

## ShowCase

### Early Presentation of Cancer Symptoms Programme

**Topic:**

Cancer

**Organisation:**

North East Lincolnshire Care Trust Plus

**Location:**

North East Lincolnshire (Yorkshire and Humber)

**Dates:**

Pilot 2007 to 2008; Now mainstreamed and ongoing

**Budget:**

£107,000 for original pilot (2007 to 2008)

**Website:**

[www.nelctp.nhs.uk/services/cancer-collaborative](http://www.nelctp.nhs.uk/services/cancer-collaborative)

**Contact:**

Julie Grimmer (Project Manager)

**Email:**

[Julie.grimmer@nhs.net](mailto:Julie.grimmer@nhs.net)

**Telephone:**

01472 232 261



### Overview

'Early Presentation of Cancer Symptoms' is a community-led programme working across deprived communities in North East Lincolnshire. It uses local knowledge and communities to encourage people to present earlier with suspected symptoms of bowel, prostate and gynaecological cancers, with the aim of reducing cancer mortality rates.

Combining social marketing, community involvement and rapid improvement methodologies, the programme developed and worked with community teams of local people to gather insight across networks and establish connections, acting as a 'passport' into communities.

### Key results:

- 50 per cent increase in the number of bowel cancers referred into services through two-week waits; 67 per cent increase in prostate cancer referrals; 28 per cent increase in gynaecological cancer referrals
- 15 per cent (in 2007/08) increase in people feeling confident in identifying cancer symptoms, with a further 13.9 per cent increase in 2009/10
- 11 per cent increase (in 2007/08) in reported willingness to act on symptoms, with a further 11.6 per cent increase in 2009/10



Cancer affects one in three people across their lives, but it affects certain parts of our communities more than others. For a variety of reasons, communities that face inequalities present later with suspected cancer symptoms. Services find it harder to engage these communities and a range of patient and practitioner delays result in higher mortality and more complex care needs.



Across North East Lincolnshire (NEL), life expectancy in priority neighbourhood areas is on average seven years less than in other neighbourhoods. Locally, whilst cancer mortality is reducing overall, there is a widening gap in outcomes between the most affluent and the most disadvantaged communities.

As well as inequalities across cancer tumours, there are local inequalities across civic engagement indicators. Influences from the broader policy contexts pointed towards generating complementary solutions that engaged services and communities in common action on cancer, and social and human capital.

### **Community-led social marketing**

NEL already had experience of the Healthy Communities Collaborative (HCC) and this

provided a starting point for developing a new approach with a more explicit focus on:

- Social marketing, specifically on behavioural goals
- Two-way learning to develop the framework, rather than more rigid paradigms
- An 'Experts on the Ground' event, to provide direction, generate involvement and focus on local needs

In 2007, NEL Care Trust Plus (NELCTP) used Neighbourhood Renewal Funding to engage not-for-profit organisation Unique Improvements to design and implement a social marketing programme aimed at increasing early presentation of cancer symptoms amongst hard-to-reach populations. The funding was initially for 15 months, which allowed for 3 months planning and set-up, followed by a 1-year pilot programme. However due to delays in appointing key staff, the programme timescale ended up being a year.

NELCTP and Unique Improvements set out a project plan based around four-month slots, followed by learning workshops:

- The first four-month slot was allocated for scoping, development, stakeholder engagement and construction of an evaluation plan. This would be followed by the first learning workshop to up-skill volunteers in social marketing
- The second four-month slot was dedicated to rolling out the work on the ground. Ideas would be tested and partnerships formed before interventions were implemented. Again, this would be followed by a learning workshop
- The third and final four-month slot was devoted to using data and local knowledge to further drive improvements, as well as beginning to pull together the evaluation, publicising successes and working to embed the work in local strategies and activities to ensure sustainability. This would be followed

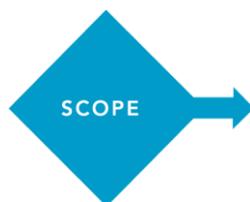
by a final learning workshop and dissemination of results and lessons learned

It was decided at the start that the programme would use 'Community Change Teams' made up of local people to engage with people and increase cancer symptom awareness. These teams would be supported by health professionals who would draw on local networks to recruit individuals.

A steering group was set up to oversee the work and guide development. This group included:

- A public health nurse
- A health trainer manager
- Specialist health promotion representatives
- A director of service improvement
- A representative from the cancer network
- Clinical nurse specialities from each tumour site
- Community volunteers

"The terms of reference for the steering group was very much around supporting the community teams to take the work forward, and if any barriers presented themselves organisationally, for them to help to offer a solution, but also very much to promote and champion the work, so that all facets of the organisation knew what was going on" (Julie Grimmer, Project Manager)



The programme team believed that the consumer is the most important participant within the change process. It therefore aimed to use local knowledge, combined with the professional evidence base, to plan locally-appropriate interventions, based on real audience understanding.

