



# **Early Presentation of Cancer Programme**

**EDUCATE. SUPPORT. INTERACT.**

**2008 – 2015 AND BEYOND**

**Education and training**

**Campaigns**

# **Community development**

**Volunteering**

**Partnership work**

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## Introduction

Early Presentation of Cancer -EPOC is a programme built upon Community Development Principles to push forward cancer awareness and early presentation messages in ways that are appropriate to individual communities.

The programme began in 2008 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 March 2015 and have a team of 4 fte Development Workers.

**The aim of the programme is to:**

**Challenge existing behaviour and beliefs associated with cancer, to raise awareness of signs and symptoms and encourage early presentation and early referral of patients with suspected cancer.**



### The objectives are to:

- † Use community development approaches and training to ensure signs & symptoms and the early presentation 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 Clinical Commissioning Groups (CCGs) and General Practitioners (GPs) to identify hard to reach communities at higher risk of developing cancer and to promote the continued use of the Rapid Referral Guidelines to support the early diagnosis of cancer.

### With the outcome of:

- † Reduced premature mortality from cancer across Lincolnshire.
- † Improved overall 5 year cancer survival rates for Lincolnshire.
- † Reduced Health inequalities across Lincolnshire, particularly relating to cancer.

## Partnership working

The programme has worked hard to set down solid roots within communities and over the years has strengthened its position by adding a strategic element to the work.

Engaging with GPs and surgeries to target identified groups within communities to improve screening uptake and / or to address particular areas with a high prevalence of specific cancers.

Partnership work with the screening teams has resulted in a more focussed approach to developing new, targeted campaigns.

The EPOC team have a presence on the Lincolnshire Adult Screening Programme Health Promotion Board where our knowledge and experience of working directly within communities is proving vital when looking at ways of promoting screening in areas of low uptake.

We also sit on various health and wellbeing boards and have been asked to bring our grass roots perspective to the meetings, which feeds into the strategic decision making process.



### Key Partners include:

Lincolnshire County Council (LCC) Public Health, Macmillan Cancer Support, Lincolnshire CCGs, Health Network Co-ordinators, LCC Healthy Schools, LCC Children's and Adults Services, LCC Libraries, Local authorities, Local employers, Voluntary and community sector groups and organisations, University of Lincoln, Colleges, Healthwatch Lincolnshire, Voluntary Centre Services, Total Voice, Carers Partnership, Age UK, NHS Cancer Screening Programmes

### Who EPOC informs:

Lincolnshire Strategic Cancer Board, Health & Wellbeing Partnerships ( feed into the Lincolnshire Health & Wellbeing Board), Lincolnshire Cancer Patients, CCGs and locality groups, EPOC Programme Board (Public Health), Healthwatch Lincolnshire, Macmillan Cancer Support, Cancer Screening Strategy Group, Lincolnshire Adult Screening Programme Health Promotion Board

## Our Work Streams and Achievements



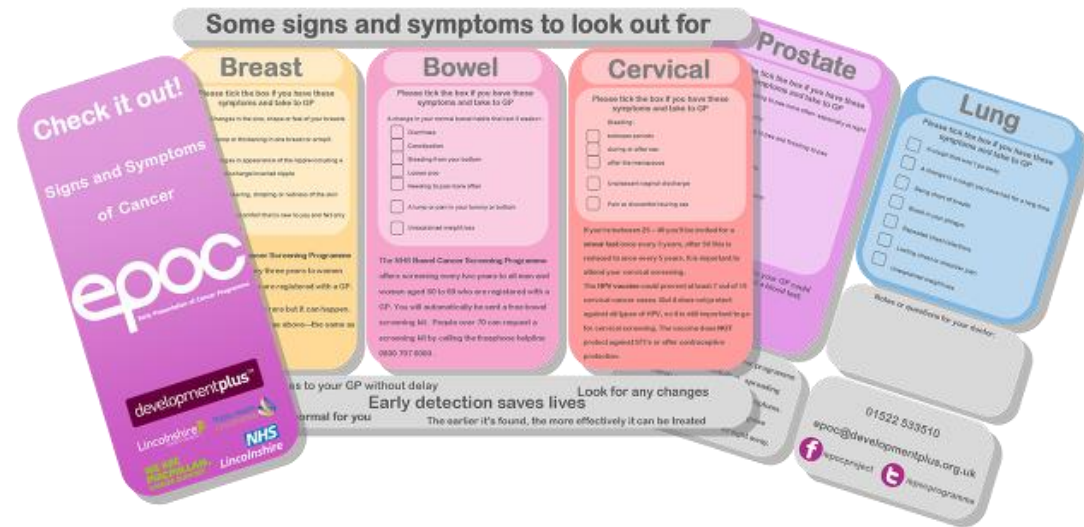
# Work taking place with Clinical Commissioning Groups (CCGs) and GP Practices

