but that treatment should work. The lady was extremely grateful to M for helping her get a diagnosis, and she has now finished treatment and is living with cancer.

EPOC Annual Report 2012/13



The chart identifies the numbers of people spoken to specifically relating to breast, bowel and cervical screening across the County.

EPOC Annual Report 2012/13

Campaigns

The EPOC work has involved a lot of campaigning both locally and linking into national campaigns.

National campaigns are promoted in an annual cycle, during the year we have supported:

- April – Bowel Cancer Awareness
- May – Be Clear on Cancer Lung Campaign
- June – Everyman Cancer Awareness & Cervical Screening Awareness
- July – Ethnic Minority Cancer Awareness
- August – Be Clear on Cancer Bowel Campaign
- September – Sexual Health Campaign
- October – STOPtober (smoking cessation) & Breast Cancer Awareness
- November – MOverner, Men's Cancer Awareness
- December – Mouth Cancer Awareness
- January – Love your Liver & Cervical Cancer Prevention
- February – Feel Good Friday, World Cancer Day & International Childhood Cancer Day
- March – Ovarian & Prostate Cancer Awareness Month

Local campaigns the EPOC Team have developed since the start of the programme have included:

Boobs & Balls

This campaign was designed to target young people aged between 14 and 24 years. We wanted to get young people to self-examine on a regular basis, so it became the norm in adult life – like brushing your teeth. Young people really got on board with this campaign; they wanted t-shirts, sports bags, wrist bands so they could get the message across to their friends and family. It has been a huge success in schools and colleges too and the team are well versed in talking to young people and not making cancer too much of a scary subject. The number of young people affected by cancer is huge and in many instances they have no one to talk about the subject to. Their grannies, granddads, aunties, uncles, even their parents could have been ill or died, but from our experience young people are kept outside family discussions.

Use The C WORD – Talk about Cancer

This campaign was developed specifically to get people to talk about cancer – not be afraid to ask people about how it's affecting them. To get over the fact that it's not catching!! And more importantly it doesn't have to be a 'death sentence'. We launched it at the Lincoln Drill Hall in November 2012.

To support this campaign we have developed a tri-fold leaflet 'checklist' which a patient can use to help them talk to their doctor about their symptoms. It covers the 5 most common cancers; breast, bowel, cervical, prostate and lung, is colour coded to link with the GP Toolkits and has tick boxes as an aid memoir which will help the patient describe how they are feeling. It also has useful information about the particular cancer and a space where the patient can write down things they want to ask their GP but might forget because they are anxious.

EPOC Annual Report 2012/13

We have developed workshop and training resources that use speech bubbles and role-play which asks participants what they would say to their friend, or other people, if they told them they had cancer. This helps people to 'practice' what they might say and it makes it easier and 'normal' to talk about it.

Pink Pants

We are in the process of developing a new local campaign based on the high prevalence of cervical cancer and the low take up of screening in our area.

The next big campaign will be our 'Pink Pants' campaign. We are currently working with volunteers and partner organisations to create promotional materials and information that will be disseminated throughout the County. The Pink Pants theme will also be used by the GP practices to promote uptake within their patient populations.

Our volunteers and groups across all areas will decide on the 'message' – it needs to be challenging, thought provoking, but most importantly recognisable, something people will know. As mentioned earlier, cervical cancer affects a very wide age range, so we have representative of all ages involved in the development of the campaign.

In relation to young women and the HPV vaccine we are developing specific information which will give factual information re the vaccine and will dispel beliefs some young women hold. For example:

- "now I have had the jab I cannot get pregnant"
- "I do not need to have screening when I am older"
- "I cannot get pregnant, now I have had the jab"

