



The  
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South Yorkshire, Bassetlaw  
& North Derbyshire

CANCER  
ALLIANCE

# BE CANCER SAFE

BE CANCER SAFE  
SOCIAL MOVEMENT

## *Evaluation Report 2019*

## Be Cancer SAFE Acknowledgements

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# Executive Summary: Key learning from Be Cancer SAFE

## Use a co-production approach to commissioning:

The key elements for the specification were informed by discussions with experts in community engagement and social movements, reviews of evidence and consultation with providers. The specification allowed for local development of the programme and allowed providers room to evolve. This approach was key in realizing innovative and locally relevant approaches.

**Assess public misperceptions:** The project has shown that public perceptions of the pathways to early diagnosis, screening and treatment are sometimes incorrect. Be Cancer SAFE Workers and champions had an important role in correcting misperceptions of how GPs and secondary care clinicians respond, as well as providing clinicians with a better understanding of how their actions are perceived.

**Use a distributive leadership style:** Distributive leadership recognises the strengths of various people and gives people the autonomy to use their judgement about how to best approach different groups. When leaders promote agency – the ability to act independently – local workers and champions are able to create productive informal conversations.

**Employ/recruit local people with knowledge of communities:** Local people can explain cancer risk in language that people understand. Making use of relationships that are already established has the potential to reduce inequalities.

**Develop different approaches to informal conversations:** Recognise that approaches that work with some individuals, groups and communities will not work with others. Share successes and failures within and across locality teams in order to explore how to tailor conversations to different people in different circumstances, who are at different stages in terms of being able to consider and discuss cancer risk.

## Recognise that prior relationships and experiences of services can influence whether people consult their GPs:

Some neighbourhoods and individuals experienced real difficulty in getting appointments with their GP. People that had this experience felt that consulting GPs about their symptoms was not worth the effort.

**Learn about cultural attitudes:** Cultural attitudes toward sharing information about cancer risk and cancer screening need to be taken into account. Areas reported that in some ethnic groups women needed to go through husbands, who may be reluctant to support attendance.

**Be prepared for fatalism and denial:** Some people believe that having a diagnosis won't make a difference to life expectancy. They also believe that it's better not to know whether you have cancer.

**Take personal history and experiences into account:** Thinking about cancer reminds many people of relatives who died from cancer. Thinking about it is upsetting and can trigger feelings of fear and anxiety. Conversely, people with personal history often make very effective champions when they are ready to discuss with others.

**Use written materials and props to promote interaction:** They are very effective in terms of getting public attention, initiating conversations, and show people how to discuss cancer.

**Maintain an information flow:** Within and across localities and with Clinical Commissioning Groups. This increases awareness of public perceptions and continually supports the need for change.

# 1. Steps to a Social Movement: The story of how BCS created a movement

## 1.1 Background

The project was commissioned in the first instance because there was concern about awareness of cancer risk and differences in uptake of cancer screening for different cancers and different population groups. More people in South Yorkshire, Bassetlaw and North Derbyshire are diagnosed with cancer than the England average. Our most deprived patients are more likely to be diagnosed with cancer at a late stage and die of cancer. They are more likely to have the diagnosis made during an emergency admission and less likely to attend for screening.

In 2016, the South Yorkshire, Bassetlaw and North Derbyshire Cancer Alliance received funding to deliver a number of interventions with the aim of increasing the proportion of cancers diagnosed at an early stage. The development of a Social Movement in Cancer Prevention, Awareness and Support was one of those interventions. (Social Movement in Cancer Prevention, Awareness and Support: South Yorkshire, Bassetlaw and North Derbyshire Service Specification, April 2018). The programme was named Be Cancer SAFE (Screening, Awareness, Fast, Early).

## 1.2 Project aims and objectives

The overall aim of the project was for provider(s) to work in partnership with local communities to co-produce and deliver a Social Movement in Cancer Prevention, Awareness and Support network by nurturing a social movement across the whole spectrum of cancer prevention, awareness and support for screening which is led by citizens and not the public sector. The ultimate aim was to engage citizens in their own health through a social movement approach.

The specific objectives were to:

1. Recruit an agreed number of local Champions based on population size
2. Work with local partners; including Clinical Commissioning groups and Public Health teams to identify communities with the greatest inequalities in outcomes.
3. Maximise the potential provided via digital platforms to connect people, utilising digital applications and connected through social media to create virtual communities and networks.
4. Work to understand the issues and barriers faced by communities in the lifestyle choices they make, the uptake of screening, and understanding of risks/symptoms related to cancer.

Social movements are an organic process rather than one which 'nudges' people in making decisions. Some of the key features of our definition mean social movement happens when we understand:

- What the issues are about cancer screening, that lie behind the messages we are trying to communicate
- Why it is hard to get messages across about cancer risk, signs and symptoms
- What the challenges and barriers are to accessing screening
- How local people help each other to find their solutions
- What encourages local communities to begin to take on some ownership of cancer awareness
- How to use opportunities to have informal conversations about cancer as a part of everyday conversations

## 1. Steps to a Social Movement: The story of how BCS created a movement



Figure 1: What social movements in health aim to achieve  
(Source: del Castilla J, Khan H, Nicholas L, Finnis A. September 2016 NESTA The Power of People in Movements)

Using Nesta's aims for social movements as a guide, the Be Cancer SAFE initiative aimed to:

1. Normalise conversations about cancer
2. Raise awareness of cancer risks
3. Democratise knowledge, by reflecting on the language and ways of communicating to best promote understanding of cancer risks and screening in local groups
4. Change cultural and societal norms about having cancer conversations
5. Identify barriers in current screening systems
6. Propose innovations that will increase uptake of screening
7. Improve people's experiences of screening

### 1.3 How and why do social movements work? The theory for Be Cancer SAFE

Social movements draw upon principles from social marketing programmes, community engagement, and peer support. The programme was underpinned by a robust international and national evidence base<sup>1,2</sup>. The movement was started by South Yorkshire, Bassetlaw and North Derbyshire Cancer Alliance by awarding contracts to organisations, who appointed BCS Delivery Leads in the localities of Bassetlaw, Barnsley, Doncaster, North Derbyshire, Rotherham, and Sheffield. The Delivery Leads in turn identified workers who could initiate conversations about cancer, and use these conversations to recruit people to be "Be Cancer SAFE Champions". Champions are individuals who volunteer, potentially

holding conversations with an average of 10 other people who may include partner, parent, child, friends and work colleagues. The underlying assumption is that discussions about cancer, which are stigmatised in many settings, become normalised when champions talk to people – who in turn discuss with others, multiplying the effect.

In general, health promotion workers may deliver prevention messages in a number of ways, ranging from the traditional scripted message to a more opportunistic approach. The Be Cancer SAFE initiative is based on a more opportunistic approach, meaning that:

- conversations are integrated within existing community engagement activities
- they are likely to be part of existing conversations
- they are based on a peer support model
- messages are embedded in conversations that happen during a range of other activities, for example a lunch club, crèche or exercise class
- these conversations will be held in the course of the Champions' everyday activity where possible
- the conversations will consider the challenges in everyday life of taking on these types of messages
- consideration of engagement with different communities will be key, this may be through a specific individual, considering place, time of day and in some cases gender

We started with some assumptions about what would happen if champions were recruited. People who are approached with cancer information may be at different stages, in terms of whether they want to have a conversation. We used what is called the 'stages of change' theory to draw up an initial model of what might happen in the project. Some people, for example, may be in what is called the 'precontemplation' stage, where they haven't considered cancer risk, signs or symptoms. Others may have thought about discussing cancer with other people. They may know someone who has cancer, or be wondering about their own symptoms. These people are in the contemplation stage, so may be in a position to take advantage of a Be Cancer SAFE event to ask questions. Engaging in the Be Cancer SAFE (BCS) discussions may help people to make plans to attend screening or consult their GP (the 'preparation' stage). Others may have attended screening or been to see their GP as a result of a conversation (the 'action' stage). They may be reporting back that they have made lifestyle changes that reduce cancer risk, or that they are more willing to get screened on an ongoing basis (the 'maintenance' stage).

<sup>1</sup> A guide to community-centred approaches to health and wellbeing, South, J. (PHE and NHS England: 2015) (<https://www.gov.uk/government/publications/health-and-wellbeing-a-guide-to-community-centred-approaches>)

<sup>2</sup> Prochaska, J.O. and DiClemente, C.C., 1982. Transtheoretical therapy: Toward a more integrative model of change. *Psychotherapy: theory, research & practice*, 19(3), p.276.

## 1. Steps to a Social Movement: The story of how BCS created a movement

### Assumptions / theory as to how BeCancerSafe might support change in screening rates?

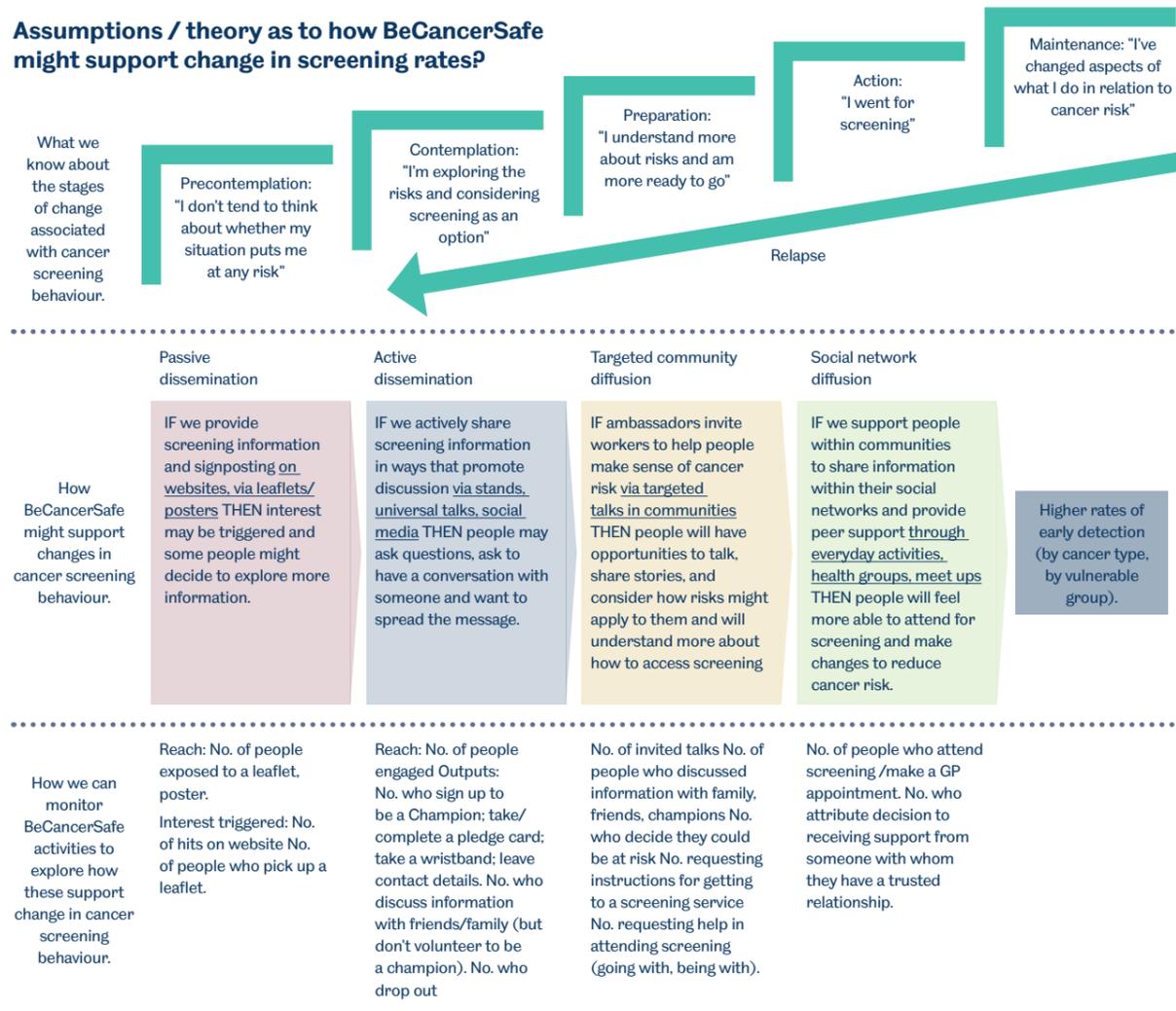


Figure 2: Programme theory for Be Cancer SAFE

### 1.4 Co-producing an evaluation

We used a co-production approach to the evaluation. This means that the people who are directly involved in delivering the programme are also key in collecting information, and reflecting on whether the initiative is working. A proportion of each locality contract was set aside to enable Project Delivery Leads and Be Cancer SAFE (BCS) workers to collect information. The BCS Project Delivery Leads worked with the BCS Project Coordinator and the Cancer Alliance Early Diagnosis Work Stream managers to develop a data collection form ('Monthly Monitoring Form'). The University of Sheffield School of Health

& Related Research (SchARR) team was asked to review the form to make sure that it was able to capture activity related to all of the objectives for the programme. We looked together at the types of information that were recorded in the first 3 months, identified other questions that needed to be answered, and agreed to add several more categories to the form. In month 8, when we were beginning to see evidence of social movement, we decided to collect additional information on what was contributing to the shift. The final categories can be found in Appendix 6.1.