**EPOC has worked across all  
103 GP Practices in Lincolnshire**

- 👤 We have developed and maintained contacts within the Lincolnshire CCGs
- 👤 Increased awareness of the EPOC Programme within CCGs and localities, and enabled them to acquire a greater understanding of the value of community-based development work in delivering health messages directly into communities.
- 👤 We give presentations at CCG meetings, at locality meetings and during GP Protected Learning Time to showcase some of the campaigns that have been created by EPOC and also highlighting the work being carried out by the EPOC team and its volunteers.

## Our Work Streams and Achievements

## Check it out Leaflet



Our 'Check- it- Out' leaflets (checklists) are available countywide and our aim is that they continue to be used by patients and GPs. They were developed alongside a focus group of volunteers and GPs in order to become a useful conduit to start a conversation regarding cancer during a limited consultation time with their GP.

The checklists have enabled patients and GPs to have an effective aid to communication and greater awareness about signs and symptoms of high incidence cancers and also screening services. The checklist will be updated for 2015-2016 to include new screening information and a larger space for patients to write down their questions and concerns before visiting their GP.

## Our Work Streams and Achievements



## Volunteer development and sustainability

Since 2008 we have recruited an average of  
**42 volunteers a year**

EPOC has a group of dedicated volunteers working across the county to provide invaluable support and links into their communities. They:

- † Run information stands & disseminate promotional materials
- † Support in development of new campaigns
- † Deliver cancer awareness sessions within their communities
- † Provide a real connection to people wanting to be cancer aware and also those affected by cancer

They have supported  
our work over **1500x**  
since 2008 averaging  
**1,610 hours** of their  
time a year



## Our Work Streams and Achievements



## Volunteer development and sustainability

**“I volunteer because I’m a cancer survivor myself. I feel that the support and information EPOC gives out to people is very important. It’s incredibly rewarding.”**

Volunteers reach sections of their own communities that workers sometimes cannot access. The result is an ability to talk to hard to reach clients, providing them with the tools to increase responsibility for their own health.

**Over the last 8 months  
volunteers have given  
625 hours of their  
time. The cost value  
equates to £4,844**

## Our Work Streams and Achievements



Volunteers from Lincoln University supported the inmates at HMPS North Sea Camp to **film a cancer awareness DVD**. Prison ambassadors decided on the content and message whilst also filming and editing themselves.

The **DVD is now shown at induction to all new arrivals** and the ambassadors give a presentation about the programme and the information and support service they now offer.

Macmillan took over lead of the ambassadors project in order to enable sustainability, but also to develop it as a **pilot scheme to be replicated across the country**.