Watch this space... for the Pink Pants campaign

EPOC Annual Report 2012/13

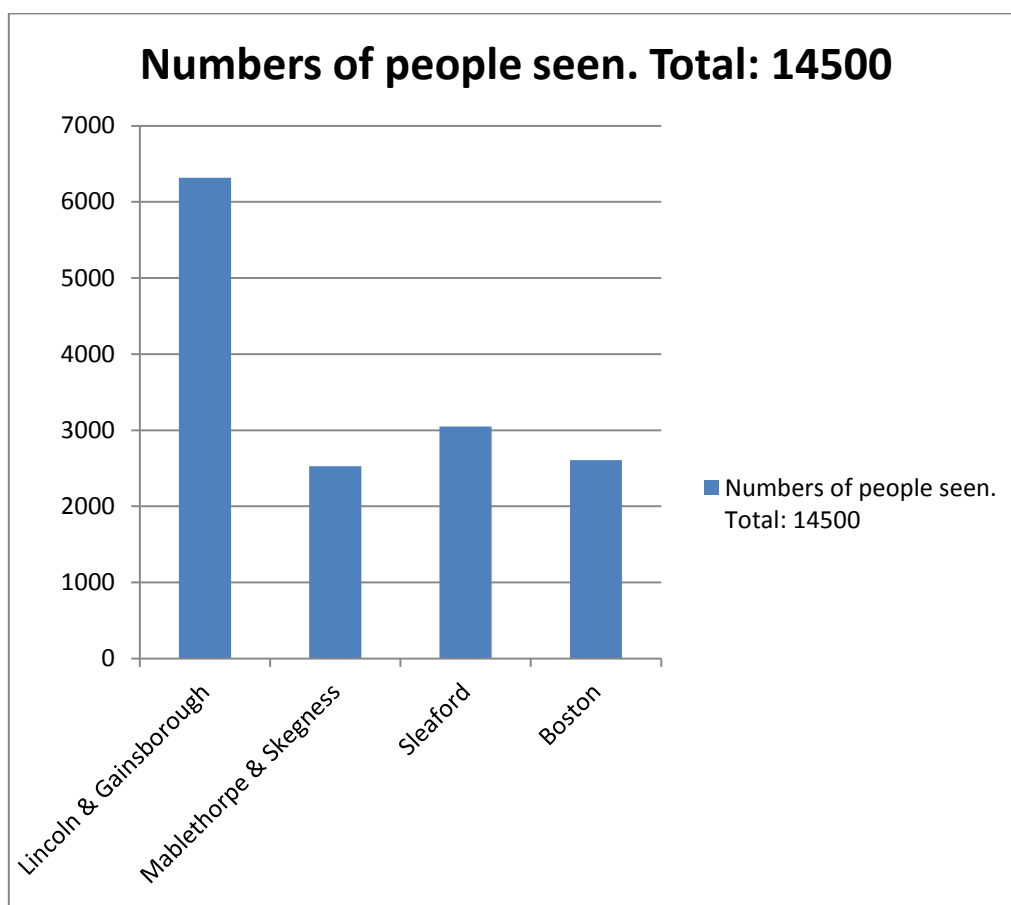
Data Collection

We have been collecting data since the commencement of the programme. We have tried to collect data to link with the KPIs (Key Performance Indicators), however this is proving difficult as we have to rely upon Health Service colleagues to provide this and in some cases they don't have the information themselves. We are continually looking at what we collect and how we collect it to refine our results. We are also working with a statistician from Lincolnshire West CCG to review this.

KPI	Rational	Total 2012/13
Events attended	Across all areas	509
People seen	Anyone who has been spoken to directly either in a one to one or group setting, at an information event or at a presentation	14,500
Questionnaires	Numbers of cancer awareness questionnaires completed at events etc.	316
Information	Information given to people or picked up by people at all events	8,840
Screening	Number of times screening has been promoted – at any event or with an individual	6,234
Campaigns	Number of times a National Campaign has been promoted at an event or with an individual	6,585
Promote EPOC website	Number of times the website has been promoted	8,791
Other – REACH	The potential number of contacts e.g. circulation of newsletters, football supporters, newspaper readers etc.	56,620
GP Practices	First contact with GP practice – number of practices. Can be contact for tools or other reasons	54
Tools introduced	Number of toolkits distributed	338
Training GPs	Number of people attending GP toolkit training either GPs / Practice Managers / Nurses	4
GP toolkit evaluation	Number of practices taking part in evaluation of toolkits	0
Volunteers recruited	Actual number of new volunteers per year	58
Volunteers attending events	Number of volunteers delivering events with the EPOC team or volunteer delivered events	497
Volunteer Lead identified	Only to be recorded once	10