How do you evaluate impact of a social movement?

While it would be tempting to define impact as a change in screening rates and increase in early diagnosis, or changes in lifestyle, it would be difficult to attribute the changes to the Be Cancer SAFE initiative. Cancer screening, for example, involves large numbers of patients moving through complex pathways, with recall intervals of between two and five years. Uptake data is published quarterly and can be 6-9 months in arrears. Consequently, detecting an effect on uptake over the short term as a result of an intervention is unlikely. Similarly, there are many factors that influence decisions to consult GPs about possible cancer signs and symptoms. In both scenarios, it would be difficult to determine whether people attended because they had a conversation with a BCS worker from other reasons for attending. There are at any given time other interventions aiming to increase screening uptake and cancer detection that could also be having an effect. The evaluation does not, therefore, use uptake data to evaluate the impact of the social movement. Qualitative methods were used for the evaluation. Information was collected on people's understanding of cancer risk and misunderstandings were documented. We also collected information on people's knowledge of early diagnosis and screening processes and pathways. We asked workers to report back on how they corrected misunderstandings and incorrect information about early diagnosis and screening.

Impact is being defined as ability to normalise cancer conversations, demystify screening, correct public misperceptions, raise awareness of signs and symptoms, and mobilise the public to provide peer support to people who have never engaged or stopped engaging as the result of a poor experience.

After the data collection form was co-produced, we used developmental evaluation, which means that analysis was done alongside activity. This followed an action learning cycle (Figure 3), where (1) public perceptions and levels of knowledge about cancer risk and screening were documented;

(2) misperceptions were catalogued and workers collaborated with health professionals to provide accurate information to counteract incorrect knowledge; (3) the relative success of informal conversations was documented, asking what increases awareness and knowledge, leading people to consider a GP consultation, or taking up screening. The learning was reviewed at team meetings and monthly meetings, where workers and delivery leads reflected on the relative success of various approaches, generated ideas and plans to increase recruitment and improve informal conversations. Site visits were also made, where some of the issues and progress were explored in greater depth.

The final evaluation report was co-constructed and circulated to workers for two rounds of comments. A final review meeting was held in order to ensure the accuracy of the information, where we used visual recording to produce some of the key learning and findings in a visual format.

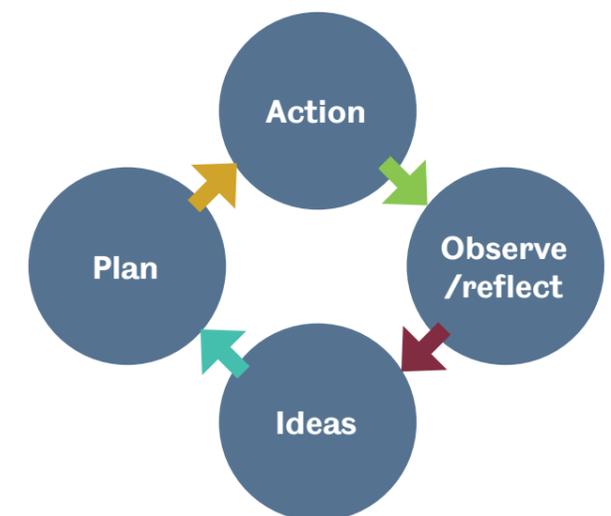


Figure 3: The BCS Action Learning Cycle

The next section reports on what happened at each step of the social movement, how each step progressed, what worked and why, and what hasn't worked. ▶

## 2. Creating the foundations for a social movement in health

Social movements happen because people in various settings and situations want something to change. The first step is to create the foundations for mobilisation by building and supporting your core team.

Research on social movements in health indicates that the ability to mobilise action on a large scale, improve services and make an impact on wider determinants is dependent upon several fundamental elements (Box 1).

### Box 1: Fundamental elements for mobilising

1. Mobilise the strengths, capabilities, resources and knowledge of people
2. Empathise with the issues of people, carers and communities
3. Build leadership and agency; support each other
4. Experiment with new ideas and approaches
5. Reflect on the stages of the movement, acknowledging when context slows progress and recognising windows of opportunity for collective action

Over the past year, there is evidence that some of these have been achieved as follows:

**1. Mobilising the strengths, capabilities, resources and knowledge of people:** Be Cancer SAFE used a model of mobilisation that relies upon people who are already connected to their localities to start cancer conversations. When delivery leads describe this model, they say that local people with knowledge of communities know how to have informal conversations. They know what sort of language to use and they recognise that the language needs to be 'everyday'. Active listening is used, to try to understand what the person's real concerns and questions may be. The information and advice that is given is tailored to individual concerns. The way that information is delivered is tailored to people's prior knowledge and their level of understanding. The effectiveness of this approach was confirmed within the project, as well as by international research. The people participating in conversations reported that it was 'good to hear it explained in a way I could understand' '[it's] explained as common sense'. There is a strong international evidence base that adapting information to different groups increases the relevance of the information, as well as increasing engagement with the messages.<sup>3</sup>

**2. Empathise with the issues of people, carers and communities:** Workers agreed that 'it's more important to be able to listen rather than talk'.

When people relate to each other as equal peers, rapport is established and people become more willing to discuss issues.<sup>4</sup> There are numerous accounts of 'being invited back' and 'being suggested to someone else'. By months 3 and 4, BCS workers reported that they spent less time making cold calls in an attempt to trigger interest. Invitations began to come in via word of mouth. There were also reports that previously unreceptive communities began to extend invitations. Local endorsements are an indicator that the workers are becoming accepted in different communities. Word of mouth publicity is a powerful indicator that the initiative is gaining momentum and being promoted without the direct intervention of the BCS workers.

**3. Build leadership and agency and support each other:** The project was dependent upon delivery leads to both lead in their locality, and lead together across localities. At the same time, the movement was dependent on people having a leadership style which was 'distributive'. In other words, recognising the strengths of various people on each locality team and giving people the autonomy to use their judgement about how to best approach different groups. The ability to act independently – which is described as agency - is critical to the success of informal conversations. When workers had knowledge of local communities, they were experienced in terms of knowing which approaches would work. There were cases, however, where the workers were going into unfamiliar communities where they did not have a presence. In these situations 'working in pairs means that people can support each other'. Workers described this as 'half listening' to the other worker's conversation, which meant that they could step in with a different approach that might work.

At the same time, workers supported each other after hearing stories of loss, bereavement, and incorrect information, which they described as "scary stories". Working in pairs provided important support.

*You have time to take a break or to decompress after a story.*

**4. Experiment with new ideas and approaches:** Workers were also supported by their local teams. Team reflection was used to identify when particular approaches were effective and when different approaches needed to be tried. Working with different groups required different approaches. For example when working with learning disabled groups, or schools, the workers discussed various approaches first with support teams in order to find the most appropriate ones. After trying different approaches, workers reflected together on which approaches worked, which didn't work, and why.

**5. Reflect on the stages of the movement, acknowledging when context slows progress and recognising windows of opportunity for collective action:** Project Delivery Lead meetings were used to discuss how to share the barriers to cancer screening and awareness raising, and ways of overcoming these, with different units and groups in the health system. Progress was also shared with the Early Diagnosis Workstream and commissioners in each locality.

<sup>3</sup> Liu, J.J., Davidson, E., Bhopal, R.S., White, M., Johnson, M.R.D., Netto, G., Deverill, M. and Sheikh, A., 2012. Adapting health promotion interventions to meet the needs of ethnic minority groups: mixed-methods evidence synthesis. *Health Technology Assessment* (Winchester, England), 16(44), p.1.

<sup>4</sup> Harris, J., Springett, J., Booth, A., Campbell, F., Thompson, J., Goyder, E., Van Cleemput, P., Wilkins, E. and Yang, Y., 2015. Can community-based peer support promote health literacy and reduce inequalities? A realist review. *Journal of Public Health Research*, 3(3).

### 3. Creating a desire to change: the elements in a social movement

We used the Nesta Health as a Social Movement model to identify the elements that were needed to mobilise cancer screening and awareness raising (Box 2).

#### Box 2: Elements in a social movement

1. Create a desire for change
2. Harness system-level support to raise awareness
3. Widen the circles of participation
4. Positive public feedback
5. Leaders and champions are identified and supported to 'advocate up'
6. Mobilising action
7. Service improvement
8. Earlier detection, reduced health inequalities

These elements were used to explain what would happen if we were successful ("the theory") and to chart our progress against the theory, as described below.

#### Element 1: Create a desire for change

The theory: If BCS workers systematically identify interested organisations and individuals, and are given opportunities to raise awareness via informal conversations, then champions will be identified who can support others to take up cancer screening.

The lead BCS organisations in each locality were organisations with a tradition of working across local communities. Local assets include people (including their knowledge and skills), places, community events or activities. Champions were opportunistically recruited from the public, using the following approaches:

- "Cold calling" where BCS workers approached owners of shops (pharmacies, barbershops, hairdressers, pubs, supermarkets), market places, and organisations that were planning events where it might be appropriate to have a stall or stand.
- "Casual contact": Workers were out and about and introduced conversations informally when appropriate into their daily work (for example, a worker might be visiting a community centre, and spotted an opportunity to discuss screening).
- Personal relationships: Workers and champions start conversations with family, friends, co-workers.
- Professional contacts: Personal introductions were made by people who were local opinion leaders, which helped to open doors.
- Community relationships: Workers used their other links with voluntary and community sector members, other community workers, public and private sector partners, to piggyback conversations on to ongoing activities.

The original targets for the programme were set proportional to population in each area (see Table 1). The overall target was 12,000 cancer champions over an 18 month period (by April 2019).

Table 1: Monthly targets for recruiting Champions April 2018 – February 2019

Areas	Targets		Apr	May	Jun	Jul	Aug	Sept	Oct	Nov	Dec	Jan	Feb	Mar
	Per Year	Per Month												
Bass	720	60	128	270	91	77	109	75	181	215	156	92	588	132
Donc	1920	160	44	290	392	670	441	296	270	408	132	203	281	186
N Der	2520	210	62	323	364	571	452	441	583	490	181	286	165	103
Shef	1800	150	0	0	20	0	0	0	54	55	156	426	256	384
Barns	1560	130	201	245	175	298	200	377	284	193	98	214	159	173
Roth	1680	140	125	160	373	145	184	378	335	228	170	120	68	94
Total	12000													

After start up, most localities were consistently exceeding monthly targets for champions.

As a result, the targets for each locality were met in month 6 or month 7 (highlighted in red) with the exception of Sheffield. Sheffield started implementing BCS in October 2019 (Table 1) and has achieved 50% of its target within the past 5 months. The overall target has been exceeded to date by 25% (Table 2).

Table 2: Targets set and targets met for recruiting Champions

Locality	Population	Projected Champion Targets (by March 2019)	Number of Champions as of March 2019	Target exceeded
Barnsley	216,000	1560	2613	168%
Bassetlaw	115,000	720	2051	285%
Doncaster	305,000	1920	3613	188%
N Derbyshire	383,000	2520	4021	160%
Rotherham	239,000	1680	2396	143%
Sheffield	570,000	1800*	1351	*
	1,873,000	12,000	16405	

\*The original proportionate target for Sheffield of 3600 was revised to reflect late start and 1 year funding period 2018/2019. Sheffield has reached 75% of its target at month 6.