## North Sea Camp DVD



**CANCER IS A WORD...**



**...NOT A SENTENCE**

Shaun continued to be involved with the EPOC volunteer group after his release from HMPS North Sea Camp

## Our Work Streams and Achievements



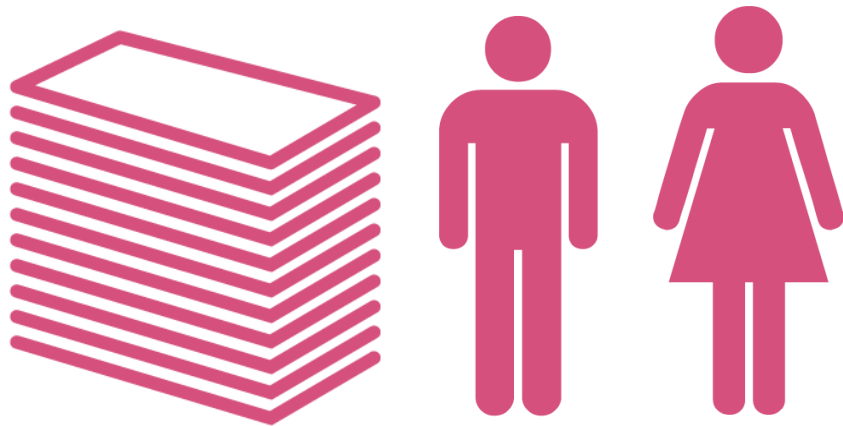
## Early presentation and development work – including screening and campaigns

EPOC awareness raising campaigns and activities are **community led** using the knowledge of local community members to deal with the issues that affect those communities.

This ensures that messages about early signs and symptoms are culturally appropriate, accessible and understood by those that are part of a particular community and enables more people to be in control of their own health and reducing the number of ‘**cancer chancers**’.

**We work closely with the East Midlands Health Promotion Team (NHS England) to target areas with low screening uptake and develop new material to support improvement.**

## Our Work Streams and Achievements



The Boobs & Balls campaign was designed to target young people aged between 14 and 24 years.

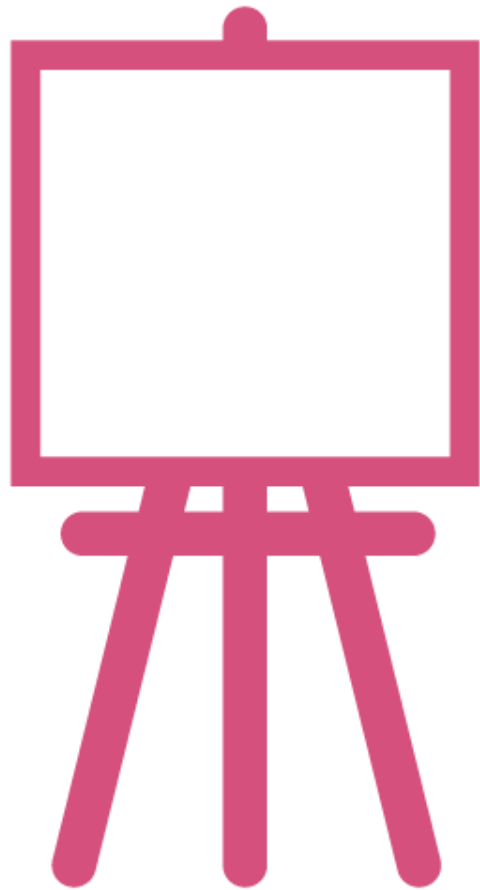
We wanted to get young people to self-examine on a regular basis, so it becomes the norm in adult life – like brushing your teeth.

Volunteers in schools and colleges were involved in creating t-shirts, sports bags and wrist bands so they could get the message across to their friends and family.