Considerable research was undertaken, including:

### 1. Review of evidence and good practice

An extensive review of previous programmes and best practice from the UK was conducted to learn what had and had not worked before.

Desk research was also conducted to establish existing local data and intervention measures to drive the programme forward.

### 2. Stakeholder input

The expertise of local service deliverers was crucial as it was accepted that the local knowledge of cancer workers was more up-to-date and relevant than generic service data. To explore these sources and engage stakeholders, an 'Experts on the Ground Event' was held in March 2007, before commencement of the programme. It brought together 100 local service providers, staff and community members to identify priorities, understand local needs, share learning, interrogate local networks and allow programme planners to prioritise areas of work. The programme invited local experts from a variety of tumour sites.

Through discussions with key stakeholders and assessment of public health data, four tumour sites were chosen to focus on:

1. Bowel
2. Ovarian and cervical
3. Oral
4. Prostate

Based on feedback from the stakeholder event, and the Neighbourhood Renewal Priority areas, the steering group and programme planners identified four target areas for the programme, which had low screening rates and strong indicators of health inequalities:

- Immingham
- Cleethorpes
- Hainton, Heneage and Park
- West Marsh

In light of the health inequalities focus of the work, distinct at-risk target audiences for each cancer type of cancer were identified:

- Cervical screening: 25- to 49-year-old women who have not been screened for the last three years
- Bowel screening: Men and women over 60 years, targeting the '40 per cent' who pilot projects have highlighted are difficult to engage (including people with poor mobility, low literacy, low engagement with care services, or with learning disabilities)
- Prostate cancer: Men over 40 years, focusing on those who have low contact with health and wellbeing services
- Oral cancer: Men and women over 40 years, who smoke and drink

Further discussions focused on which secondary audiences to target, including which members of the community might be recruited as volunteers to help communicate with the primary target audience. It was identified that these may include individuals who had experienced personal loss as a result of late presentation of symptoms, as well as those who wished to strengthen their own commitment to their community.

### 3. Understanding local needs

Various methods of enquiry were used to understand local needs and ascertain the attitudes and behaviours of individuals regarding their response to cancer symptoms and cancer services. Three focus groups were held with older people and one focus group held with local young women in a community setting.

In addition, local people were recruited by health professionals using existing local networks to form Community Change Teams. By understanding implicit and explicit reward mechanisms, different methods were used to recruit team members, such as invitations to share in celebration of the work, talks and

conversations across community and personal networks, and training as outreach workers to increase local understanding of screening and recruit individuals into existing health services.

These Community Change Teams were mobilised in each of their communities and interviewed target audience members through one-to-one conversations. A structured questionnaire specific to each tumour was used to prompt conversation. These were developed to help understand levels of social capital, symptom awareness and behavioural goals. Over 900 pre- and post-intervention questionnaires were gathered by Community Change Team members, from a wide variety of target audience groups and venues.

Teams were supported to discuss qualitative data at each of their team meetings to identify themes and develop insights. All new materials and resources were pre-tested using one-to-one interviews and group discussions.

### Insights

Research with community members and local service providers revealed a range of insights, which were used to re-configure the whole approach to cancer presentation.

Cancer specific:

- There was a real lack of knowledge about symptoms and risks
- People found it difficult to express their health concerns or describe symptoms to health professionals
- Fear of finding cancer prevents people from being screened. Many believed that a cancer diagnosis meant they would definitely die from the disease and did not know good treatment outcomes could follow from early diagnosis of cancer
- Men are reluctant to see their GP or seek health advice from professionals
- Bowel cancer was specifically hard to discuss as many felt it to be a taboo area and particularly unpleasant

- Family and peers could play a large role in supporting symptom recognition and presentation

Programme specific:

- A strong focus on audience consultation was desired and a move towards a model where consumers are in charge of the actual process of generating solutions
- Shared ownership should be developed, rather than behavioural changes instigated by existing services and professionals
- The community itself (rather than the health service) should be supported to articulate its own vision of health and wellbeing
- Communities want to be helped ‘to do’, by developing skills and confidence, as well as the external conditions that allow them to ‘try out’ new behaviours
- Tacit, local knowledge (as well as explicit, professional knowledge) should be valued and local human capital should be invested in as a real asset



A variety of approaches were developed, resulting in a diverse methods mix. As continual insight and development was built into the programme, and as the confidence of Community Change Teams grew, more complex approaches were developed as the programme proceeded.