### 3. Creating a desire to change: the elements in a social movement

The original programme aim was to recruit local champions, specifically focusing on communities with the greatest inequalities in outcomes across the Cancer Alliance footprint. Screening data was used to identify indicating areas with low uptake at the beginning of the programme. Evidence of spread was collated by collecting the first 3 digits of Champion postcodes. Some localities also collected information on gender, ethnicity and age. These were periodically reviewed against the locations where BCS workers recruited Champions, to assess whether there was enough targeted effort (see Figure 4). Targeting was defined in different ways by each locality, according to their local situation.

Some localities, for example, started in areas where they had prior relationships and worked with local groups to establish connections to other groups that may be seldom consulted. Others started with establishing a presence with a wider audience, and used that to get introductions to events in deprived areas and general practices. Although screening uptake was one indicator of possible areas, lack of knowledge about cancer risk is not limited to areas of deprivation or 'hard to reach' groups. Decisions about working in local areas were informed by opportunities, local Champions and local interest.

Challenges to recruiting were reported in some of these areas. For example, some neighbourhoods which had experienced limited access to primary care also felt that trying to access screening via GPs was not worth the effort. Building trust is challenging in some neighbourhoods and some groups. Areas reported that in some ethnic groups, information about cancer risk and how to access screening needed to go through husbands, who may be reluctant to support attendance. Recruiting was harder in communities where discussing cancer is frowned upon.

Workers reported that being present and participating in local activities - without pushing messages - was successful in eventually opening doors but there are still places with limited access.

#### Element 2: Harness system-level support to raise awareness

The theory: If health providers and commissioners in each locality raise awareness of the movement, then public curiosity will be triggered, creating opportunities for informal conversations.

*The wife did not speak much English but her husband did not want her to talk to us. [It was] very hard to engage with the ladies because of language difficulties but especially more difficult when their husbands are so controlling. I think that the ladies do want to engage, but are unable to because their husbands are there. ...and sometimes, because of their cultural beliefs and their husbands' attitudes/opinions – they will not attend screening although they may understand the importance of this.*

#### Engagement Mapping - Targeted Work, December

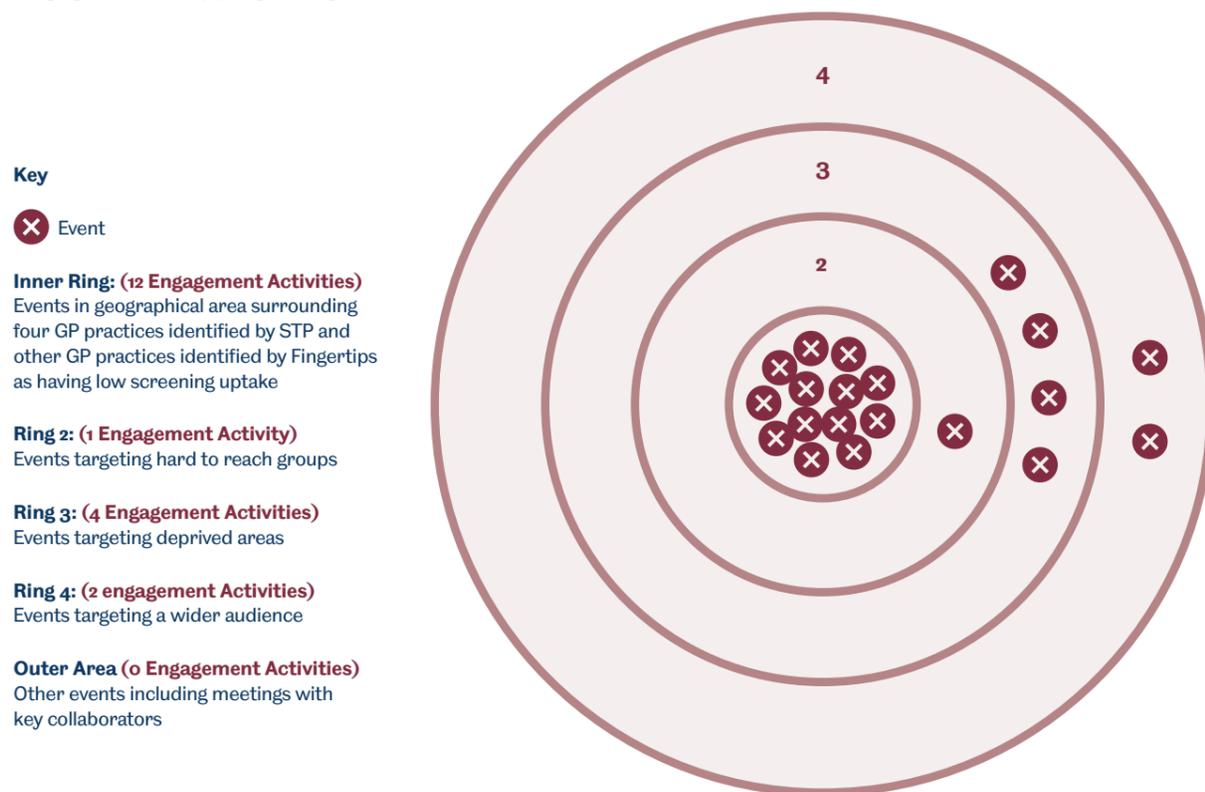


Figure 4: Sample map illustrating shift in effort toward progressive targeting



Figure 5: The BCS Brand

### 3. Creating a desire to change: the elements in a social movement

Social media links were set up and a library of resources was established on the South Yorkshire, Bassetlaw and North Derbyshire Integrated Care System website.

Generic messages, and merchandise were developed including posters, leaflets, Easy reads, pens, lanyards, wrist bands, and badges.

#### Element 3: Informal conversations reduce stigma about discussing cancer

The theory: Informal conversations give people an opportunity to discuss cancer while allowing them control over the amount of discussion they would like to have. Workers with experience in tailoring conversations to different needs and concerns are able to establish connections which may lead to more in depth discussion.

Starting informal conversations happens differently depending on the setting. Cold calling often starts with a conversation that is about anything but cancer or the BCS project. For example, it might be the weather, or what's in the shopping basket. Once a connection has been established, the workers will introduce the project.

*We start with: 'hello do you mind if I tell you a little bit about what we're doing'. Most of the time people will engage with us.*

Although all localities use cold calling, there was agreement that this can be a difficult way to start a conversation. The use of freebies can attract interest initially.

*It is easier when we have freebies on our table – e.g. Pens; Badges; Mugs etc.*

Visual Health promotion aids are also effective.

*Prosthetic breasts and testicles; Examples of the various sizes of lumps; Jar of Tar; Visual display of the prostate and different conditions that can affect the prostate. [These all help] with starting a conversation and people find it easier when they can see what we are talking about.*

One locality noted that

*Many of my sessions will be presentations to a captive audience and it is much easier to engage in conversations.*

The success of various approaches, however, varies by location. A captive audience may have been organised by a local gatekeeper, but does not necessarily ensure that the group will be interested. It can also be challenging to engage an entire group in conversation. Cold calling and standing on stalls may seem more challenging, but offer opportunities to engage people in real conversation.

Workers have also used an embedded approach, where information is made available to community groups or workplaces while people are engaged in other activities such as an arts and crafts class or a coffee break at work.

*It's important not to be in people's faces but to let the people come to you.*

*They see things sitting on the table, and sooner or later someone points it out to another person. We're in the background, that gives us an opening to provide a bit of information.*

### 3.1 Barriers to presentation and accessing screening: What we have learned from Be Cancer SAFE

Workers identified the barriers that people experience when considering screening. We used the stages of change theory (Figure 6) to as a framework for presenting the barriers that were preventing people from moving from precontemplation to action.

#### Assumptions / theory as to how BeCancerSafe might support change in screening rates?

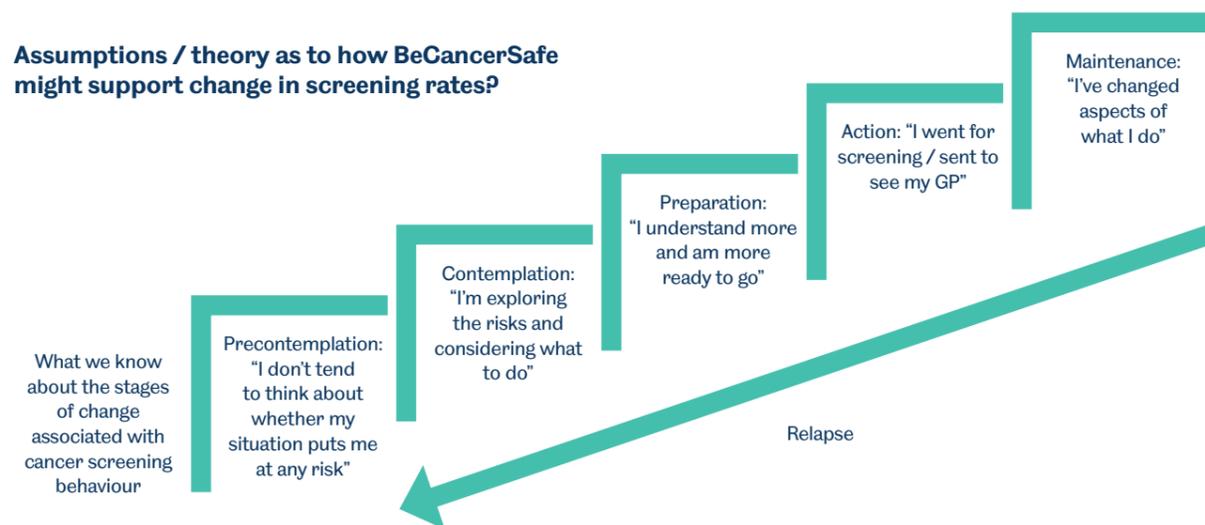


Figure 6: Barriers by stages to accessing screening

### 3. Creating a desire to change: the elements in a social movement

One of the major findings concerned public misperceptions of the early diagnosis and screening pathways. The project has shown that public perceptions of the pathways to early diagnosis, screening and treatment are sometimes incorrect. As can be seen below, patients often thought that their GP could provide screening or refer them for screening. Be Cancer SAFE Workers and champions had an important role in correcting misperceptions of how GPs and secondary care ought to respond.

#### 1) Precontemplation Barriers:

- Fatalism and denial: In some areas, people believed that having a diagnosis wouldn't make a difference to life expectancy. They also believed that it was better not to know whether you had cancer.
- Sad stories: Some people didn't want to know because they had relatives who died from cancer, so thinking about it was upsetting and triggered feelings of fear and anxiety.

All of these people are in the precontemplation group, which may represent the biggest challenge as they don't have faith/trust that engaging with the health system will prolong their life. Indeed, they may feel that taking up screening threatens their wellbeing and short term quality of life.

2) Contemplation Barriers: Some people are willing to contemplate cancer risk, but need more information about screening. They may be willing to acknowledge that they might have symptoms, but need to discuss with a GP. They aren't able to make plans to attend screening because there are several barriers.

- Literacy issues: People simply didn't know that screening was available, because they are unable to understand the invitation letters.
- Age limits: Older people weren't aware that they could 'opt in' to screening after they had reached the age limit
- Change in age restrictions: People who had reached the age of 50 weren't aware that the screening schedule changed from 3 years to 5 years.
- Newcomers: People who had recently moved to England didn't know the process for receiving screening invitations or requesting a GP appointment.
- Lacking an address: People have moved to a new address, or have no fixed address, so cannot be sent the usual invitation letter.
- Unable to get a GP appointment: People experience delays in getting an appointment to discuss with their GP.
- Unable to discuss with the GP: People may get an appointment, but find they have trouble communicating their signs and symptoms to the GP.
- Addressing signs and symptoms: If people feel that their concerns haven't been addressed, they may not go back when they have symptoms warranting investigation.

3) Preparation: People who are given information about what they are eligible for want to know how to attend. There are a number of barriers to accessing screening in South Yorkshire.