## Boobs and Balls campaign

**19,729 people** have been shown how to check their breasts and testicles since 2011





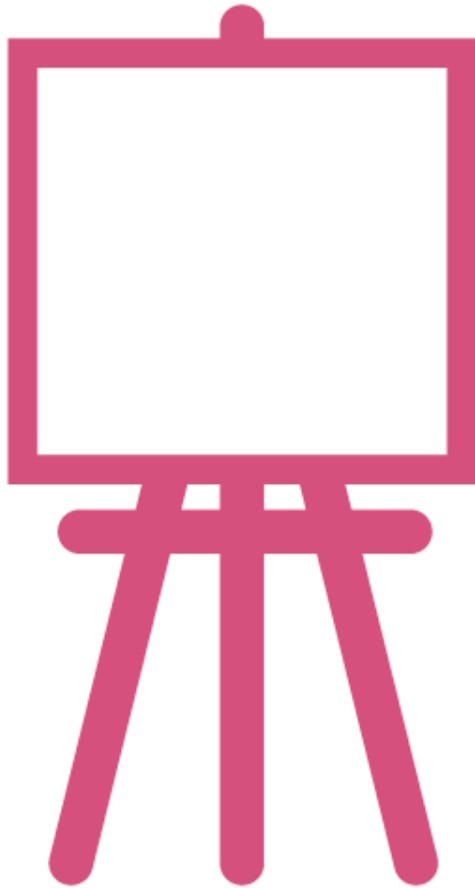
### Training delivered accredited and non-accredited

EPOC delivers information sessions about cancer awareness, early presentation and the importance of attending screening.

We have created a selection of workshops which last for an hour that can be tailored to identified need.

EPOC has created a Cancer Awareness Course which was accredited at Level 2 by CERTA (formerly the Open College Network). It includes all elements of the training workshops we currently deliver and consolidates them into a 10 hour course.

On average we deliver **64 workshops a year**  
seeing **31 people a time = 1, 984 people**



### 10 hour cancer awareness course

This was originally piloted in Mablethorpe college in 2013, developing on from our one hour sessions. It has been offered as both accredited at level 2 and non-accredited.

**C-Word**, talking about cancer, current understanding of the learners, myth busters and general information

**Boobs & Balls and the bits in-between**, self-examination, screening, HPV vaccination

**Lifestyle & Safe Practice**, this would include risk factors, smoking, drinking, and diet

**Lifestyle & Safe Practice**, this would include risk factors, sun awareness, and safe sex

**Signs & Symptoms**, recognising signs and symptoms of the above in more detail

**Behaviour Change**, review C Word (in the light of the learning) promotion, action plan, pledges and the way forward

**56 people have completed the course**

**560 hours of knowledge between them**



## The Problem

In response to information showing a downward trend in cervical screening uptake across the county one of our key targets during 2013/14 was to look at why women were not attending appointments and promote the benefits of cervical screening in areas of low uptake.

## Creative solutions

- † **Pink paper.** All practises were provided with a ream of pink paper, headed with the PP logo. These were used to send out initial appointment letters inviting women to attend their cervical screening.
- † **Appointment purse card.** Handy purse sized information card about cervical cancer and screening, the importance of attending and what to expect, space to write appointment info.
- † **Support practises.** EPOC delivered community feedback straight to the surgeries. One practise set up a text messaging service to remind women to attend. Another changed clinic times for sample takers in order to be more accessible to women who worked.
- † **Information sessions.** Delivered in children's centres, colleges and women's groups on HPV, screening and symptoms

## CASE STUDY: PINK PANTS

### The Information

Working in partnership with the eight GP practices in and around Boston and Lincolnshire Public Health, we were asked to look at ways of improving cervical screening rates for the 25 to 49 years old by 3%, achieving an average CCG wide target of 75.7%.

During 2012/13 we spoke directly to nearly 6,000 women about cervical screening. They told us of the barriers they face in relation to attending screening appointments. Issues such as fear and the timing of appointments were being mentioned again and again, especially from women who work.

We recognised that a variety of approaches were required to achieve the increase in uptake we desired. We needed to focus on the target population, as well as with the screening service provider, GPs and the CCGs. EPOC demonstrated the effectiveness of community development in delivering health messages and meaningful campaigns where it needs to be heard – in the heart of communities.

## What if...?

All GP practices continued to use pink paper for appointment letters...