**Good practice handbook**

From the review of evidence and good practice, a handbook was created, which summarised findings and provided an overview of best practice methodologies. The handbook was used at learning events as a framework, which allowed team members to develop a clear understanding of their priorities for the

programme, successful methodologies that could be emulated, and the required stages of activity that would guide the programme.



**Training for Community Change Teams**

The programme promoted collaboration between local services and communities by using Community Change Teams. These teams act as a bridge, joining up local people with service deliverers. Training for Community Change Teams began from their recruitment during the scoping phase and continued throughout the programme to ensure their skills were continually developed.

The decision on which cancer tumour sites to focus on within each community was decided by the programme planners in conjunction with the Community Change Teams, following their scoping work in each area:

- Immingham (bowel cancer)
- Cleethorpes (ovarian and cervical cancers)
- Hainton, Heneage and Park (prostate cancer)
- West Marsh (oral cancer)

“When we’d recruited volunteers to our project, one of the first things we did was to encourage them to go out into their local communities. We

had teams that were based on those ward areas, and we asked them to go out and do some scoping, and we found out what people knew about the different cancers. We used those surveys to inform where the knowledge was particularly poor and to decide which cancers should be the focus in each area” (Julie Grimmer, Project Manager)



It was identified that at each stage of activity ideas would need to be tested out and audiences engaged with, so that specific insights needed for community-specific interventions could be continuously developed.

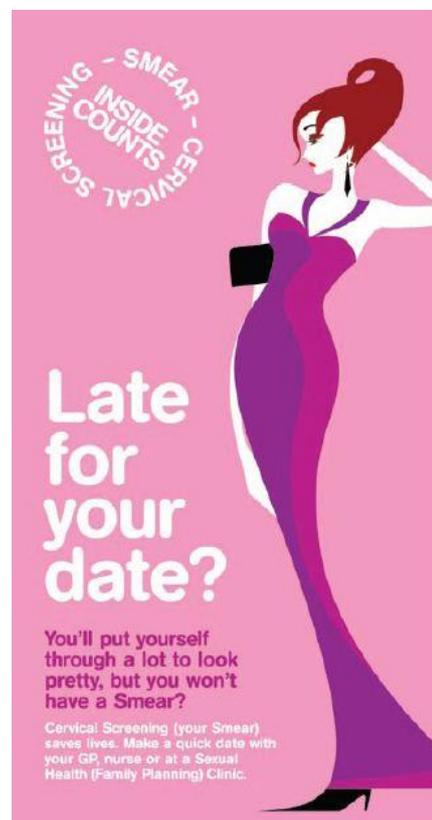
### Community-specific interventions

Cleethorpes Team (ovarian and cervical cancers)

- Pre-testing of proposed interventions led to a focus on engaging primary care staff. Strong links were developed with local general practices and three staff from primary care were recruited to the team
- Designed interventions to raise the awareness of practice staff and inform changes to service delivery, such as: reinforcing female screening staff as the norm; offering music to relax attendees; and introducing longer appointments to allow time for answering questions
- Developed 'Inside Counts' materials, including lip balms and emery boards, to reverse a local decline in smear test uptake by younger women

- Developed radio commercials with Viking FM station
- Street teams targeted different groups of young women at local hairdressers, bars, beauty salons, stalls in shopping centres and college groups
- Developed a fashion show in conjunction with local retailers to raise awareness amongst young women and disseminate information in a non-medical setting

“One of the things that the community team members found extremely useful was the development of free giveaways, because it’s that old chestnut that everyone likes a freebie. They found that to be a very powerful engagement tool with community members. It’s one thing having a stall with leaflets on, it’s another if you’ve got a stall with emery boards, or lip balm or pens even, that have got key messages on. It immediately gives the opening to the community member to actually talk on a one-to-one basis with a member of the public, rather than just giving a leaflet that might just go in the bin” (Julie Grimmer, Project Manager)



## Immingham Team (bowel cancer)

- A 'Bowel Cancer, Don't Sit on it' campaign was delivered at venues where older people congregate socially, such as GP surgeries, the local civic centre, sheltered accommodation, bingo halls, social clubs, pubs, supermarkets, libraries and local workplaces
- Staff were trained and engaged to support people to use and return bowel cancer home screening kits
- Delivered bowel cancer screening training across local communities and services
- Developed skills and resources to support a range of staff across diverse workplace (not just health) settings, to promote bowel cancer screening
- Secured successive articles in local media, featuring team member's personal stories



## Hainton, Heneage and Park Team (prostate cancer)

- Collaborated with local Personal Medical Service drop-ins to use men's health MOTs to raise awareness of prostate cancer
- Linked with Humberside Fire Service to develop resources targeting men about prostate cancer, including materials on backs of buses and presence at the local Fireman's fete
- Engaged men at a match day at Grimsby Town Football club, by handing out 1,250 wallet-sized information cards, answering individuals' questions, and including an article in the match day programme
- Targeted wives and partners to encourage men to act

### Meetings and learning workshops

Monthly steering group meetings were held, where all of the teams reported their activities and progress. Each team also met monthly to plan and manage local interventions.