- Location and transport
- Screening clinic hours
- Need for child care
- Waiting times: The time between getting an appointment and being screened may seem very long, which puts people off

4) Action: People who do attend for screening report back that it was a negative experience.

- Concerns about the long process - people feel they are waiting a long time to get the results
- Concerns about being forgotten - some people may have slipped off the system
- Painful screening experiences
- Impersonal screening experience
- Embarrassing or distasteful experiences
- Late detection of cancer: People who were not initially invited for screening - but were subsequently diagnosed - are reluctant to get screened in the future.

When people have had any of these negative experiences, they are more reluctant to attend in the future. Further, they may tell other people about the experience, which can put others off attending.

5) Maintenance: People who report positive screening experiences are more inclined to continue to get screened.

### 3.2 Evidence of barriers to accessing screening

The above barriers were regularly identified in every locality. In this section, we provide a detailed description of the barriers. The next section explains how BCS workers were able to address individual barriers and move people toward Action and Maintenance.

#### Precontemplation Barriers

- Denial – don't need screening
- Fatalism – early diagnosis won't make a difference
- Sad stories – avoiding discussions about cancer

People who weren't thinking about screening were often unaware that they might need it. They might say

*I'm young. So I must be healthy and I don't need that.. 'If I feel fine now, that's all that matters'.*

Another misconception was that

*women who haven't been sexually active don't need to go for their cervical screening.*

Others were afraid of what they might find out.

*There was a fear amongst the women when conversations were being had – what would happen if we had breast cancer? This month, all the women I spoke to acknowledge the importance of screening. However, out of ten females 3 stated they would rather not know if they had cancer; 7 stated they were too scared to go.*

*I had 4 rejections from men who advised that they didn't want to know about the message as they were happier not knowing if they had cancer.*

### 3. Creating a desire to change: the elements in a social movement

For some it brought back painful memories that they didn't want to be reminded of.

*One gentleman said he finds it difficult to talk about cancer, as his father passed away from cancer & his granddad.*

In some areas, people had fatalistic views.

*They believe even if you 'catch it early, you still die so [you may be] better off not knowing.*

*Several of the people that I spoke to today cited friends and family who have never been to the doctors and most likely never will. A few people mentioned being scared of finding out that something is wrong, and others said that people believe that 'illnesses just work themselves through'.*

#### Contemplation barriers

- Literacy issues
- Age limits
- Change in age restrictions
- Newcomers
- Lacking an address
- Unable to get a GP appointment
- Unable to discuss with the GP

Some people simply didn't know that screening was available, because they are unable to understand the invitation letters.

*The screening invitation letter is not suitable for people with learning disabilities or people who speak another language and that it frightens some of them.*

*[People] do not speak or read English, so cannot understand the screening invitation letters. They see the NHS logo and assume they have been sent the letter because they are ill.*

There were lots of questions about age limits for screening.

*One lady had been told by her doctor that she was now too old to do screening.*

*Older people weren't aware that they could 'opt in' to breast and bowel screening after they had reached the age limit.*

*Across all localities, females over the age of 65 years old wanted to know if they can have smear tests. Many females over the age of 70 wanted to know why they could not be routinely called for breast screening.*

A number of people were concerned about age restrictions.

*Some women have raised concerns with regard to the possibility of lowering the age range for cervical cancer screening.*

*Older ladies said that they think that they should be called for a Mammogram and not have to remember to ask for one because the statistics show that 1 in 3 ladies over 70 are affected by Breast Cancer. These ladies said that they feel when they get older, they are fobbed off because of their age.*

Telling people about opting in reassures them and they are often keen to act. System constraints, however, can still act as barriers:

*A lady over 70 with a family history of breast cancer really had to push for a screening appt. Her GP eventually wrote to the radiography dept who then allowed it.*

*When the lady had to reschedule due to a funeral she was told that the appt had been cancelled altogether.*

People from countries where prostate testing is routine needed to know the UK policy.

*She asked if men in the U.K automatically got tested for prostate as in their home country of Iran they were checked every year.*

Moving around can mean that people are lost off the screening register, and in some cases it can be difficult to get back on.

*Lady did not attend her breast screening due to being out of the country at the time. When she returned home, she tried contacting the Breast clinic three times but there was either no answer or she was transferred to another department. She has since stopped trying.*

With some groups, getting on the register is the first place is also an issue.

*Gypsy & Traveller communities all said that because they move around it is hard to engage with professionals.*

*The workers have also said that they have issues with the GP practices in the local area, refusing to register ROMA patients unless the community worker will guarantee that the client will attend and they will attend with them. Generally, they appreciate the offer of healthcare as this is not provided in their country.*

Some of them continue to get screened in their home country:

*The local pharmacist was Polish and confirmed that people go back to Poland for cervical screening as it is far more comprehensive than it is in the UK.*

People across all localities described a number of barriers to getting an appointment with the GP. People were challenged to get through on the phone.

*One person said in order to get an appt you have to queue outside the practice at 8 am as no one ever answers the phones.*

This creates situations where people give up even though they have symptoms.

*She says because it's so hard to see a GP you very often talk yourself out of bothering so illnesses i.e. cancer could be missed.*

Problems getting an appointment were cited every month, across all locations in Doncaster but were not unique to this locality.

*Some people said that although they may be worried about something to do with their health, they do put off going to their GP as it is so hard to get an appointment.*

*A young adult contacted GP surgery at 8.40 to book an appointment. She was on hold for 30 minutes before hanging up.*

The situation in some places was confirmed by health professionals.

*The pharmacist advised that the real problem was people getting through to the surgery. A lot of people go to the pharmacy for advice as they can't get into the surgery to see a GP.*

### 3. Creating a desire to change: the elements in a social movement

Advising people to see their GP, therefore, does not necessarily enable screening. In fact, it may create a negative situation where people become frustrated and stop thinking about going for screening.

*When speaking to people and suggesting that maybe people put off getting medical advice, one lady got quite angry and said they aren't putting off getting medical advice - they simply can't get into the GP surgery for it!*

*One lady laughed when I told her to visit the GP if she had any symptoms of cancer and advised 'you want to try and get into my doctors and speak to staff there'. She said the advice is always 'go to the GP if you have concerns' but if you manage to get an appt, the GP is not interested.*

This suggests that in some local areas, the problem is wider than simply promoting screening uptake. It is indicative of a history of interactions where patients feel dissatisfied with primary care.

When people do get an appointment, negotiating follow up appointment systems is difficult.

*One lady advised that when seeing the GP she has been advised to make a follow up appt one month later but when she tries to book this appt she can't because you can only book 2 weeks in advance. When she calls back in 2 weeks time all the appts are gone.*

Communicating signs and symptoms is difficult when speaking with the receptionist, locum or GP. People who cannot explain symptoms to the receptionist may not make it through the appointment triage system.

*During the consultation with the GP, people said that they feel rushed sometimes and do not articulate all of their concerns. One lady said that although she had discussed her concerns, i.e. some worrying symptoms with her GP and asked to be referred for further testing, the GP did not feel that it was necessary. She said that she was made to feel as if she was wasting his time.*

*They also said that when they go to their GP, most of their concerns are put down to their age and getting older.*

A number of people went to their GP because of family history.

*She was referred early for a 'Smear Test', as she was showing symptoms. The test showed she had abnormal cells, which was dealt with. However, when she asked to be retested earlier this year, she was told she was too young to be considered for another Smear Test. Her GP was supportive, but implied the current legislation prevented her from being referred for a second smear. The young woman is currently left in limbo.*

*Her sister had recently died of breast cancer and there was a family history as her auntie has also passed away with Breast cancer. She was finding her GP was not supportive as she has requested genetic testing.*

*She was told that as her mother was in her 60s when diagnosed [with bowel cancer] that she is still too young for screening.*

These people wanted to discuss their concerns with a BCS worker.

#### Preparation barriers

- Location and transport
- Screening clinic hours
- Need for child care

People who are given information about what they are eligible for want to know how to attend. Barriers to accessing screening can include clinic hours, need for transport, parking and child care.

The older women said they rely on their husbands or children to take them to any appointments. If they are not available, they don't go and miss out on their appointment/screening.

Going for breast screening was a nightmare because of parking - expensive and very busy.

Women who go for screening often lose an hour's pay and also have to pay for childcare to attend the screening appointment.

It's not a barrier that only affects adults of child-bearing age. Some people over the age of 50 said that they look after their grandchildren regularly, and may find it difficult to get a suitable appointment to attend their screening. [Bass, Donc]

#### Action barriers

- Concerns about the long process - people feel they are waiting a long time to get the results
- Concerns about being forgotten - some people may have slipped off the system
- Painful screening experiences
- Impersonal screening experience
- Embarrassing or distasteful experiences

Barriers at the action stage are defined as things that happen during the screening process that make it more likely that someone will not attend in future. Anxiety, embarrassment, pain, and delay may make people more reluctant to contemplate future screening. Further, they may tell other people about the experience, which can put others off attending.

Waiting to get tested or get results can be quite anxiety producing.

Spoke to a lady who gave feedback about a long wait for a Smear Test of over 2 months and was told by the Receptionist 'It's not as if it's life or death'.

A lady was very concerned that it had taken more than 3 weeks for her cervical screening results and that her GP surgery could not help or advise her where to enquire.

One lady who found a lump went to the 8 to 8 service and was told that she needed her GP to refer her for further testing. She then called and booked an appointment and saw a Nurse who said that it was not necessary to refer her for further testing, so she went away feeling worried still. She went back 2 more times and then saw a Locum who said that she should have been referred for further tests since she first went to a GP. The Locum then referred her. She said that it is still worrying even when you are referred, as there is a 2 to 3 months wait before you can see a consultant. She is now undergoing some tests.

Another woman said that she's dissatisfied with the length of time it takes for the results of a CT scan to come through. She has recently had a scan for lung cancer, and said that she won't receive her results for another 2 weeks. When she asked the hospital whether the results would come through faster if there was something wrong, she was told no. Her dissatisfaction lay in the thought that two weeks can be a long time to delay if there is an issue and can mean the difference between life and death.

### 3. Creating a desire to change: the elements in a social movement

People are concerned that they may have been forgotten:

*When the G.P contacted the Gynaecology department [they] said 'there is nothing on your records, when we get something we will write to you'. She has been waiting for 7 weeks now and is getting anxious. She is worried that they may have forgotten about her.*

*As she is having regular checks, she was told by BH 'Do remind us because you'll slip off the system'.*

#### Impersonal and painful experiences

*1 lady said that the breast screening at XXX Road is like a conveyor belt process, very quick and abrupt sometimes.*

*[The smear test was] painful as clinician was reportedly less than gentle.*

*[She] in fact ended up having a very painful procedure which involved a specialist machine. It was very traumatic. She was given a leaflet prior to procedure, however was not talked through it. [The Champions reflected that] giving leaflets doesn't help unless a professional/nurse goes through it.*

#### Embarrassing or distasteful experiences

Women said that investigations for breast and cervical cancer were embarrassing. All localities heard that submitting samples for bowel screening deterred a number of people.

*One older woman said that she bins all of her bowel screening kits because it's too disgusting to send her poo back through the post.*

People did not understand how a GP decides when to do a test. As a result, in some cases people felt that the health system had failed to detect their cancer early enough.

*One gentleman who was terminally ill with Prostate cancer, asked why the PSA test was not offered as part of the Well Man Checks at 60 and 65. He was told that his cancer had been present for a significant length of time and so it would have been picked up earlier if the PSA test had been offered.*

*Female (32 yrs) had all smear tests but it did not pick anything up but she said that she felt something was wrong so had to push GP for further tests and has just finished Chemotherapy and radiotherapy.*

*1 male said that he had asked his GP for a PSA test several times but it was refused, he then saw a Locum and asked again and he was sent for the test. He was then diagnosed with Prostate cancer and it had already spread to his liver and he was angry but did not want to complain.*

*His GP was very reluctant to carry out the test as the gentleman wasn't showing any symptoms. The GP eventually agreed to carry out the test, which showed a high level of PSA. The test was repeated two weeks later, with the same result. Further examination revealed that the gentleman had advanced prostate cancer. The cancer has now spread to his spine and the gentleman is undergoing radio and chemotherapy.*

When the cancer isn't detected early, it can put people off going to the GP.