EPOC Annual Report 2012/13

Boobs and Balls	Number of events where Boobs and Balls is promoted	754
Promotion of Macmillan in Every Community (MIEC)	Number of times MIEC is promoted in various areas	52
Develop priority target groups	Specific group development linked to prevalence of cancer in specific areas	20
Quarterly reports	1 each quarter for each area	16
Breast	Numbers of people specifically referred or given information	7,076
Bowel	"	6,003
Cervical	"	5,878



This chart identifies the number of people directly spoken to and given information re cancer in general

EPOC Annual Report 2012/13

Key Performance Indicators – achievements during the year

Indicator	Measure	Activity / Commentary 2012 /13	Work plan	Total number
20 new volunteers recruited each year in each area	Registration with the programme	Over the year we became aware that the 'lead volunteer' model in some rural areas, was not feasible, so we concentrated on developing volunteering in a different way	2	58 across all areas
40 events attended in each CCG	Records of events	We have been targeting bigger events this last year and have made the decision not to attend smaller monthly events e.g. coffee mornings	3	509 across all areas
Courses- Behaviour change intention pledges signed on the course, reviewed at six months	Questionnaires and signed pledges	We have ran 32 courses this year and all students worked with have produced a video or promotional material or artwork to present to others	5 Cross cutting	32
Promote EPOC through social media	Number of hits on the website, Facebook and Twitter	We have had some issues with our website this year which has meant that we have been unable to collect regular data. The website is now under reconstruction however we continue to promote EPOC through our Facebook and Twitter pages	2 + 4	Issues with website
Numbers of people presenting to GPs with EPOC leaflet	Leaflets returned by practice	We will be working with the CCGs and GPs to find a way of collecting this data. Leaflets are obviously being picked up as we have requests to replace them.	1	Leaflets in surgeries, libraries, pharmacies and community locations
Devise and promote awareness campaigns	Initiated campaigns	The main campaigns have been Boobs & Balls, Use the C WORD – Talk about Cancer and we are preparing a Cervical Screening campaign	5	3 Local 16 National
Increase in people attending for cancer screening	Campaigns based on cancer screening information received from the National Screening Programmes/Public Health Targets matrix. Aim for positive change from 'red' to 'amber' or 'green'	We are working very closely with GPs and practices to target geographical areas and specific demographics to increase uptake of screening appointments	4	Work continuing to grow with screening colleagues. Anecdotal evidence suggests a rise in the up take
On-going audit activity to identify barriers to screening	Information collated and passed to practices to action	Research and consultation is being carried out by the team.	1 + 4	On-going

EPOC Annual Report 2012/13

Indicator	Measure	Activity / Commentary 2012 /13	Work plan	Total number
All GPs in each CCG using rapid referral guidance toolkit.	Based on the evaluation of tool kit (carried out by Macmillan) we will evidence use across all CCGs	Every GP in the County, across all CCGs have been issued with the toolkit and patient 'Checklists' are now available in practice waiting rooms	1	All GPs across all CCGs now have toolkits
Continue to develop positive relationships with a diverse range of communities and agencies	Number of new contacts made with organisations and within the community.	Schools, colleges, prisons, workplaces, local authorities, NHS Services, community groups, Voluntary Centre Services.	Cross cutting all themes	On-going

Key to work plan themes:

1. GPs and CCGs

Rapid Referral Guidelines, GP Checklist, other work as requested by CCGs

2. Volunteering

Development of volunteering opportunities to ensure long-term sustainability

3. Promotional and development work

Local work and events – pharmacy campaigns, library drop-ins, work with schools and colleges

4. Screening

Promotion of screening services an improved uptake of services

5. Campaigns

Developing local campaigns according to need and promotion of national campaigns