In addition, two-day learning workshops were built into each stage of the programme. By inviting local people and service deliverers, programme planners could showcase best practice, present local individuals with an alternative future, and shift individuals' perceptions about their existing health opportunities and the alternatives they would like to see. After each learning workshop, teams would go into an activity phase, where they would be set an eight-day challenge to, for example, plan, carry out mapping, or survey their local population.

### Dissemination strategy

Since the programme wanted to influence how organisations do business locally, the programme sought to engage local practice-based commissioning groups and other parts of the CTP in the benefits of community-led social marketing. A dissemination strategy was developed to influence organisations and share

learning regularly with key opinion leaders through meetings, presentations and involvement in joint activity.



Because the approach had a strong community focus, stakeholders were mobilised from across the health economy, voluntary sector, private businesses and community networks. In particular, engagement with private business has been successful in an area where the NHS has not typically engaged with confidence. In addition, personal and professional relationships have opened up a wealth of networks between community members, which otherwise would have been closed. Greater access to networks has also resulted in additional benefits, such as funding sources to spread the work.

As the programme continued, all developed ideas were pre-tested with the target audience and adapted where necessary. Examples include testing the effectiveness of engaging men through drop-in health MOTs, developing key messages to support young women to go for cervical smear tests, and incorporating attitudes and behaviours in service practice and the use of 'vouchers' to support people in articulating symptom concerns at the point of exchange with GPs. Community Change Teams meet every month to refine local audience understanding and set out delivery targets specific to their community.

Based on the insight that family members and peers play a key influencing role in getting the target audience to recognise and present cancer symptoms, activity targeted partners at community events and through conversations. Also specific messages and resources, such as 'for the one you love', were developed for bowel

cancer screening to capture this key motivation to action.



As the programme progressed, the Community Change Teams became more empowered to ensure that work got carried out and taken further. One example was the successful campaign on prostate cancer where the team worked with the local fire service to produce the campaign materials and implement bus advertising.

“The prostate cancer team developed a fireman poster to advertise about prostate cancer. They engaged with the local fire service, met the firemen and set up all the photo shoots. That was a good giggle for them, because he was lovely, and they tied a knot in his hose, and they had a bit of a laugh and a joke. They wanted to get that promoted further and that ended up on the back of buses going round the area for four weeks. That wouldn't have happened if it hadn't been for one of the team members who suggested it. I immediately said, 'that's going to be too expensive', but she by this stage had become very empowered, so she wasn't happy to leave it at that. She went away to check out the costs and came back to me and said 'actually did you realise it's only going to cost

this much and couldn't we get funding from somewhere to help with this', and we subsequently applied to a charitable organisation and got the funding." (Julie Grimmer, Project Manager)



As the Community Change Teams obtained more experience, they developed their skills and knowledge about what did and did not work, including knowing which events were the most appropriate to attend to try and start conversations with the target audience about cancer symptoms. For instance, family events were found not to be successful, so teams directed their efforts to events where the target audience would be more likely to feel comfortable having conversations on this topic.

"The teams have got quite smart now about where are the best places to go to interact with people. Initially they tended to look for anything that's going on in the area and see if they could go to it. Family fun days don't tend to work so well because it's not necessarily something a family wants to talk about when they're out with their little ones. Sometimes the teams have come back and said that actually we didn't feel this was a good place to be." (Julie Grimmer, Project Manager)

Importantly, to ensure people moved from recognising possible symptoms to taking the action of presenting these symptoms to a health professional, the Community Change Teams worked to make direct links with local services, such as drop-in centres, dentists and GP surgeries, helping to develop clear pathways and ensuring the approach is as joined up as possible.

A series of monthly measures are compared against baseline data and shared across the Community Change Teams to understand impact and inform Plan-Do-Study-Act cycles.

Pre- and post-measurement is taken across community cohorts annually. A series of community and clinical measures cover a range of outcomes and the teams are well positioned to assess short and longer term impacts.