*Her husband was peeing blood and therefore went to his GP. He was first given antibiotics but continued to pee blood. The second time he saw his GP, he was given antibiotics again. Therefore went to urology on his own accord and discovered he had 4 tumours in his bladder. The result of this is the wife of the patient now refuses screening.*

*A woman whose diagnosis was missed said that she often keeps quiet about this as she doesn't want to put other people off going to their GP or taking up their screening.*

It is important to note that the frustrations expressed by people about primary care may not be an indicator of poor service – it can also be a sign that people need to be shown how to communicate better with their general practice. The next section shows how BCS workers facilitated better communication.

#### 3.3 Shifting the barriers: Addressing individual barriers to early diagnosis and screening

Did informal conversations raise awareness about cancer risk and support screening? The success of the initiative rested upon opportunistic and informal contact, so it was decided not to ask people to share contact details for a follow up survey. A number of people, however, did announce that they were going to get screened and some came back to tell BCS workers what they had done. This section looks at how the sharing of information and conversations about cancer worked to shift people from one stage to the next.

Our original model for Be Cancer SAFE (Figure 2) assumed that written information which was widely distributed via media, stands, events and targeted talks would raise awareness of cancer risk. The hits on websites and social media activity indicated that this was the case, but the materials also helped to get public attention and promote interaction.

*We try to bring up the shocking Bassetlaw statistics early in a 'did you know' about local cancer statistics to get their attention and for it to be more personal/relevant to them.*

Leaflets helped champions to trigger action (Box 3).

#### Box 3 Raising awareness promotes screening and early diagnosis

In all localities, leaflets were routinely left in places where people were willing to champion. The leaflets enabled the champions to suggest that people ask for an investigation of cancer signs. For example, in North Derbyshire, engaging barbers through BCS leaflet dropping led to increased knowledge and awareness among barbers. One noticed a potential cancerous mole on a customer's skin. After sharing the information, the customer went for screening and received an early diagnosis of Stage 1 skin cancer.

Materials also promoted interaction and group discussion.

*The A3 documents helped to start new conversations and to get groups talking to each other. Models, props, and easy read documents were useful with everybody, not only people with learning disabilities.*

### 3. Creating a desire to change: the elements in a social movement

Written information, however, needs to be handed out with a conversation.

*You can't just hand somebody an easy read document; you have to talk people through it really simply.*

The information can be used to help people to explain to the receptionist why they need an appointment.

*In the areas where access to GPs or not trusting GPs seemed to be a key factor, the team might instead talk about strategies to try and help lever access. For example, arming people with the information that they might need (for example, taking the bowel screening leaflet with them and showing the receptionist).*

Leaflets can also potentially help people to describe their concerns:

*I took a pen and circled the parts in the leaflet that matched what he was telling me, and told him to show it to his GP.*

Booklets were used to help many people who were unable to understand decisions made by their GP:

*He enquired about having a PSA test carried out and was told there was no need as he wasn't showing any symptoms. He asked us what affects PSA levels, so we discussed the information contained in a booklet from Prostate Cancer UK. This confirmed what he had been told by his GP. He took information away to read and will contact his GP again if he feels the need, once he's read the information.*

Champions also went back to the health service when they needed to explain the testing processes better. For example, one woman told a Champion that

*Despite a family history of Prostate cancer and symptoms, her husband's GP refused to do PSA test. He was later diagnosed and the cancer had spread to the bones.*

The Champion asked professionals: When is the PSA test offered? Is there a way to get it done if a G.P. refuses to do it until a patient is 60? The information was used to provide explanations to people who cannot understand why they aren't offered a test.

Translating and helping people to understand the language facilitated screening uptake.

*In my experience, when these ladies receive any medical letters, they bring it to the group or their colleagues who can read English so that they can translate the contents of the letters for them. The community workers have fed back that they do attend appointments once the letters have been translated for them. I have done many awareness sessions with these groups over the years and I have been given the feedback that some of them will attend their screening.*

Clarifying how to access screening and encouraging people who were concerned also helped:

*Spoke with 16 different women who all believed that because they had never been sexually active with a man that they did not need to go for their cervical screening - encouraged to go and dispelled myth.*

*One woman said that she was told because she had had hysterectomy that she didn't need breast screening - was encouraged to talk to her GP about this or give the breast screening team at hospital a call.*

*She has noticed bleeding when going to the toilet, which is causing her concern. As she is over the age for bowel cancer screening she was unsure what to do. We gave her the national number for opting back in to the bowel screening programme and advised her to contact her GP as soon as possible.*

There is evidence that people who participated in conversations at stands, public presentations and targeted talks had lots of opportunities to ask questions. They were given advice by workers about who to contact so that they could explore whether they were at risk. They also shared concerns about symptoms, and received reassurance.

*One lady advised she was not happy that you can't access cervical screening after 64 as her mother was diagnosed in her 70s. She was concerned that it's hereditary and could affect her in later life. We advised that cervical cancer isn't thought to be hereditary and in most cases is caused by HPV.*

Having this sort of information helps people to feel more in control.

The informal conversations are instrumental because they help people to consider their attitudes about cancer risk and cancer screening. Through discussions with workers and champions, people start to consider what other people like them might do in similar situations. If they lack the knowledge to know what to do, workers can provide it to make it easier to get an appointment or attend screening (Figure 7). When attitudes and norms were addressed, and people were shown what to do, they stated their intention to attend or get a consultation. As discussed in section 3.4, there is a strong evidence base showing that intentions to pursue a health behaviour are strong predictors that the person will follow through.

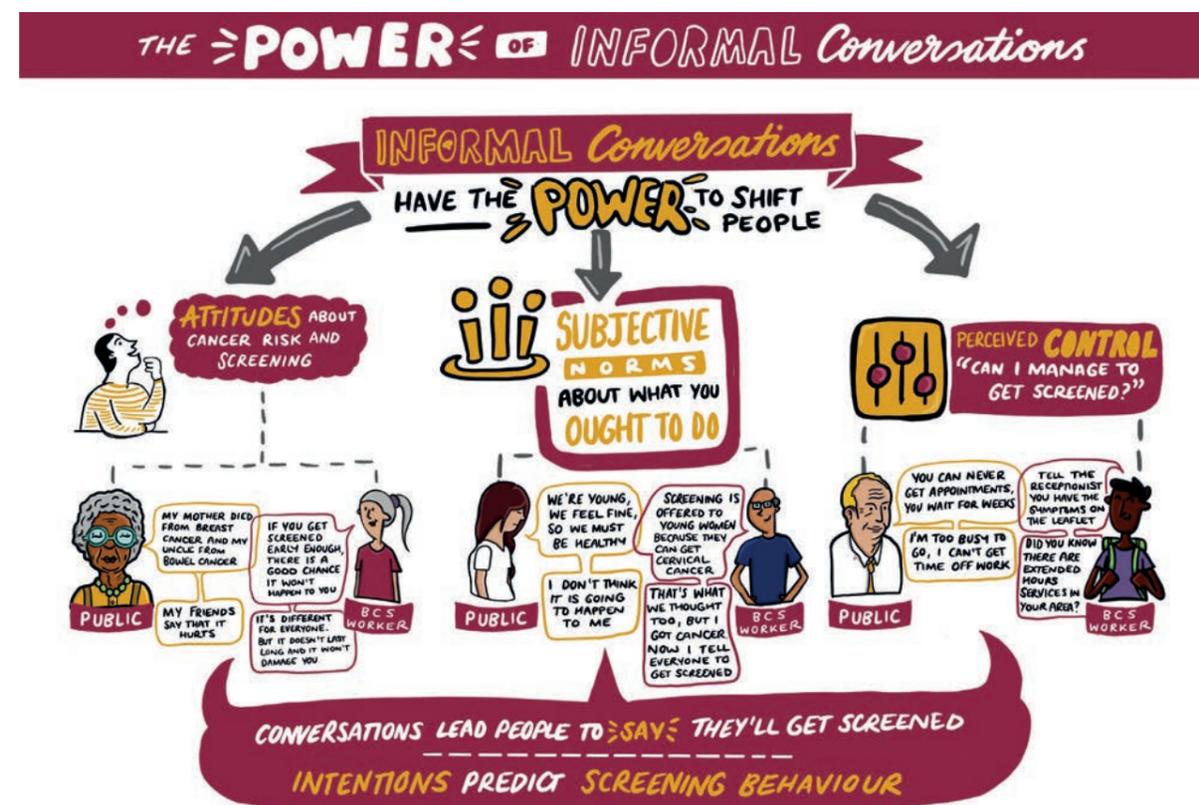


Figure 7: Informal conversations encourage people to consider cancer risk

### 3. Creating a desire to change: the elements in a social movement

Social support: People were supported to discuss cancer, and to persist in getting GP appointments.

*One man will encourage his wife to go for her mammogram (he said that she found it very painful so did not like to go).*

*When she first went to the the doctors, with a lump in her breast, she was told that if it was painful, it was not cancer. Her son insisted on test and it was found to be stage two cancer.*

They were also encouraged to find the time with practical information about locations and schedules.

*She said she'd been meaning to go but it was just too busy and couldn't get time off work.*

*One lady said we had prompted her to book her smear test - its easy to forget when you are busy.*

Resources such as Jo's Trust Time to Test campaigning and availability of Extended Hours encouraged these women to make the time.

Workers felt that all communication was facilitated by the fact that they weren't experts. They were local people who used everyday language. They can approach the public saying "we know what you know". That helps people to relate. They can also take what they learn from health professionals, and construct an explanation in plain language. For example, when workers heard from the public that the cervical screening age is too late, they went back to the Cancer Alliance Early Diagnosis Workstream. People in the group explained the reasons for the age limit. Then the Worker decided how to explain the information to the public.

*One lady had been told by her doctor that she was now too old to do screening. After a discussion, we identified that she could still ask for Bowel and Breast screening and the GP had probably meant just Cervical. The lady commented that just having a logical conversation based on the BCS information had made it much easier to understand and was very helpful.*

#### Element 4: Widening the circles of participation.

The theory: Connecting people up can lead to widening circles of participation, where meaningful contact with individuals who are passionate about promoting change inspires organisations to take up the cause.

Groups discussions can build understanding and facilitates screening uptake.

*I have done many awareness sessions with these groups over the years and I have been given the feedback that some of them will attend their screening.*

Some situations require 'peer endorsement' e.g. visible support from contacts who are trusted in a community.

*The [local person] took us round in her car, people saw us with her, that helped.*

*Deprived areas are hard because they are on everyone's target list of places you have to go [this refers to other third sector organisations with funding, or projects]. Therefore the people in these areas are mistrustful. On the other hand once you earn their trust and come again and again they will talk to you. Having an introduction from trusted people in the community short circuits that process.*

When after initial contacts are made, connections snowball.

In other cases, BCS workers already have long standing relationships which means they are automatically invited to raise issues, and they are also trusted to provide direct support.

*Most women raised that they would find it useful if there was more information/awareness about BC, that would push them to go for screening. Ideally a Urdu/BME worker*

Working relationships with other organisations can be utilised to 'open doors'. Localities produced maps which showed how the circles of participation widened (Figure 8), moving from initial contacts to establishing relationships where workers were 'invited in' rather than knocking on doors. Successful interactions meant that one contact lead to another. Workers no longer had to use universal events and 'cold calling' to spread the message. When they were invited in to businesses such as supermarkets and pharmacies, they contacted other businesses in the same chain or serving similar customers, and used leverage to spread messages. These linkages produced cancer champion networks within organisations, across professional groups, and across particular settings.