## CASE STUDY: PINK PANTS

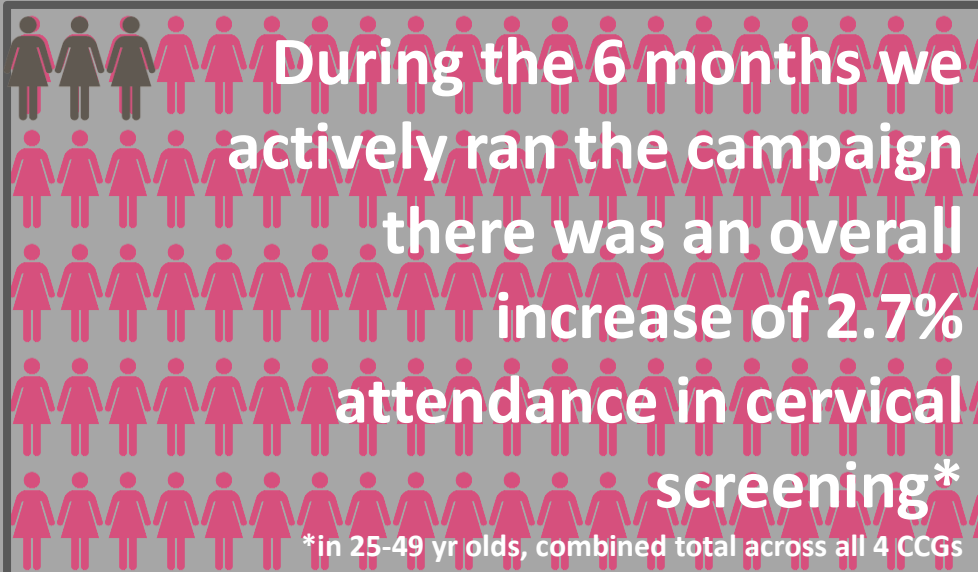
### Results

After an initial pilot in the Boston locality the Pink Pants campaign was launched countywide in January 2014. The EPOC team actively ran the campaign for six months alongside training sessions, support to surgeries who wanted information stands and free initial attendance packs.

**Over 2000 women were directly engaged in the Pink Pants campaign during this time.**

**7,205 women directly engaged through Pink Pants campaign**

**Between 2012-2015 EPOC have given 14,889 women information on cervical screening**



**What if...?**

**Screening could be done at the same time as your shopping...**





## CASE STUDY: PINK PANTS

### Results

- ↑ A community led campaign continues to be used across the county
- ↑ In areas where GP practices have led with the campaign the increase in uptake rates is sustained
- ↑ The Skegness and Coast locality continue to use the paper to boost attendance
- ↑ One practise set up a text messaging service to remind women to attend.
- ↑ Another changed clinic times for sample takers in order to be more accessible to women who worked.

### What if...?

- ↑ Screening could be done at the same time as your shopping?
- ↑ All GP practices continued to use pink paper for cervical screening appointment letters?
- ↑ Sample taking clinic times could be altered?
- ↑ There was an intervention between 16-24?
- ↑ Teenagers understood why they need a HPV jab?

These are some of the questions we bring to the table when working with partnership agencies. We believe that a sustained combination of these solutions could improve uptake in Lincolnshire, and we continue, alongside our partners, to work towards this.