### Progress against key objectives

*Objective: Increase awareness of cancer symptoms*

Initial data from the pre and post community questionnaire tool suggests that between pre-implementation and 2007/08, there was a:

- 15 per cent increase in people feeling confident in identifying cancer symptoms , with a further 13.9 per cent increase in 2009/10
- 11 per cent increase in reported willingness to act on symptoms, with a further 11.6 per cent increase in 2009/10
- 7 per cent increase in people knowing where to go for advice about cancer

*Objective: Increase in earlier presentation of cancer symptoms*

Increases in referrals, measured by two-week wait referral data (against an aggregate three-year baseline):

- Bowel cancer – 50 per cent increase
- Prostate cancer – 67 per cent increase
- Gynaecological cancer – 28 per cent increase

- Eight GP case studies were recorded of patients acting on the programme team's activities – these resulted in four positive diagnoses
- Five referrals to GPs concerning testicular (not in the programme) and prostate cancer symptoms

*Objective: Maximise bowel screening rates*

- 57 per cent uptake of bowel cancer screening in 2009/10 (compared with 55.2 per cent in 2008/09)

*Objective: Increase cervical screening rates*

- Increase from 79.8 per cent in 2006/07 to 81.6 per cent in 2009/10
- Significant increase (4.9 per cent) in the younger age group (25- to 49- years-old) between 2008/09 and 2009/10

*Objective: Increase rates of volunteering*

- 53 team members involved
- 213 completed training opportunities

*Objective: Increase social, bridging and bonding capital across communities*

- The pre- and post- questionnaires looked at community perceptions of the ability to change attitudes and perceptions of their area. This improved by 7 per cent in 2007/08 with a further 8 per cent improvement in 2009/10

### **Community impacts**

- 232 community events delivered in a variety of settings, including shops and workplaces
- 22,509 significant contacts made by teams, defined as engaging in conversations about cancer symptoms
- 39 new local resources developed

- 676 distribution points established, for example in pubs, clinics, workplaces and hairdressers
- 126 media exposures gained



The work and successes of the programme have been widely shared with key stakeholders and other organisations interested in the model for community-led social marketing. A DVD of the programme has been produced and used at presentations to the Board, steering group and other key players. The programme has also been recognised as best practice by the Department of Health.

Since the pilot, the programme has been mainstreamed within NELCTP and has been expanded to other geographical areas in NEL, beyond those originally identified. Unfortunately the work focusing on oral cancer in West Marsh is no longer running, due to members of the particularly small Community Change Team in that area having to discontinue their involvement for various unexpected reasons. However, further work focusing on lung cancer is planned to be rolled out in 2010/11. The community-led social marketing model is also now being applied to other topic areas such as heart disease, stroke and promoting skin health. In light of reductions in public spending and the reorganising of NHS bodies, work is currently underway to investigate the possibilities for the Early Presentation of Cancer Symptoms Programme to become part of a social enterprise in the near future.

### **Lessons learned**

#### **The strengths of community-led social marketing**

The model of community-led social marketing involves not just a strong focus on consultation, insight and testing ideas with the target audience, but a move towards a model where consumers are in charge of the process of generating solutions.

By constructing conditions for staff and communities to learn and work together, partnerships can develop that provide a model for service/patient collaboration. Co-production approaches to social marketing have the potential to unlock a variety of creative and alternative solutions that are not always accessible to professionals. Especially in the UK, when opportunities for influencing the confidence and capability of staff are great, so too is the need to make the case for co-production social marketing approaches. Valuing people as solutions, not as the problem, sets not just the 'guinea pigs free', but the possibilities for improved impact too.

“Yes, I’ve learned a lot. And not only that, as a team, we’ve also gelled. And it’s been fun. And it’s not just been learning, it’s been fun, so therefore it’s better. You learn more if you’re happy.” (Mary Wheatley, Team Member)

### **Recruiting community champions**

Patient support groups are a great source of very powerful advocates, because as survivors they are keen to give something back. Clinical nurse specialists can also provide some good leads and it is worth selling your cause to existing community groups.

“One piece of advice about what not to try, don’t try going to a bingo hall when they’re just about to play bingo, because we nearly got lynched! The most successful thing is once you’ve got a small nucleus of people, is getting them to bring a friend along, because you can double your numbers quite quickly, and people feel much safer when they’ve got a friend. It encourages and supports them.” (Julie Grimmer, Project Manager)

### **Stakeholder buy-in**

Ensure that you obtain buy-in from your key stakeholders early, as they will be vital for the implementation and sustainability of your programme.

In particular, ensure that you work closely with your Community Change Teams and provide them with the support they may need throughout the course of the programme. Supply them with good training, because if they have been well trained they will feel empowered and confident enough to go out into the community and reach those people others often would not be able to.