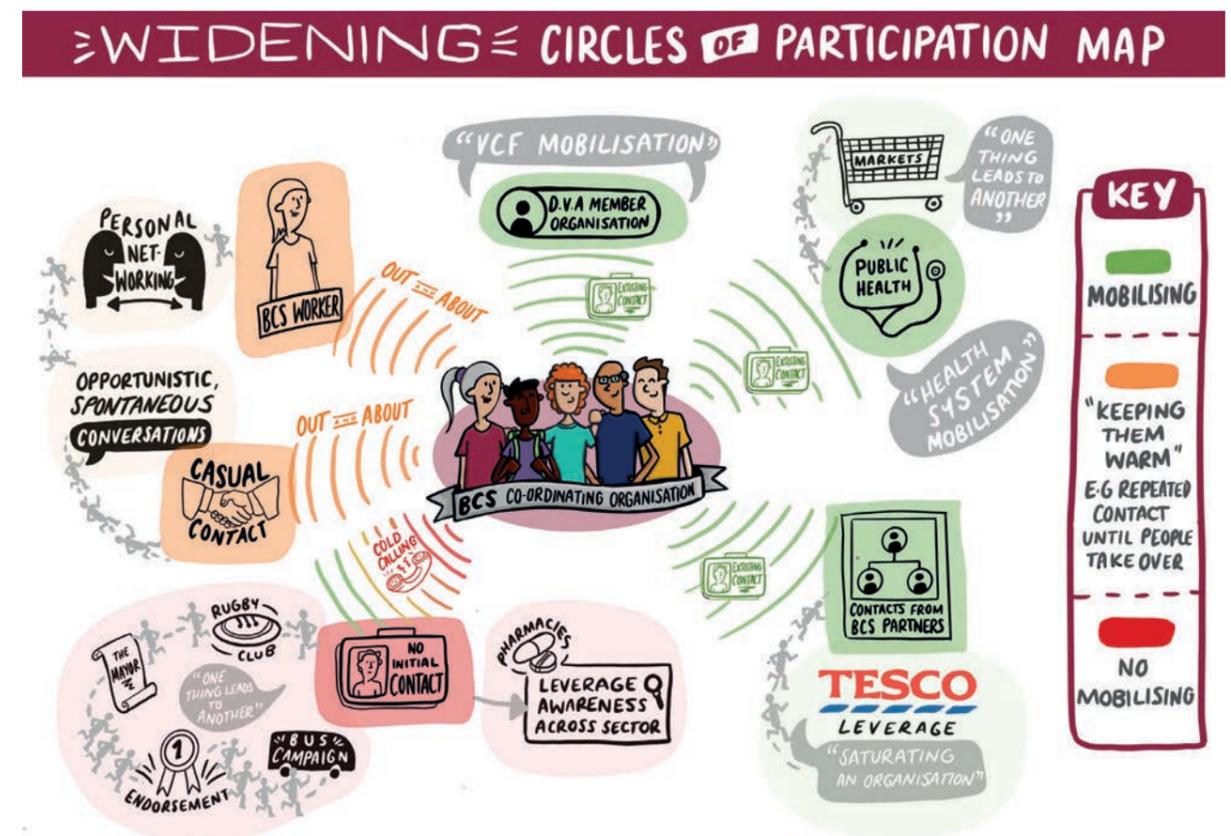


Figure 8: Widening circles of participation

### 3. Creating a desire to change: the elements in a social movement

#### Case Study: Tapping into local assets

The circles of participation map (Figure 7) shows how initial contact with key local influencers spreads the BCS message and leads to organisations acting as champions. For example, the BCS team emailed all local sports teams about the BCS programme. The Rugby Club Chairman, who had a personal link to cancer, replied to say they could help with a sponsorship deal at the club. The deal consisted of presenting BCS messages and activities via team photos and newspaper articles. The BCS team, along with other team sponsors, were invited to a fireworks night, where they met the Mayor. The Mayor signed up to be BCS Champion, and said he is happy to help with future BCS activities. The Derbyshire Times was following the Mayor throughout the year, which opened up the opportunity to get the BCS message in the newspaper. The BCS team used their connection with the Mayor to get his support with a funded bus advertising campaign in February. The Mayor helped launch the campaign, travelled on a bus with the BCS team, and the story was featured in the local media. This illustrates how funded sponsorship and campaigns can be effectively combined with local assets, where people contribute their time, their networks and other resources to the movement.

There is no 'right way' to widen circles of participation. Some localities started with universal events, gradually focusing on particular areas, some targeted first and expanded to universal events, while others did both concurrently.

#### Element 5: Influencing change via informal conversations

The theory: Collaborating with other people in the health system builds confidence about sharing accurate information. When BCS workers receive positive feedback from the public, they have increased confidence that they can influence change through informal public conversations. If BCS workers collaborate across localities they can share tips about effective conversations.

#### Case study: Collaborating with professionals to build confidence

A champion who happens to work at local hospital trust in the histopathology lab invited the BCS team to visit the lab. As a result of the visit, the team had an increased understanding of the screening process from the laboratory perspective. Their confidence in the wider aspects of the screening process was incorporated into their engagement within communities.

Members of the public had questions and concerns about many aspects of testing and screening as shown in section 3. When workers were unable to answer questions on for example prostate tests, HPV and cervical screening, they went back to health professionals to get accurate information. This information was then combined with the informal conversation approach and used to effectively correct public misperceptions, as well as inform discussions with clinicians as to how their responses

are sometimes perceived. Workers developed their approaches to informal conversations over time, reflecting with each other after going out in pairs about the approaches that worked and didn't work with the public. They were alert to the concerns of the people they were interacting with, considering how to make effective responses to concerns with the overall aim of getting people to consider cancer risk (Figure 9).



South Yorkshire, Bassetlaw & North Derbyshire Cancer Alliance | Early Diagnosis Workstream – Social Movement (#becancersafe) | Tuesday 26th March 2019 | 3 pm to 5 pm



Figure 9: Discussing people's concerns about screening

Feedback from the public was key: hearing people say that they intended to go for screening after an informal conversation provided instant feedback on the effectiveness of the interactions, and having people come back to say that they had actually attended provided further reinforcement.

Reflection was also a regular part of the agenda for monthly Delivery Lead Meetings, where challenges and tips were shared. A Discussion Group was also set up online to promote mutual support, and workers visited each other's localities and worked on co-produced events. All of these strategies promoted confidence, as well as keeping the group energised.

### 3. Creating a desire to change: the elements in a social movement

#### Element 6. Leaders and champions are supported to 'advocate up'

The theory: Presenting information on what is influencing GP presentation and screening uptake to people who are in a position to change practices and systems will trigger discussions and reflection on how to increase access to screening.

Barriers to taking up screening have been consistently documented in the 6 localities. These barriers have been communicated back to commissioners and providers in a range of ways, including:

- Meetings with cancer screening coordinators, who met with primary care to discuss how to link activities to screening rounds
- Monthly feedback to the Cancer Alliance Early Diagnosis Workstream Group
- Actions taken by members of the Cancer Alliance Early Diagnosis Workstream Group, in their respective localities, at commissioning level

In areas with low uptake general practices were targeted. Access to practices was challenging in some cases. Regular meetings with the screening coordinators were opportunities to note the value of the free health promotion being offered by BCS.

*One woman tried to book a smear and was told by her GP it would be 12 weeks. When BCS fed this back to the health service, they emailed general practices saying we need to reduce this.*

#### Elements 7 and 8. Mobilising action and improving services

The theory: Recognising that many parts of the system have a role to play in raising awareness, and developing collaborative approaches between the social movement and the health system, is key to improving screening and early diagnosis.

A large number of contacts have been made with providers and commissioners, where people can come together to review barriers to presenting with signs and symptoms and screening and identify possible strategies for raising awareness.

The original programme specification noted that there was interdependence between sectors:

- Local communities
- Key local community leaders
- Local Voluntary and community sector organisations including charities
- Local Clinical commissioning groups
- The Cancer Alliance
- Local Authority public health teams
- The 'Co-ordinator' provider
- Other providers of this specification
- Providers of similar community based services or interventions

All of these have a role to play in creating and sustaining a social movement to Raise awareness of signs and symptoms and promote screening. There were a number of examples of working together to promote joined up thinking. For example:

*An important contact was a woman in the breast clinic screening service. She let BCS know which areas were going to be invited for breast screening and they were able to distribute flyers when the invitation went out from the screening service.*

Mobilising action and improving services are both dependent on the social movement's ability to 'orbit around' or 'dock into' existing services and systems (Figure 10).



Figure 10: Ability to collaborate across social movements and systems promotes change

Collaboration can be more effective in achieving health and health system goals than efforts carried out by single agents. In some localities, long term collaboration already existed. The Doncaster service was started in 2002, to deliver Cancer Awareness, so has observed changes that happen over time. Although they have an long term link with the CCG, they noted that

*the Be Cancer SAFE Project has strengthened our links with the Cancer Alliance. We work together with our Public Health Colleagues to deliver Cancer Awareness in Doncaster. We are*

*also working together with other providers of this specification (Cancer) – e.g. The Regional Screening Team; The Cancer Lead Nurse; The Clinical Nurse Specialists.*

New partnerships are evolving which recognise the need to join up different services related to cancer screening. When people from different groups get together with a common mission, and experience productive working, the relationships can produce 'partnership synergy', where the whole is greater than the sum of each individual's contribution.

### 3. Creating a desire to change: the elements in a social movement

#### Case study: Partnership synergy

The new Barnsley Early Detection and Prevention Steering Group has been formed in order to:

- Bring together multiple organisations (including charities and volunteer groups), to ensure that work within the town is targeted to where it is most needed.
- Work collaboratively, exchanging information and sharing knowledge to improve Screening uptake and reduce inequalities in priority groups/areas.
- Review and agree recommendations to address priorities in the Barnsley Health Improvement Plan to meet National and local Screening uptake targets.
- Work smarter across the area and limit duplication.
- Identify barriers to the screening programmes and develop shared plans to overcome these where possible.
- Act as champions for the screening programmes across Barnsley with the wider health community, and other public and voluntary organisations.
- Escalate issues/areas of concern to SYB Screening Programme Boards, SYB Screening and Immunisation Oversight Group and Barnsley Health Protection Board.

Key driver and Chair Tracey Turner (PHE SY&B Area Team) worked with BCS Barnsley Project Lead Alison Thorp to both develop the TOR and ensure that key services and areas of work were represented. Our representatives are:

- Screening and Immunisation Coordinators (SIC) SYB
- Local Authority Public Health Cancer and Communications Representatives
- Local Authority Adult Learning Disabilities Representative
- Local Medical Committee Representative
- Barnsley CCG representative – Primary Care Quality lead/ Commissioning contracting lead/Cancer lead/ Communications lead
- Service provider representatives for ANNB, AAA, Bowel, Breast, DESP and Cervical Screening Programmes.
- Cancer Alliance Social Movement team – VAR
- CRUK facilitator
- NHSE commissioned Community and Engagement representative
- GP practices representatives

Other localities were already working in this way with established operational groups reaping the benefits of coming together in a coordinated and strategic way and the relationship forged between Screening and Be Cancer SAFE spurred on/gave this development impetus to develop integrated delivery plans which incorporate peer support.

'Docking' into existing services and groups

The Health as a Social Movement report describes social movements as autonomous and flexible groups that can decide which activities to pursue without having to adhere to bureaucratic requirements. Over time, however, some movements may become more integrated with health systems and that is beginning to happen in some localities. The process is described as 'orbiting around' and 'docking into' formal NHS services to inform service delivery and improvement. All localities currently have an NHS structure for managing cancer screening and treatment.

#### Case study: How a movement can "dock into" health services

One example of how the movement docks into existing structures and adds value is illustrated using the organisational map of Barnsley below (Figure 11).