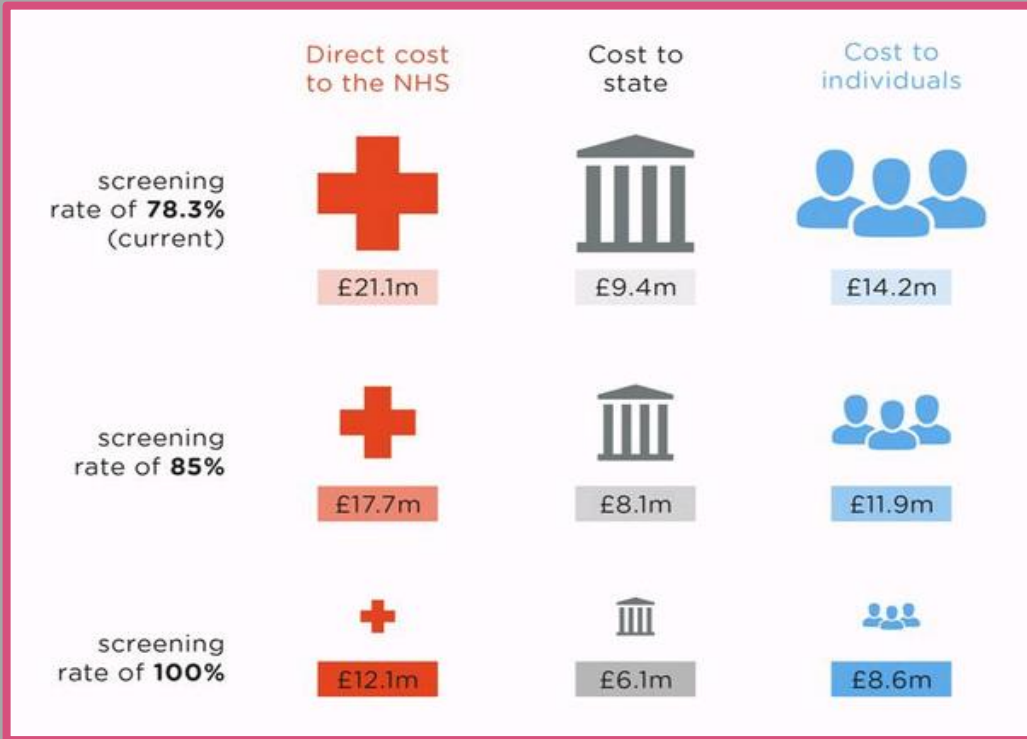


What if...?

Sample taking clinic times could be altered...



How much does cervical cancer cost a year?