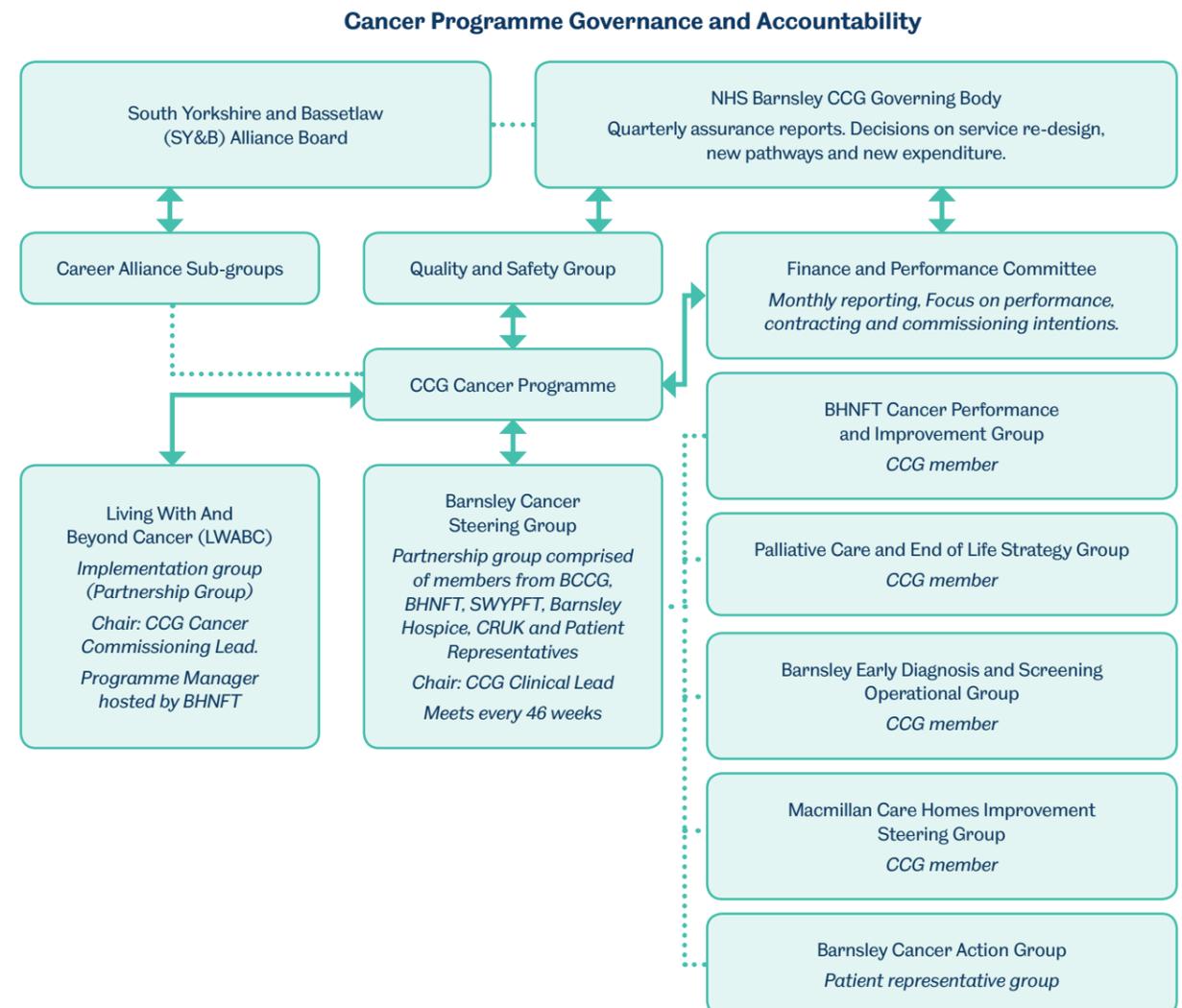


Figure 11: Organisational map of cancer services

### 3. Creating a desire to change: the elements in a social movement

The docking in process was started in Barnsley by inviting those who are actively leading the movement to standing meetings. Be Cancer SAFE, for example, has been invited to share key learning about cancer screening experiences with the groups above. Relationships with groups may vary. With the ED Workstream Group, BCS presented their work and kept the group informed via a monthly Highlights Report. The Workstream uses the information in the report to explore issues with services. At the local level, BCS collaborates on development of strategic plans by working with the Barnsley Cancer Steering Group.

*By attending the group BCS and sharing her knowledge, [the BCS Delivery Lead] is encouraging services to think about how they improve access for patients who do not attend appointments early or who simply don't attend for screening.*

Finally, people leading on social movements may become integrated, collaboratively developing new groups within NHS institutions. For example, the Barnsley Screening Early Detection and Prevention Group has been established with BCS and the regional screening coordinator, in order to plan how to actually implement changes to the screening programmes and promote collaboration across stakeholders on a wider system approach.

#### Element 8. Earlier detection, reduced health inequalities

The theory: Mobilising action in health services and health systems will produce improvements in local services that lead to earlier detection of cancer and achievement of target screening rates.

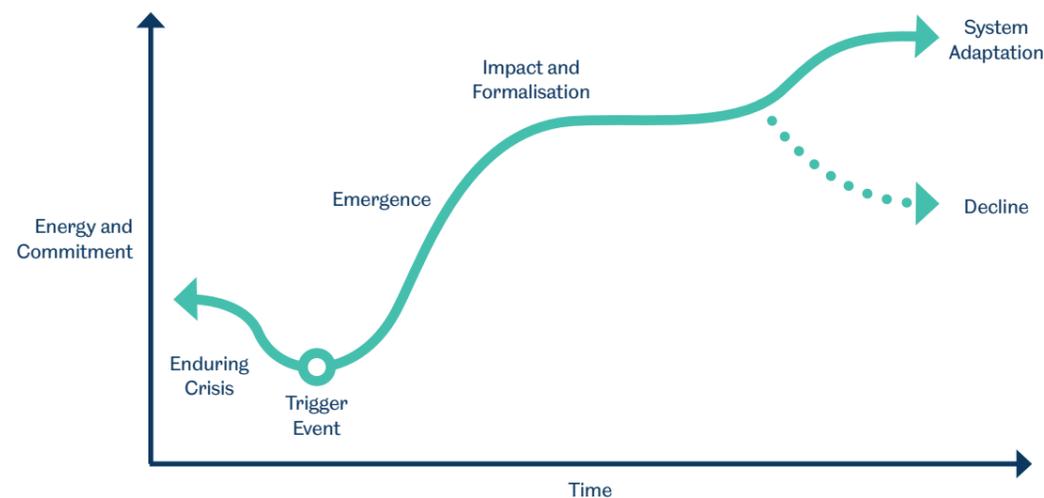


Figure 12: The social movement wave (Source: del Castilla J, Khan H, Nicholas L, Finnis A. *The Power of People in Movements*. Nesta. September 2016.)

The initiative is at a critical stage in terms of having impact because it is poised between getting people to plan to attend screening and enabling people to attend. It has also identified that informal conversations raise awareness. The evidence so far indicates that it has been successful in shifting people to contemplate attending, and getting them to actually attend. People are also stating that they intend to visit their GP. Success now depends on health services and health system responsiveness - whether the barriers that have been reported are actively addressed across localities, with formal adjustments to service delivery. If system adaptation does not occur, then the movement will likely decline (Figure 12).

### 3.4 Comparing the evidence to international theories of what works

BCS workers noted instances where people said they would attend for screening.

*One lady booked in for her smear test straight after I had a conversation with her.*

People came back to BCS workers to report that they had attended screening as a direct result of the interaction with the worker or a champion.

*One person attending one of the events [which] raised importance of screening, awareness & symptoms went on to have a mammogram and all clear.*

*One lady said that as a result of our talk at the BME planning group, she has already been to see her GP as she had found a lump in her breast.*

This is considered good evidence that BCS was able to shift attitudes, because research shows that people who state that they intend to do something are far more likely to follow through if they are given the support needed to complete the action.<sup>5</sup>

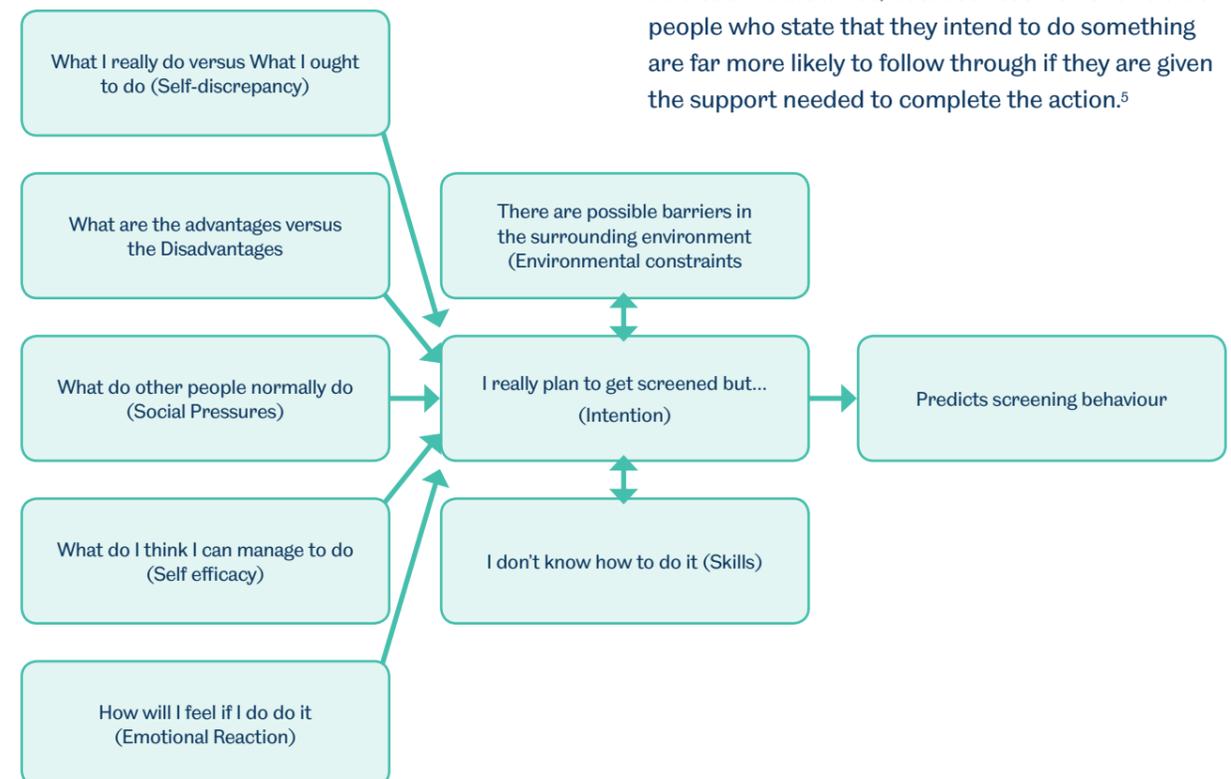


Figure 13: Intentions predict behaviour. This model was used to develop an explanation for the effectiveness of informal conversations.

### 3. Creating a desire to change: the elements in a social movement

#### Box 4: How informal conversations promote consideration of cancer risk

In contexts where discussing cancer is not the social norm, endorsement by local people may create informal opportunities for conversations. If workers listen to how people feel about cancer screening, they are able to have a conversation about the advantages of screening versus the disadvantages. People with a family history of cancer may be able to consider the possible advantages if they hear stories from other people about attending and the benefits of early detection. If people who see barriers to attending (such as location, clinic hours) are given information on accessible venues, then they are more likely to say that they will attend. If people are given the language needed to explain their symptoms (through use of leaflets and education materials) then they are more likely to make appointments to discuss with their GP.

Conversely, the effectiveness of informal conversations is diluted if BCS workers are not endorsed by local people. Messages from workers will not encourage people to consider cancer risk in situations where people are not ready to believe that early detection increases chances of survival. Encouragement to discuss symptoms with their GP will not be as effective in places where there is a history of negative interactions with primary care.

#### Maintenance

Changes made within services will potentially reduce the likelihood that people will have a negative experience of screening. Changes made to embed discussion of cancer within services could potentially normalise cancer conversations. If people have positive screening experiences, and feel more comfortable talking about cancer, then it is likely that they will be able to consult their GP earlier and attend for screening, but this needs longer term evaluation.

*Because I have seen a change over time, I believe that with the current easy access to information and advertising campaigns and increasing media coverage on cancer, people will engage more in the future. But for parts of our community, I believe that we still need projects like the Be Cancer SAFE to become a permanent engagement role in the community because it does make a difference.*



Figure 14: Key findings for informal conversations

## 4. How to create a social movement: What worked

This section of the report is for people and organisations who would like to mobilise social movements for health in their own areas.

The key performance measures for the programme were:

- The number of Champions identified based on the locality %
- 90% of Champions are 'local people' which by definition means they have lived experience in the local community.
- The extent to which the provider allows peers to use their own judgement to decide how to share messages.
- Adjustments used to adapt approaches to local context including factors such as location, environment, time, gender.

The findings of the report commissioned by NHS England on Health as a Social Movement: Theory into Practice were compared with the findings from the Be Cancer SAFE initiative.<sup>6</sup>

While some of the elements of success were the same, the BCS initiative provided more insight into what works.