Higher cervical screening coverage would save the NHS £9m a year

'Behind the screen' report – Jo's Cervical Cancer Trust & Demos

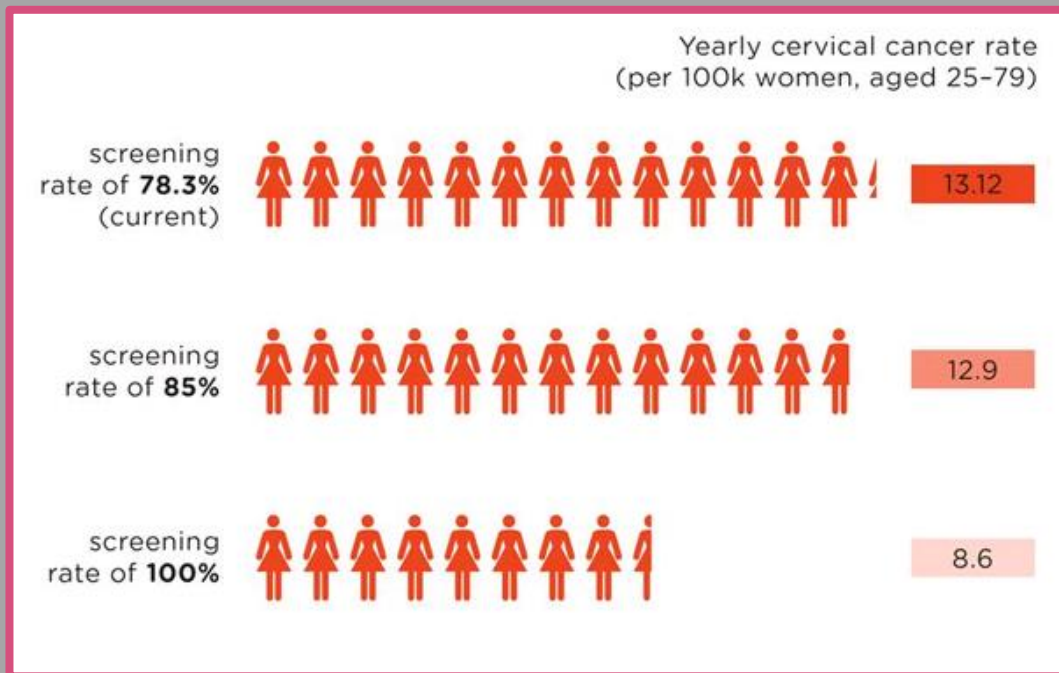
## CASE STUDY: PINK PANTS

If screening uptake rose to 85% coverage numbers diagnosed would drop by 14% in just one year and deaths would fall by 27% over five years.

If 100% screening rates were achieved deaths from cervical cancer in England could halve and incidence would reduce by a third (35%) over five years.



How many women are diagnosed with cervical cancer a year?



Higher screening coverage could result in a **35% reduction** in cervical cancers a year

'Behind the screen' report – Jo's Cervical Cancer Trust & Demos

## CASE STUDY: PINK PANTS

The average cost to the NHS per person diagnosed with stage 2 or later cervical cancer is **£19,261**, whilst for those at stage 1a, the cost to the NHS is around **£1,379** per person.

The combined financial burden of cancer-related costs, additional living arrangements and loss of income for women diagnosed with more advanced cancer is **£1,102** a month. However, early detection reduced the financial impact on individuals and their families to just **£360** a month.

Where we go from here...



Between 2008 – 2015 we have:  
spoken to **155,944 people**  
attended **1,770 events**  
reached **over a million** people  
using press and media

The cost of one full time development worker is around  
**£40,000 per year**

The cost of treatment for someone diagnosed with  
cancer at stage 2 or later is on average around  
**£30,000**

Where we go from here...



## The Service Model

The EPOC programme is incredibly transferable and lends itself well to other long term conditions such as diabetes, heart disease or dementia where awareness is an issue, and early intervention could make a difference.

The main principles of the work:

- 👤 Community development
- 👤 Volunteering
- 👤 Partnership working

The model is based around building the public's self-efficacy, improving their decision making and developing self-confidence to make changes in their lifestyle. It's about attitude and motivation that affects changes in behaviour.

Lessons learnt for improving the service:

- 👤 Collect hard evidence of impact from the very start
- 👤 Use a sample of 50 people we have come into contact with and follow up over the course of the programme
- 👤 A dedicated volunteer co-ordinator improves service performance

Where we go from here...



**“EPOC works tirelessly to build links with local health services and to develop screening campaigns”**

**Tony Hill, Director of Public Health,  
Lincolnshire County Council**

*“The patient checklists have proved a really useful tool to help people communicate their worries to the nurse or GP...really effective in helping adults with learning difficulties communicate their worries and questions about their signs and symptoms”*

Community Nurse

*“We have forged a strong collaborative working relationship with all members of this team...They have been proactive in the delivery of key initiatives relating to the cancer screening programmes to the population of Lincolnshire.”*

Screening and Immunisations Manager

*“The EPOC programme is vital in supporting key objectives to ensure our priorities are met within this CCG. The team work non-stop to provide creative solutions delivered with passion; successfully meeting the community’s needs is at the heart of everything they do. And they do it brilliantly.”*

Lincolnshire GP

## Where we go from here...

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. A lady she worked with told M she was worried about puckering of the skin around 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 lady was extremely grateful to M for helping her get a diagnosis and she has now finished treatment.

## Success Stories

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.



Early Presentation of Cancer

Telephone 01522 533510

Email [epoc@developmentplus.org.uk](mailto:epoc@developmentplus.org.uk)

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 Twitter @epocprogramme

[www.epoc.me](http://www.epoc.me)

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