### Box 4: What worked to create the BCS movement

- Handing over control: Control for creating the social movement was handed over to localities by the commissioner. Project Delivery Leads in each locality handed control over to BCS workers, who used their local expertise to develop a range of strategies to identify interested organisations and individuals.
- Collaborating with other people in the health system: Collaboration increased learning and built confidence about sharing accurate information.
- Using people with knowledge of local communities: BCS workers were local people who could use their own judgement about how to share messages, and adapt their conversations so they reflected the local context and language.
- Using a peer support model: The peer model promotes active listening to individual attitudes and concerns.<sup>7</sup> This created a shared understanding about people's concerns about cancer and cancer screening in the context of their lived experience. As a result, more champions than expected were identified. These champions supported others to discuss cancer signs and symptoms and take up cancer screening.
- Using people who weren't 'experts': Workers did not present themselves as health professionals, but rather as people who had also had experiences with cancer. This enabled people to find common ground and increased willingness to listen to key messages about cancer risk and screening.
- Having informal conversations: Information was presented opportunistically, if people were ready to engage. People were allowed to decide their own level of engagement. In some cases, this was described as 'planting a seed' for further consideration, in other cases people wanted an in depth discussion.
- Endorsement of the BCS programme: People in health and social systems, local leaders and champions' endorsements gave the programme credibility and helped them to gain access to communities. In some neighbourhoods, however, it will take more time to find connections and for positive relationships to develop.
- System level support: helped to 'brand' the BCS initiative and give it a presence.
- Publicity materials: were effective in engaging people in informal conversations and raising awareness across diverse groups.
- Educational materials: Some of the materials and tools were particularly effective in helping people to understand how to interpret their risk, and how to discuss their signs and symptoms with other people.
- Connecting across localities: BCS workers connected with each other and collaborated across localities to share knowledge and experience of good practice in mobilisation.
- Positive feedback from the public: The workers also received positive feedback from the public about their interactions. This led to workers developing increased confidence that they can influence change through informal public conversations.
- Engagement in everyday, informal conversations and collaboration with widened anchor institutions, VCS organisations, health services and public health led to more linkages. As a result, targets for recruiting champions were exceeded. Champions helped BCS workers get 'invited in' rather than knocking on doors. One contact led to another. This ripple effect meant they no longer had to use universal events and 'cold calling' to spread the message.
- Working with decision makers: Presenting information on what is influencing screening uptake, and levels of cancer awareness, to people who are in a position to change practices triggered discussions and reflection on what needs to be improved.

<sup>6</sup> Arnold S, Coote E, Harrison T, Scurrah E, Stephens L. Health as a Social Movement: Theory into Practice. New Economics Foundation / RSA. <https://www.thersa.org/globalassets/hasm-final-report.pdf> [Accessed 18 March 2019]

<sup>7</sup> Harris, J., Springett, J., Booth, A., Campbell, F., Thompson, J., Goyder, E., Van Cleemput, P., Wilkins, E. and Yang, Y., 2015. Can community-based peer support promote health literacy and reduce inequalities? A realist review. *Journal of Public Health Research*, 3(3).

## 5. Next steps

Workers felt that participating in the Be Cancer SAFE movement gave them opportunities to work in teams that supported the development of peer support skills and expanded their networks (Figure 15). They felt that they developed approaches to effective informal conversations, helping people to overcome their concerns about discussing cancer. Commissioner noted that the opportunities to hear stories changed the conversation around provision of services that aimed to increase awareness of cancer risk and screening.

Localities were asked: What should happen next? (Figure 16)

Project delivery leads have recommended that localities consider:

- Encouraging CCGs that haven't yet commissioned a local service to consider doing so
- How arrangements can be made to integrate the informal conversation approach and other learning from the programme into other health promotion initiatives.
- Continuing the use of social networks and media to promote cancer awareness.
- How to continue to maintain the flow of information to health services that deal with cancer awareness, early diagnosis and screening.
- How to continue to use stories to change conversations at the commissioning level and continue to provide feedback on how to improve access to services.



Figure 15: Some key elements supporting BCS workers

Figure 16: Next steps



## 6. Appendices

### 6.3 Be Cancer SAFE Screening Guide for Staff

#### National Screening Programmes - Guide for Staff

The national screening programmes are aimed at large numbers of apparently healthy individuals with no symptoms. You will be invited to take part at different times throughout the year. Screening is carried out in order to detect cancer at an early stage, before it has spread to other parts of the body. The earlier the cancer is found, the better the chances of successful treatment, which means that the patient has a better chance of surviving. It is important that you make an informed choice whether or not to participate.

**Early detection** means the early detection of cancer, before it has spread to other parts of the body. This means that the patient has a better chance of surviving. Sometimes the tests themselves have risks or side effects so it's important you make an informed choice whether or not to participate.

**Breast Screening (Mammogram):**  
Offered to women **aged 50 to 70 every 3 years**. Rolling programme which invites women from GP practices in turn so not every woman receives an invitation as soon as she is 50. **Women aged 70 or over can self-refer.**  
(NB Some women aged 47 to 49 or 71 to 73 may receive an invitation as part of a national pilot to explore the benefits of women receiving two extra screening invitations in their lifetime and for women to receive their first screening invitation by their 50th birthday.)  
You may need extra time at your appointment if, for example, you're a wheelchair user, you have a disability, you have breast implants or you are anxious. If you are over 70 and want to opt back in, you require an interpreter or you need to change your appointment – **please ring the Rotherham Breast Screening Unit on 01709 424807**. View or print the **Rotherham Patient Journey leaflet**: <https://www.vardotherham.com.uk/wp-content/uploads/2019/12/EBreast-Screening-Leaflet-Rotherham-2018.pdf>

**Cervical Screening (Smear):**  
Offered to patients **aged 25 to 49 every 3 years** and patients **aged 50 to 64 every 5 years**. Please tell the surgery if you need extra time due to language barriers, a disability or if you are feeling anxious. Ask your surgery for details if you are having difficulty getting an appointment at your own surgery or there's another reason which makes attending at your own surgery difficult (you work shifts, you're worried about seeing people you know) ask your surgery to book you into one of the Hubs who offer evening and weekend appointments.

**HPV Immunisation:**  
In schools, girls aged 11 to 13 will be offered the HPV (Human Papillomavirus) Vaccine, boys from September 2019. They can have the vaccine up to the age of 18 through their GP. **Women who received the HPV vaccine as girls still need to take up their cervical screening when invited.**

**Bowel Screening:**  
Offered to men and women **aged 60 to 74 every 2 years**. Those **aged 75+** can opt back in by ringing the Hub on **0800 7076060**.  
NB The existing FOB (Faecal Occult Blood) Test will soon be replaced by FIT (Faecal Immunochemical Test) screening kit requiring only one sample rather than the previous three. GPs will have access to a different FIT test for those patients who present with symptoms of bowel cancer. It is very important that patients who present with symptoms still complete the FIT test issued by the GP even if they have completed the FIT for screening previously as the thresholds are different.

**Diabetic Eye Screening:**  
Offered annually to people with diabetes from the age of 12.  
For more information Tel: 01228 434576 or 434577.

**AAA Screening (Abdominal Aortic Aneurysm):**  
Offered to all men in their 65<sup>th</sup> year who can self-refer.  
For more information Tel: 01709 649100.

**Screening**  
Screening tests are available for a number of different cancers. If you are invited for screening, you mean if you don't think you have any symptoms.

**Awareness**  
Be aware of changes to your body or unusual symptoms. Check your body regularly for any changes.

**Fast**  
If you are experiencing symptoms, act fast. Book an appointment with your GP as soon as possible. Talk to your GP about all your symptoms, no matter how small you may think they are.

**Early**  
Early detection of cancer greatly improves survival. If you are worried about your health it's better to be Cancer Safe and have your symptoms checked as soon as possible.

Visit <https://www.nhs.uk/conditions/nhs-screening/> for more information about these national screening programmes.

**Whether you choose to participate in the screening programme or not it's really important to know your body, to recognise any unusual changes for you and to see your GP with any concerns. It's probably not cancer but please have a chat with your GP sooner rather than later.**

If you'd like to know more about the signs and symptoms of the most common cancers see the **Signs and Symptoms - Guide for Patients**.

### 6.4 Be Cancer SAFE Signs and Symptoms Guide for Patients

#### Signs and Symptoms of Cancer - Guide for Patients

**Screening**  
Screening tests are available for a number of different cancers. If you are invited for screening, you mean if you don't think you have any symptoms.

**Awareness**  
Be aware of changes to your body or unusual symptoms. Check your body regularly for any changes.

**Fast**  
If you are experiencing symptoms, act fast. Book an appointment with your GP as soon as possible. Talk to your GP about all your symptoms, no matter how small you may think they are.

**Early**  
Early detection of cancer greatly improves survival. If you are worried about your health it's better to be Cancer Safe and have your symptoms checked as soon as possible.

Even if you choose to complete your screening you still need to know your own body and to recognise when something is different for you. Beyond this simple message, it is helpful to know some of the signs and symptoms of the most common cancers. Please download or print off the leaflets below and use them to support a conversation with your GP or even a loved one who you have concerns about.

Signs and symptoms A5 leaflets and A4 posters are available to view and print off from:  
<https://www.vardotherham.org.uk/be-cancer-safe/be-cancer-safe-flyers-posters/>  
Unfortunately, leaflets and posters are not currently available in different languages however Easy Reads are available and, proving popular.

For further information and support please visit:  
**Breast Cancer:** <https://www.breastcancer.org.uk/>  
<https://www.nhs.uk/conditions/breast-cancer/>  
**Cervical Cancer:** <https://www.lostrust.org.uk/>  
<https://www.nhs.uk/conditions/cervical-cancer/>  
[www.fearsofsmear.dhb.nhs.uk](http://www.fearsofsmear.dhb.nhs.uk)  
**Bowel Cancer:** <https://www.bowelcancer.org.uk/>  
<https://www.nhs.uk/conditions/bowel-cancer-screening/>  
**Lung Cancer:** <https://www.blf.org.uk/support-for-you/lung-cancer>  
<https://www.nhs.uk/conditions/lung-cancer/>  
**Prostate Cancer:** <https://prostatecanceruk.org/>  
<https://www.nhs.uk/conditions/prostate-cancer/>

**All of the national charities highlighted offer a telephone helpline if you need more information or to access support.**

**Screening**  
Screening tests are available for a number of different cancers. If you are invited for screening, you mean if you don't think you have any symptoms.

**Awareness**  
Be aware of changes to your body or unusual symptoms. Check your body regularly for any changes.

**Fast**  
If you are experiencing symptoms, act fast. Book an appointment with your GP as soon as possible. Talk to your GP about all your symptoms, no matter how small you may think they are.

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Unfortunately, leaflets and posters are not currently available in different languages however Easy Reads are available and, proving popular.

For further information and support please visit:  
**Breast Cancer:** <https://www.breastcancer.org.uk/>  
<https://www.nhs.uk/conditions/breast-cancer/>  
**Cervical Cancer:** <https://www.lostrust.org.uk/>  
<https://www.nhs.uk/conditions/cervical-cancer/>  
[www.fearsofsmear.dhb.nhs.uk](http://www.fearsofsmear.dhb.nhs.uk)  
**Bowel Cancer:** <https://www.bowelcancer.org.uk/>  
<https://www.nhs.uk/conditions/bowel-cancer-screening/>  
**Lung Cancer:** <https://www.blf.org.uk/support-for-you/lung-cancer>  
<https://www.nhs.uk/conditions/lung-cancer/>  
**Prostate Cancer:** <https://prostatecanceruk.org/>  
<https://www.nhs.uk/conditions/prostate-cancer/>

**All of the national charities highlighted offer a telephone helpline if you need more information or to access support.**

South Yorkshire, Bassetlaw and North Derbyshire Integrated Care System hosts the main Be Cancer SAFE webpage with links to delivery partners, where you can find electronic copies of all the BCS tumour site posters and leaflets including Easy Reads: <https://healthandcaretogethersyb.co.uk/what-we-do/working-together-future-proof-services/cancer/south-yorkshire-bassetlaw-and-north-derbyshire-cancer-alliance/be-cancer-safe>

